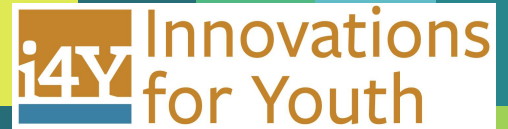


# Inclusion of vulnerable and marginalized youth in research: Who, why, what, when and how?

Colette (Coco) Auerswald, MD, MS, FSAHM  
Associate Professor  
UC Berkeley School of Public Health  
Co-Founder of i4Y



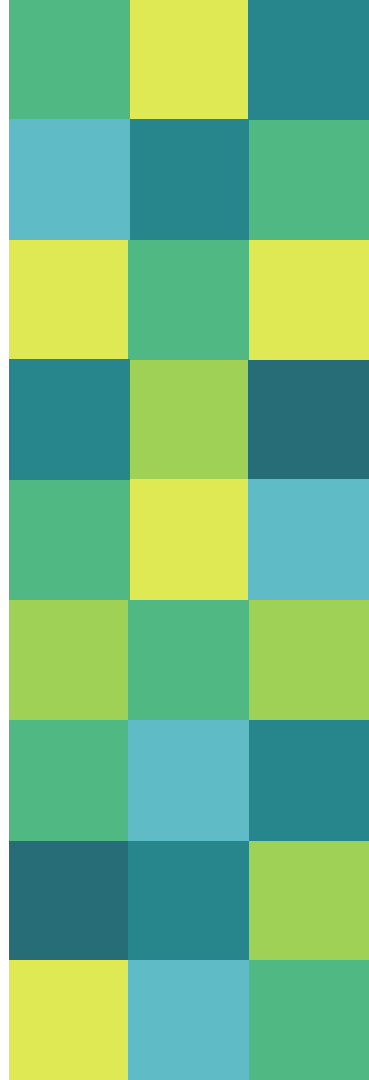
**Who?** Why? What? When? How?

# Who?



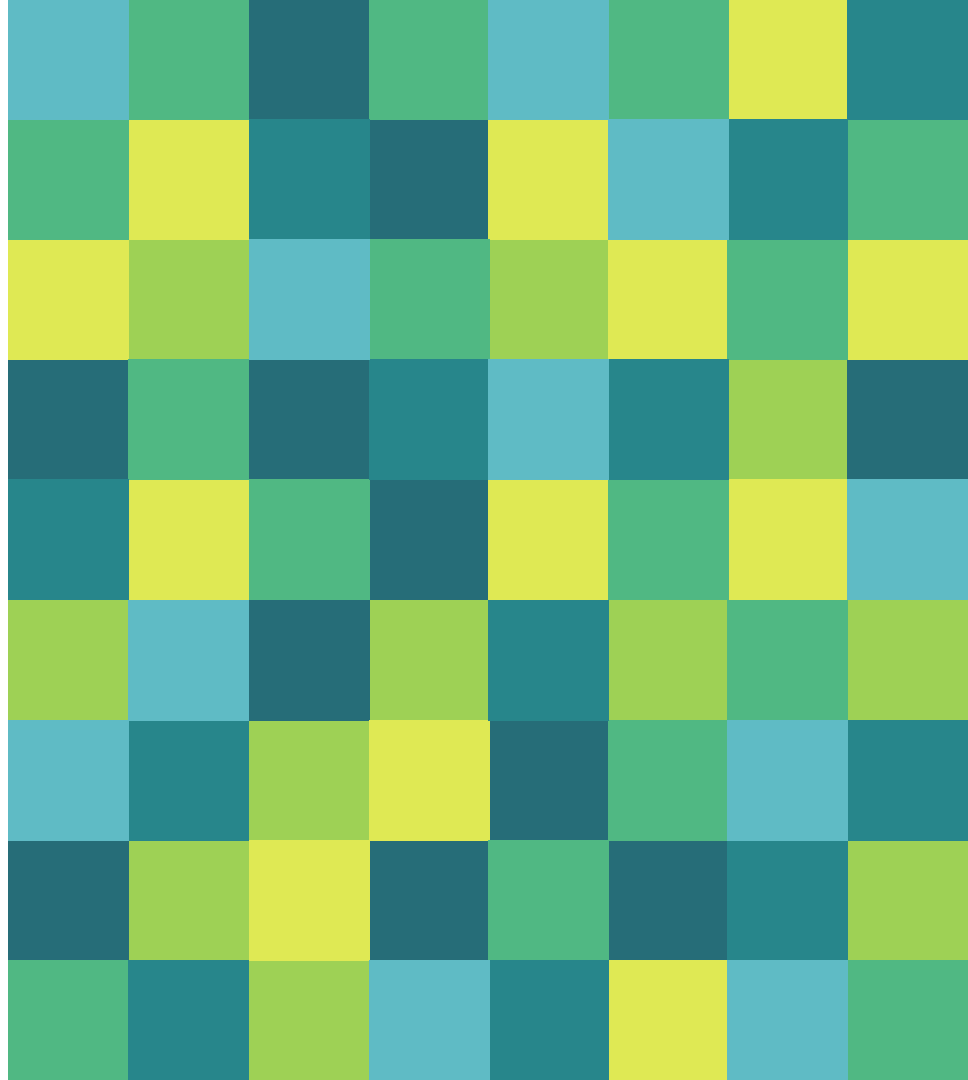
**Who?** Why? What? When? How?

**Disadvantaged, vulnerable and/or marginalized adolescents** are youth who are excluded from social, economic and/or educational opportunities enjoyed by other adolescents in their community due to numerous factors beyond their control.



**Who?** Why? What? When? How?

Who are  
disadvantaged,  
vulnerable and/or  
marginalized  
adolescents in  
your community?

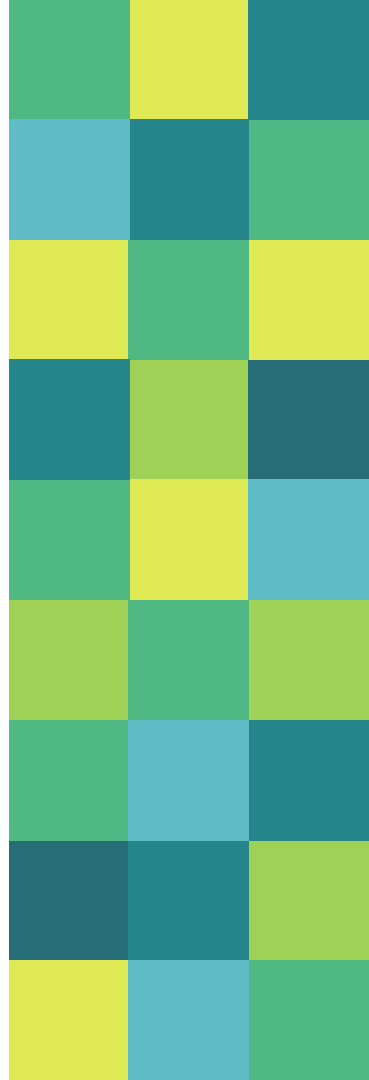




Art credits: Elvis Wolf, Micah Bazant, Melanie Cervantes, Kelly Bairds, Fox Fisher

Who? **Why?** What? When? How?

# Why?



# Homeless Youth Experience Greater Mortality

Death rate for homeless group overall 9x the death rate for non-homeless age, gender, and race/ethnicity matched controls.

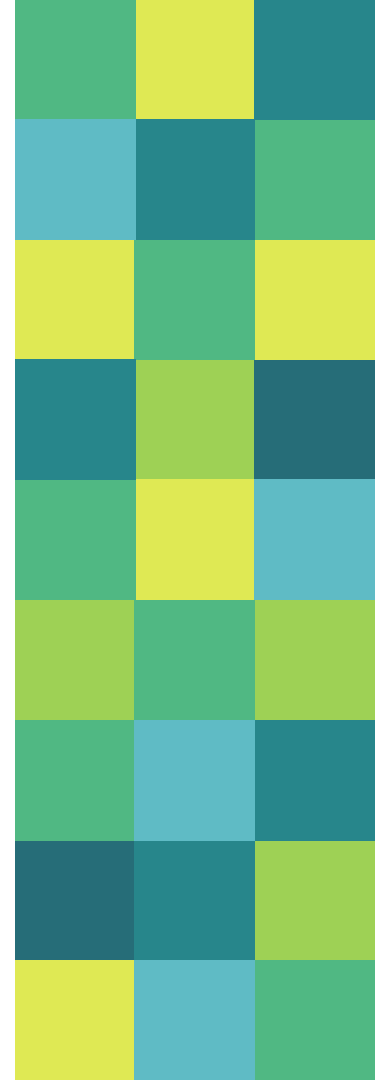
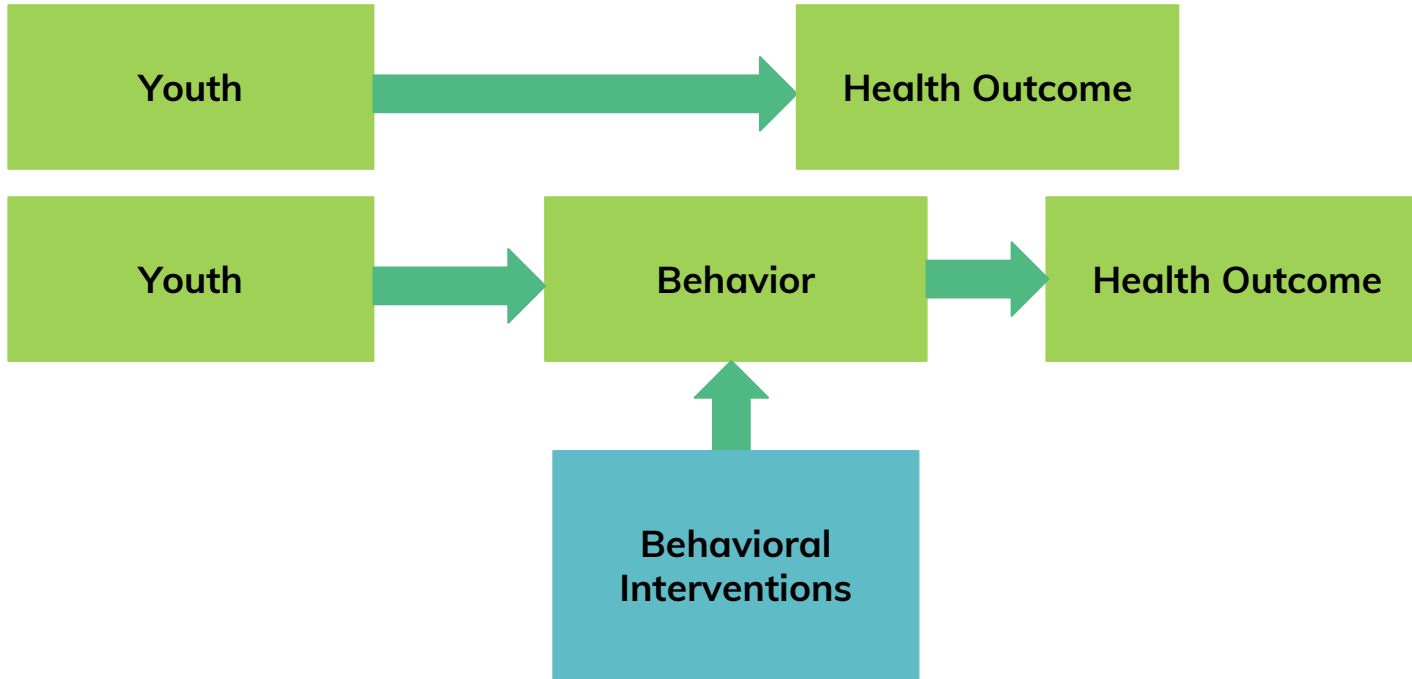
## Housed Youth



## Homeless Youth



# Disparities by Behavior

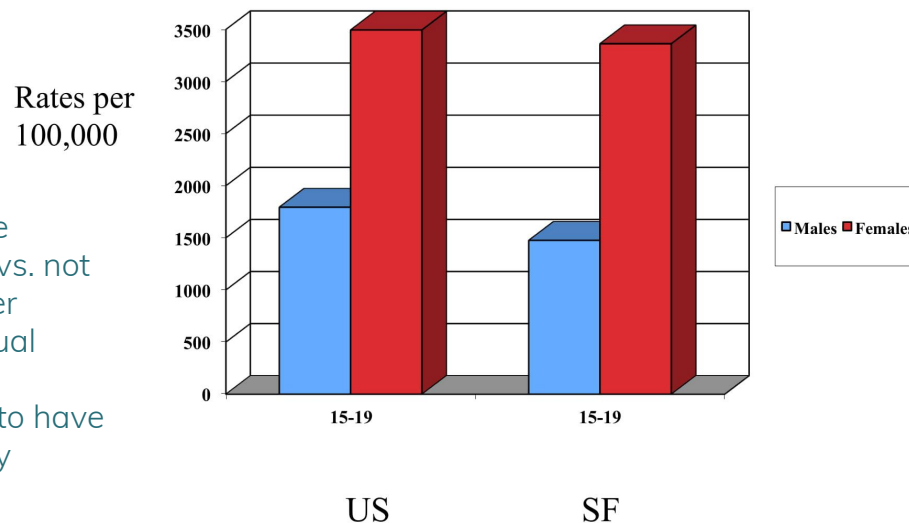




# Who? Why? What? When? How?

## STI Disparities By Race: STI Paradox

Rates of gonorrhea in African American males and females, 15-19 y.o. and 20-24 y.o., in the US and in San Francisco, CA (2001)



Boys are:

- More likely to be sexually active vs. not
- Onset sex earlier
- Have more sexual partners
- Are more likely to have had sex recently

Source: CDC and San Francisco Department of Public Health, STD Control Section.

“

## Social Determinants of Health:

*“Conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”*

From: [Healthy People 2020](#)

# Social Determinants of Health

Life Course

Economic Environment/  
Poverty/Opportunities



Youth



Behavior



Health  
Outcome



Overall  
Health &  
Wellbeing

Behavioral  
Interventions

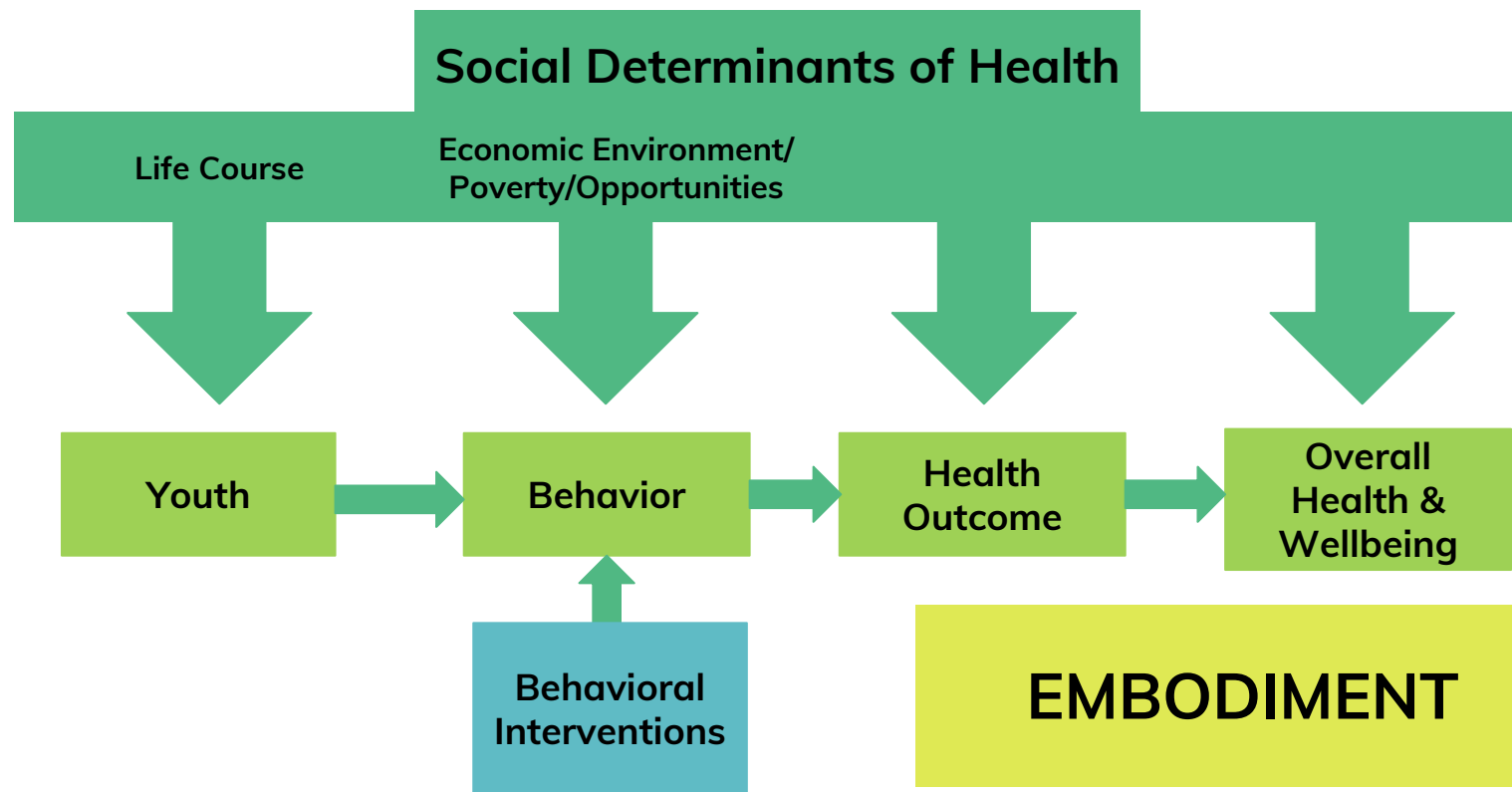


“

## Embodiment:

*“We literally incorporate, biologically, the material and social world in which we live: no aspect of our biology can be understood in the absence of knowledge of history and individual and societal ways to living.”*

From: Krieger, N. (2005). Embodiment: a conceptual glossary for epidemiology. *Journal of Epidemiology & Community Health*, 59(5)



# STI PARADOX? Gender disparity in STIs

OR of GC for African American young women relative to young men in economically marginalized neighborhood of San Francisco



(OR data—controlling for partner number)

# STI PARADOX? Gender disparity in STIs

TABLE: Odds Ratio for Having a Partner With Specified Characteristic by Gender in a Random Digit Dial Household Sample of 14- to 19-Year-Old African American Youth From an Economically Marginalized Neighborhood in San Francisco

Partner Characteristic	Teen Girls	Teen Boys	Odds Ratio
> 5 y older	18%	4%	1.48 (1.08 - 2.03)
Perceived history of incarceration	61%	8%	1.86 (1.50 - 2.29)
Perceived history of gang membership	16%	9%	N.S.
Perceived other partners	21%	33%	N.S.

# Social Determinants of Health and STIs

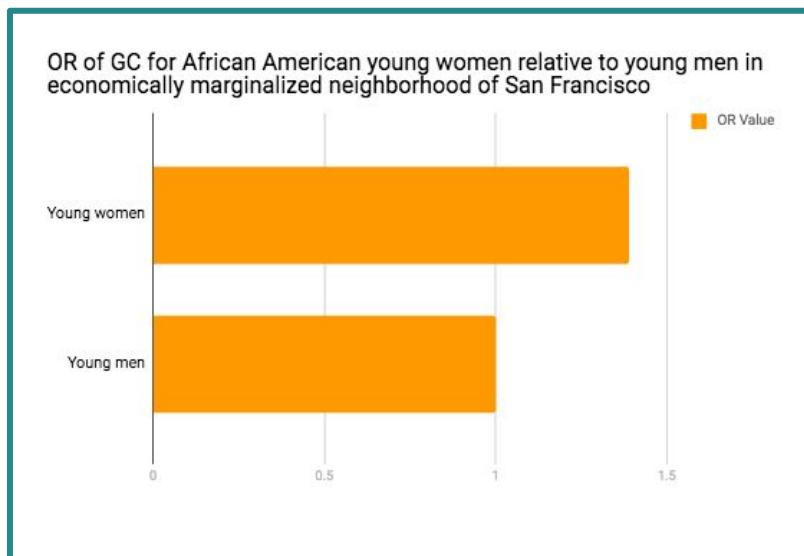
TABLE: Odds Ratio for Having a Sexually Transmitted Infection (STI) by Partner Characteristic Controlling for Number of Sex Partners in a Random Digit Dial Household Sample of 14- to 19-Year-Old African American Youth From an Economically Marginalized Neighborhood in San Francisco

Partner Characteristic	STI	No STI	Odds Ratio
> 5 y older	14%	86%	1.79 (0.45-7.21)
Perceived history of incarceration	17%	83%	6.56 (1.77-24.27)
Perceived history of gang membership	9%	91%	N.S.
Perceived other partners	14%	86%	N.S.

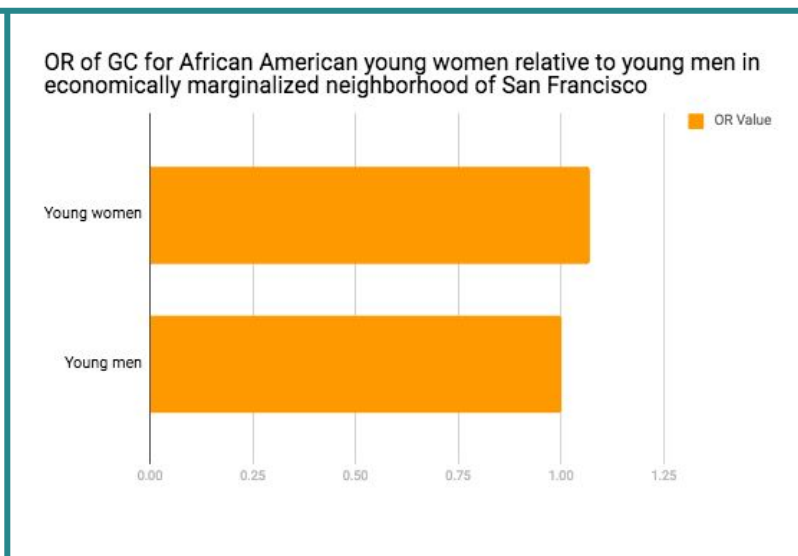


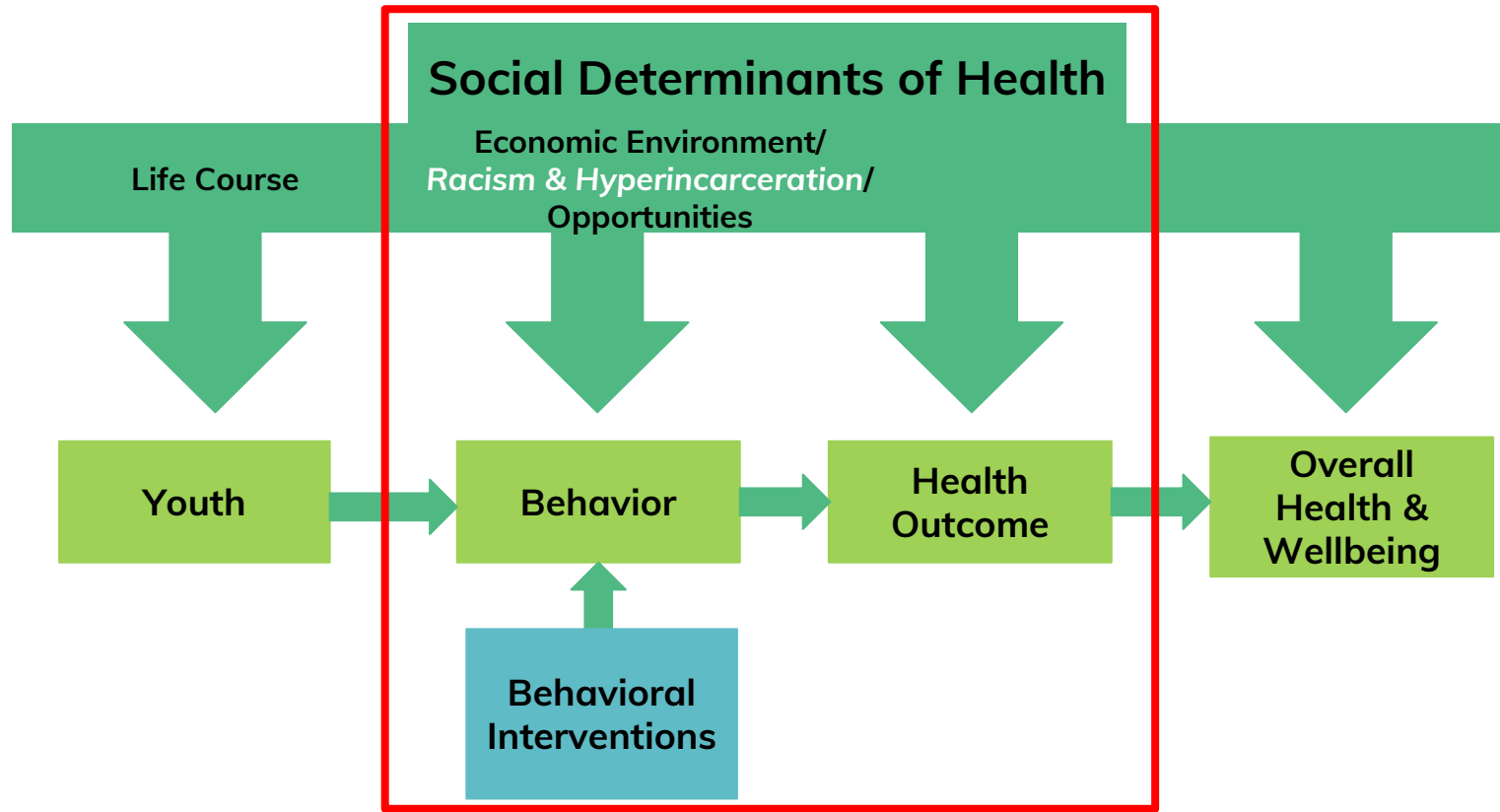
# Social Determinants of Health and STIs

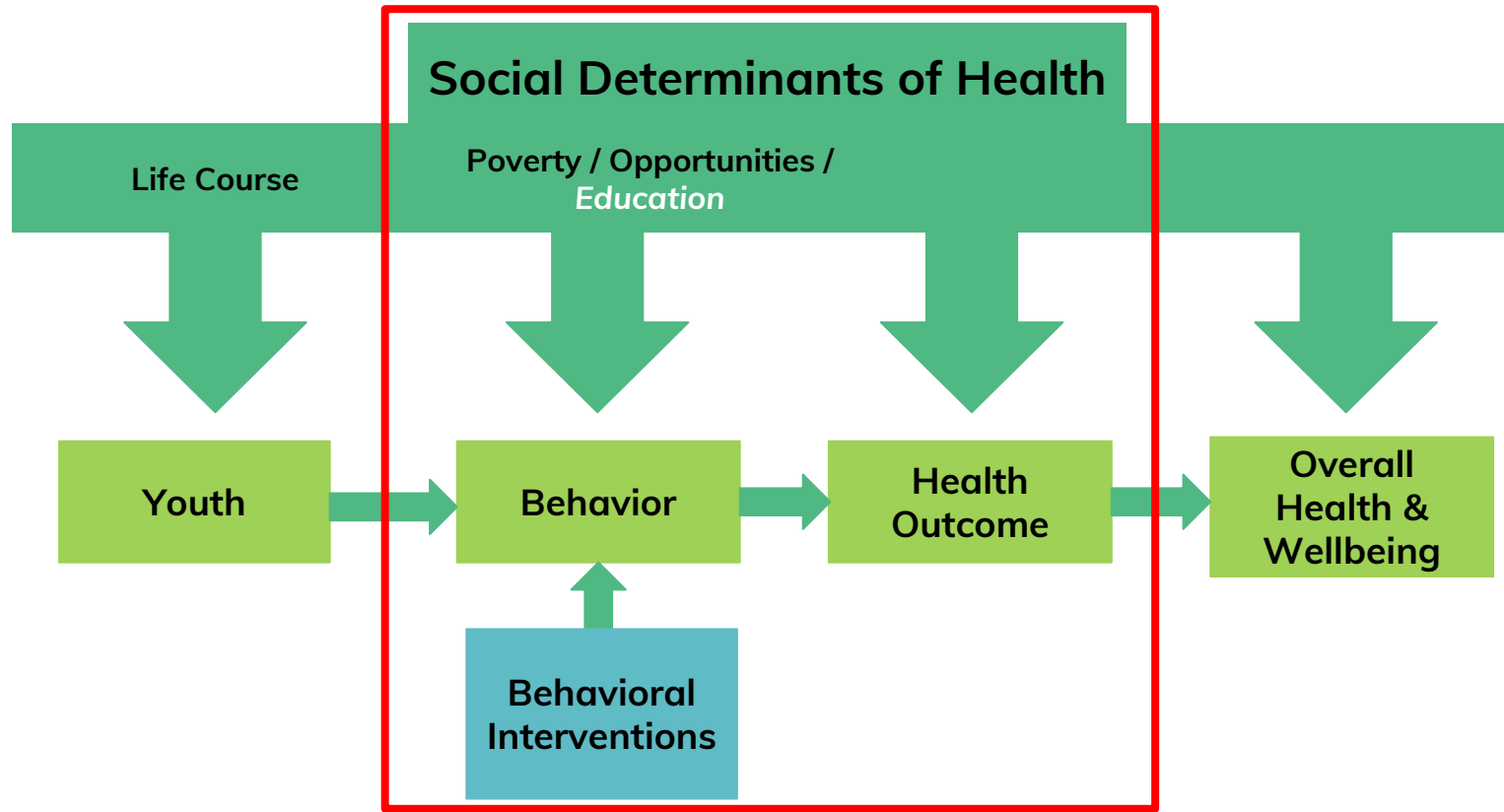
**With** effect of incarceration



**Without** effect of incarceration







# Homeless Youth Experience Greater Mortality

Death rate for homeless group overall 9x the death rate for non-homeless age, gender, and race/ethnicity matched controls.

## Housed Youth



## Homeless Youth



# Let's review some concepts

## 1. Marginalized Youth

- Are a diverse group of adolescents
- Differ by region

## 2. Disparities

- In health and wellbeing affect marginalized youth
- Are insufficiently explained by individual behaviors

## 3. Social Determinants of Health

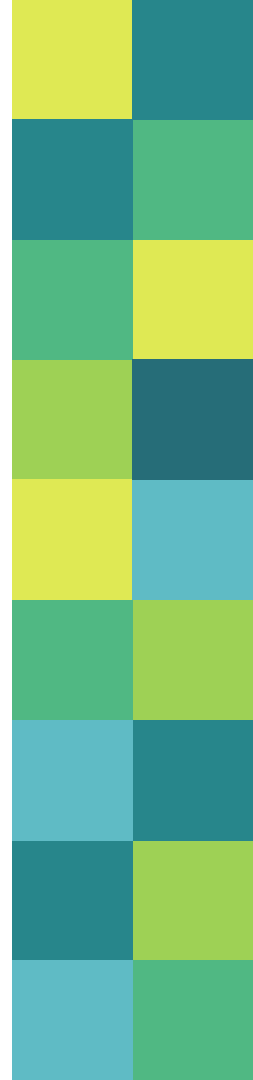
- Affect the context and consequences of individual health behaviors

## 4. Embodiment

- Is the direct effect of the SDoH on health and wellbeing

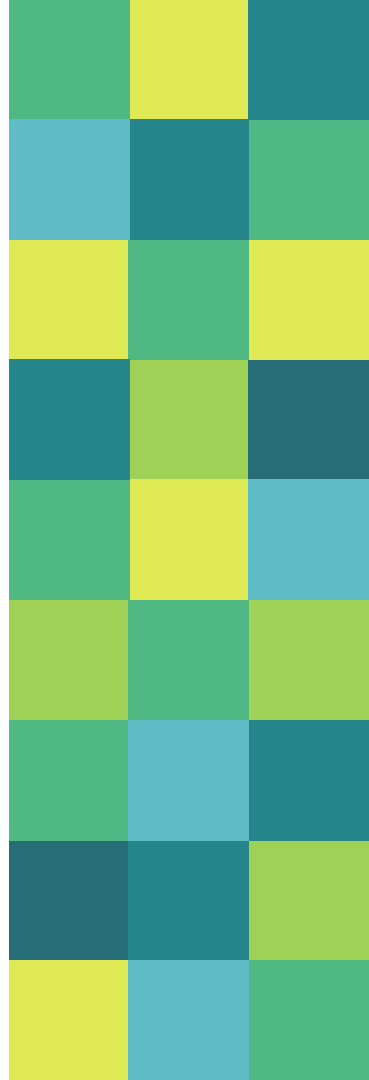
## 5. To intervene on the SDoH:

- Behavioral interventions are insufficient
- Need “upstream” or structural interventions.



Who? Why? **What?** When? How?

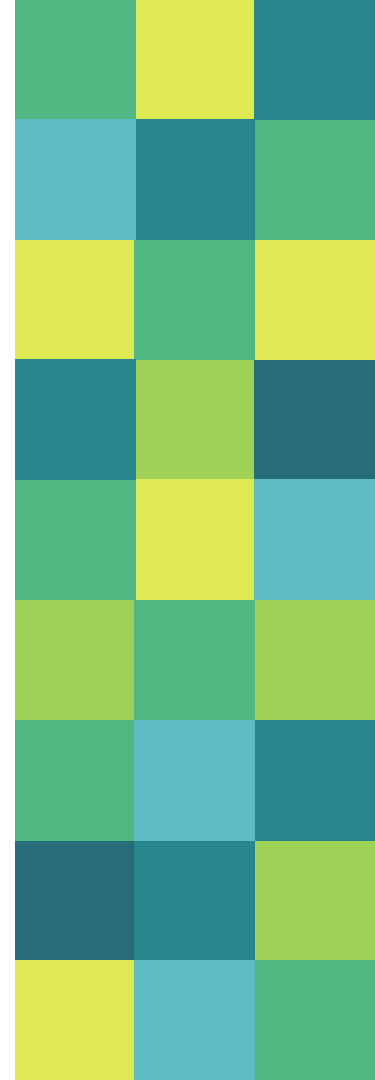
# What?



Who? Why? **What?** When? How?

## Barriers and Challenges

- Inadequate data
- Challenge to recruiting and obtaining representative samples.
- Stigma
- Use of developmentally inappropriate definitions and approaches
- Limited variables (often individually focused and risk-focused)



# Social Determinants of Health

Life Course

Economic Environment/  
Poverty/Opportunities



Youth



Behavior



Health  
Outcome



Overall  
Health &  
Wellbeing

Behavioral  
Interventions



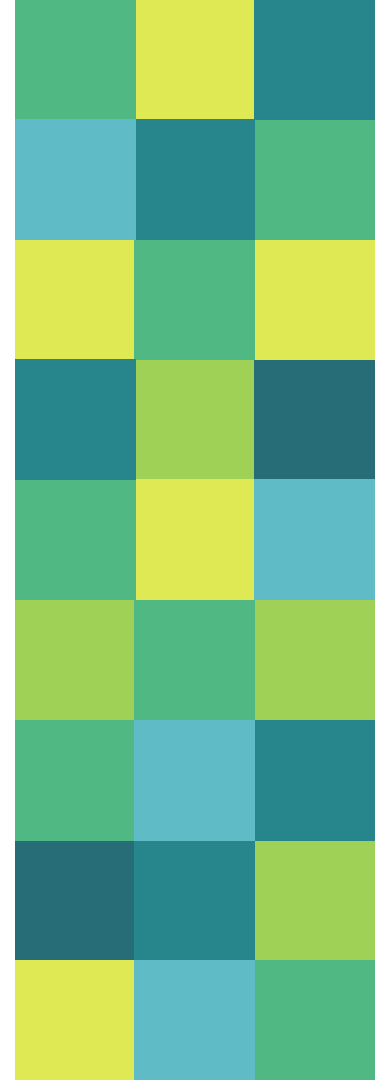
EMBODIMENT



Who? Why? **What?** When? How?

## Barriers and Challenges

- Inadequate data
- Challenge to recruiting and obtaining representative samples.
- Stigma
- Use of developmentally inappropriate definitions and approaches
- Limited variables (often individually focused and risk-focused)
- Concerns about research ethics



Who? Why? What? **When?** How?

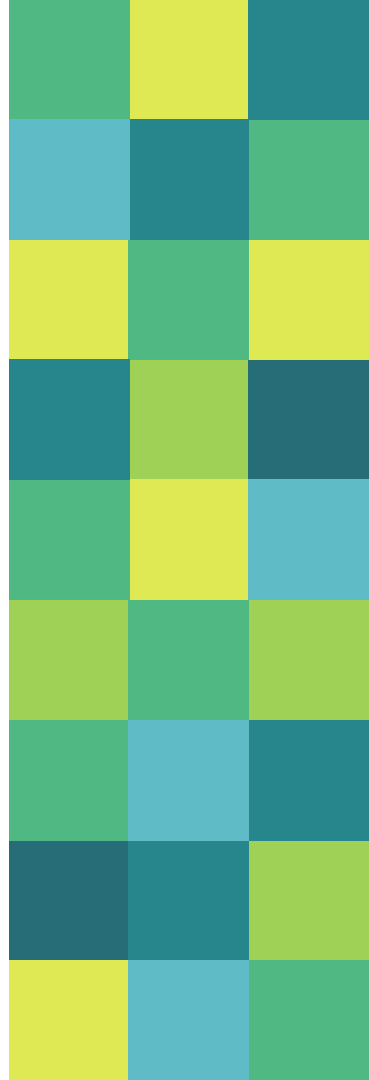
# When?



Who? Why? What? **When?** How?

# Benefits for Youth

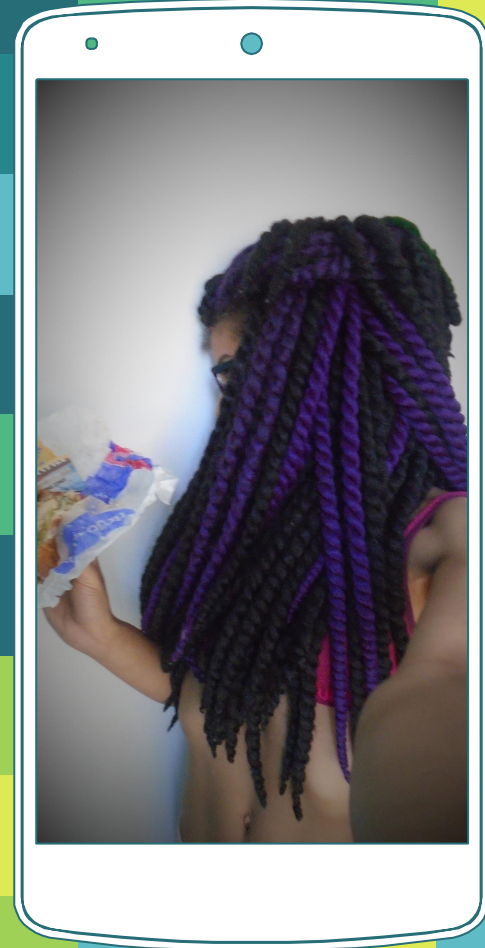
- Connect youth to supportive adults and peers, and to social safety net services
- Reverse internalized stigma



Who? Why? What? **When?** How?

Increased sense of self-worth

“I learned that we matter. That was the overall lesson. I mean, the people that showed up to the initial gala, there were a lot of people here and that just got me teared up on the way home.”



Who? Why? What? **When?** How?

# Benefits for Youth

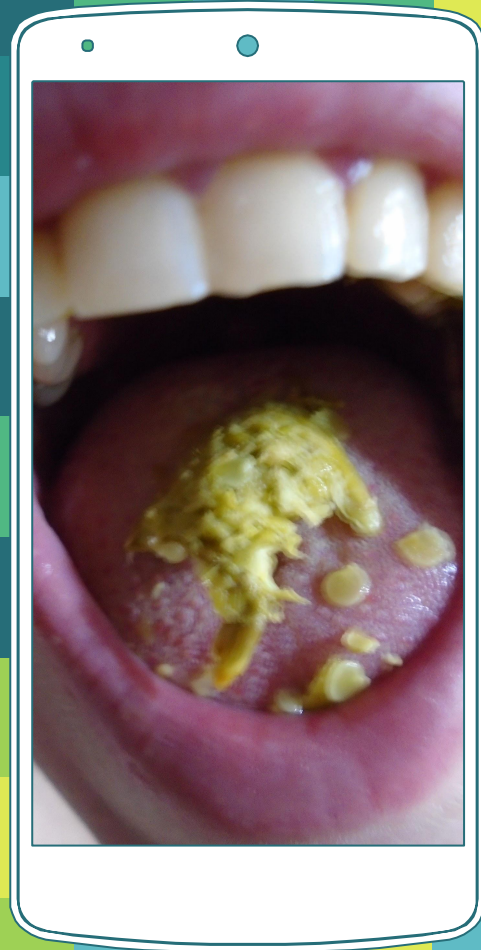
- Connect youth to supportive adults and peers, and to social safety net services
- Reverse internalized stigma
- Promote skill development and promote sense of empowerment/agency



Who? Why? What? **When?** How?

Increased self-confidence in creative expression and public speaking

“I learned how to give the feeling of – in your words, of how you felt about the picture, why you took it. It felt invigorating because it was something that I was able to speak on, that I felt needed to be spoken on. It was very different, ‘cause I normally don’t.”



Who? Why? What? **When?** How?

# Benefits for Youth

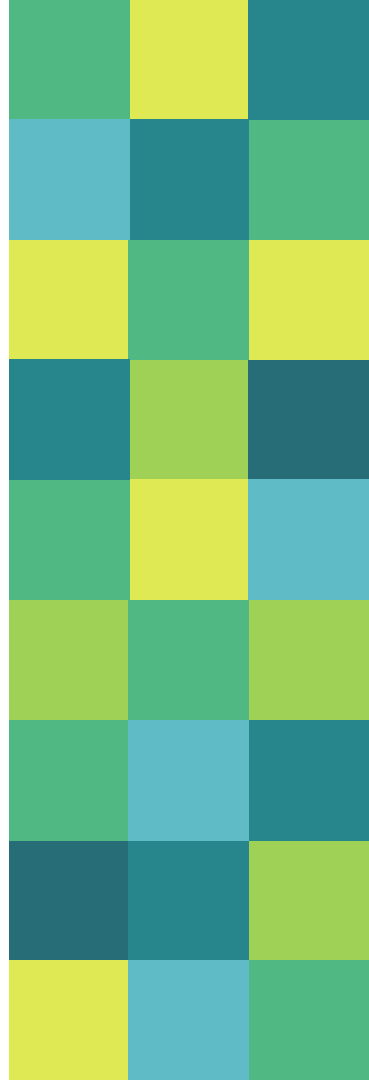
- Connect youth to supportive adults and peers, and to social safety net services
- Reverse internalized stigma
- Promote skill development and promote sense of empowerment/agency
- Increase civic and social competencies
- Improve the social capital for participating youth



Who? Why? What? **When?** How?

# Benefits for Community

- Increase ability to address community needs
- Develop and recruit of a new generation of leaders

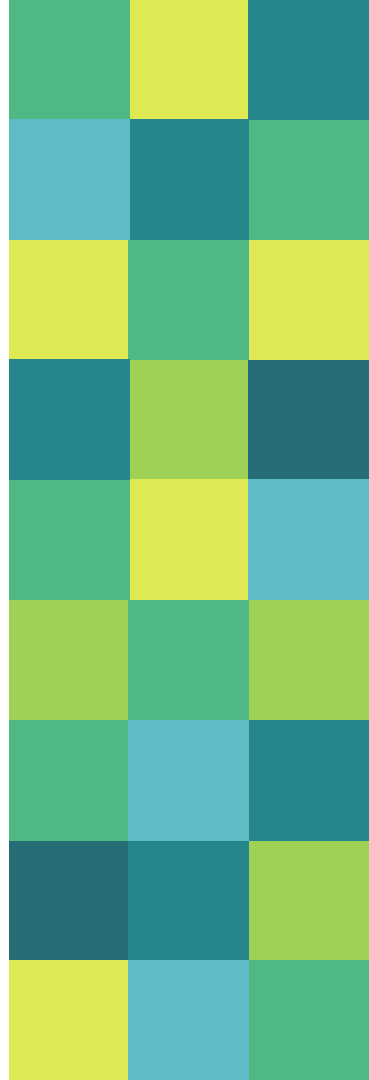




Who? Why? What? **When?** How?

# Benefits for Research

- Access to hard-to-reach youth
- Maximize validity
- Increase uptake of the research/increased buy-in
- Improve feasibility, effectiveness and acceptability of resulting interventions
- Improve attention to research ethics



Who? Why? What? When? **How?**

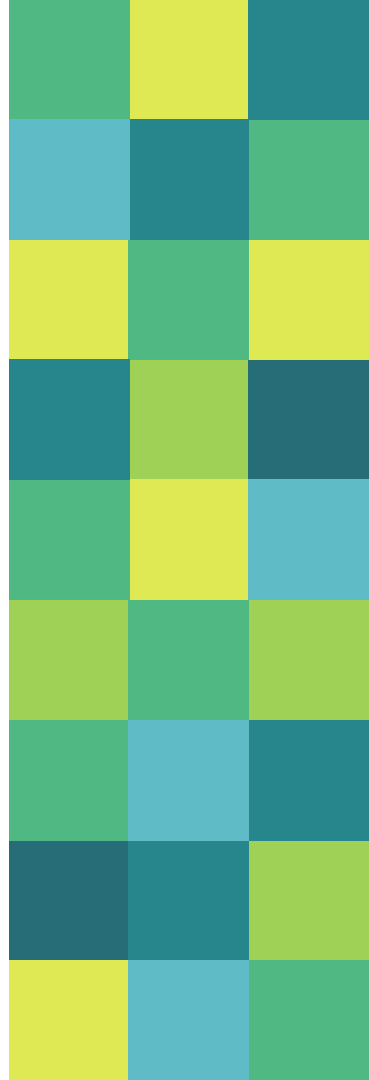
# How?



Who? Why? What? When? **How?**

## Best Practices

- CBPR/YPAR
- Inclusive team
- Sampling/recruiting a representative sample
- CBPR/YPAR
- Range of variables (individual/contextual; risk/protective; modifiable structural factors)
- Mixed methods
- Appropriate data collection approaches
- Longitudinal data
- Ethical guidelines
- Dissemination



# Youth-led Participatory Action Research



# Youth-led Participatory Action Research

Youth identify issues they want to improve, conduct research to understand the issues and possible solutions, and advocate for changes based on research evidence.



# Sampling / recruiting a representative sample



# Convenience Sampling

Recruitment of who are easy to reach, often those who are accessing services.



# Convenience Sampling

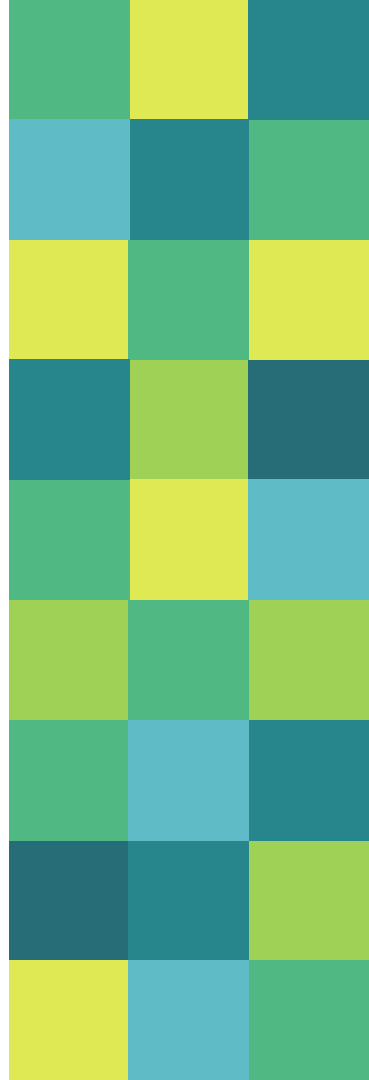
Recruitment of who are easy to reach, often those who are accessing services.

## Strengths

- Readily available
- Cost-effective
- May be able to build on relationships with providers

## Weaknesses

- Non-probability sample
- Results biased towards adolescents who access services
- Limitations often overlooked
- The probability of selecting a member of the population of interest is unknown





# Purposive Sampling

Recruitment of participants with specific characteristics within a population



# Purposive Sampling

Recruitment of participants with specific characteristics within a population

## Strengths

- Can be used to ensure the inclusion of all sub-sets of a population if the characteristics of the population are well known

## Weaknesses

- The probability of selecting a member of the population of interest is unknown
- May introduce systematic bias



# Targeted Venue-based Sampling

Sampling youth from venues or places where they live, work or socialize.

Informed by formative research using qualitative and/or quantitative data to construct a list of sites where adolescents may be found and recruited.



# Targeted Venue-based Sampling

## Strengths

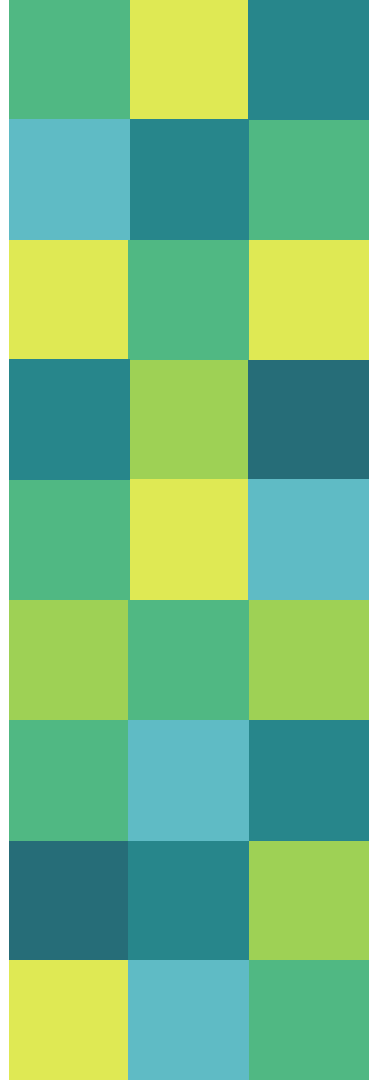
- Target population is visible
- High-quality formative research can maximize validity
- Can ensure inclusion of sub-groups through selection of venues where members of sub-groups spend time
- Can be effective for sampling highly mobile populations
- Can adjust sampling in response to information in the field
- Can be paired with outreach interventions

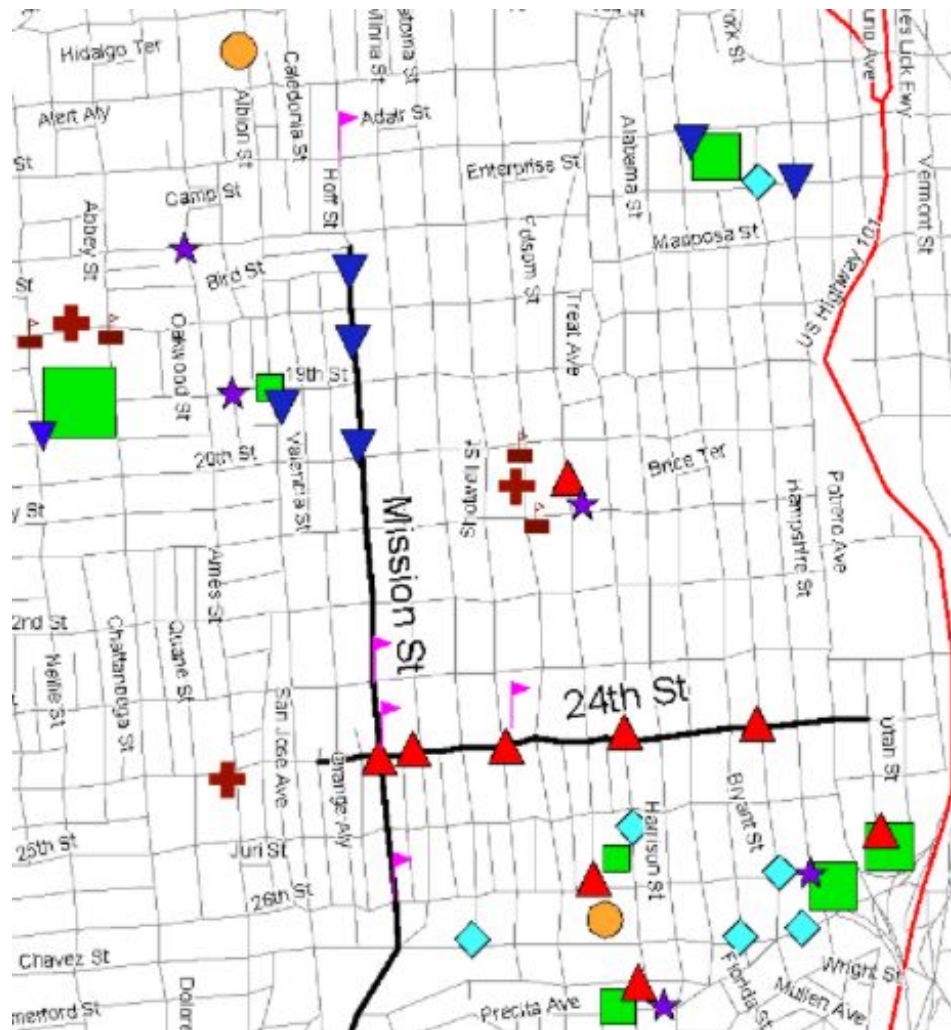


# Targeted Venue-based Sampling

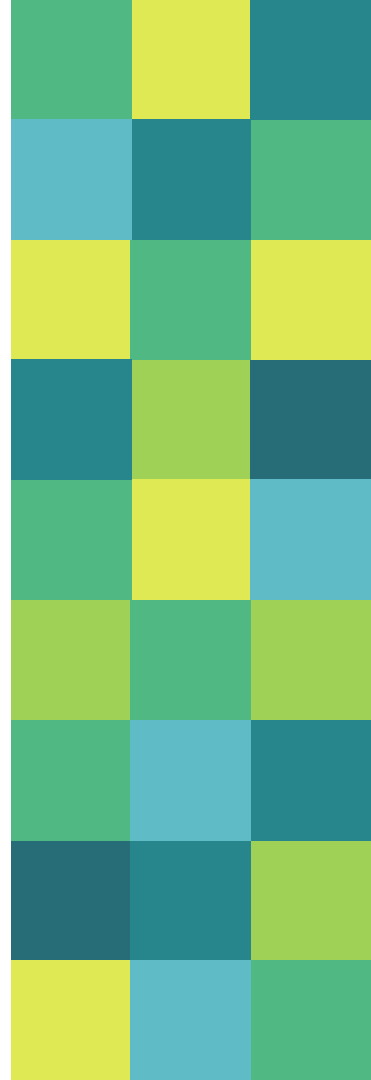
## Weaknesses

- Non-probability sample
- Sampling may be biased and difficult to replicate
- Sample may not be representative of target population
- Leaves out those who do not attend venues
- Over-represents frequent venue-goers
- The probability of selecting a member of the population of interest is unknown
- Labor intensive
- May require difficult hours of operation
- Safety issue depending on venues

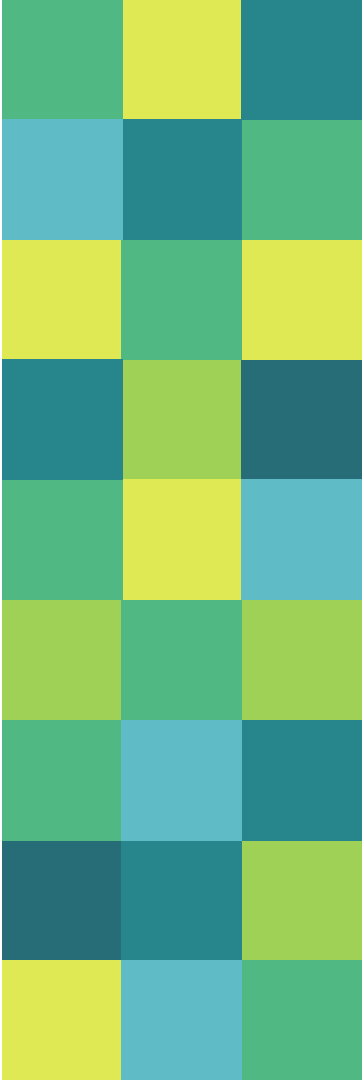




-   Gang Venue
-  Park
-  Street Corner
-  Rec Center
-  School and School Venue
-  Housing Project
-  Day Labor Venue



Venue Location	Venue Score	Description/ Specific Location/Time to Recruit	Types of Youth Who Are There, M/F Distribution, Volume of Traffic	Other Notes
Between 17th and 18th and Mission	3	18th and Mission, NW corner	Taggers, 15-17 years old, mostly male (VL/?VML taggers)	Clicking/BSI to pick best sites in this area
Sycamore and Mission	2	?	May be one entrance to "alleys" where FK taggers and Surenos hang out, i.e., San Carlos and Lexington. Primarily a M venue. Hours: anytime after 12 into the night.	Researchers should go in pairs here
Between 18th and 19th on Mission	3	Taqueria Cancun	Impotant block to recruit Surenos (19th st. set) who are here from mid-day into the night. They are male, 16-25 years old, some female associates may be at the site too.	?
20th and Mission	2	Ritmo Music Store at SE corner	Regular youth. M/F site? Many youth approached were monolingual Spanish speakers. Probably best to sample after school; other hours/weekends?	Need clicking and BSI's during the school year too, because of proximity to high school
20th and Mission	3	Outside Donut Shop on SW corner	MS Surenos hang out; they are generally older (over 21). The MS set is Salvadoran.	Clicking/BSI



# Time Location

Variant of targeted venue-based sampling

Approximates a random sample by employing a comprehensive list of venues w/ days of the week and times

Investigators then conduct random selection of venue, day, and time (VDT) periods, followed by systematic counting and recruiting of eligible adolescents.

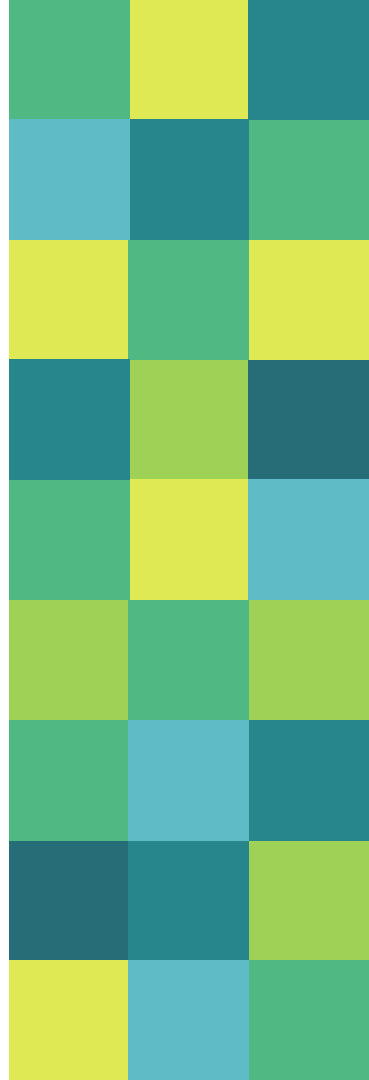




# Time Location

## Strengths

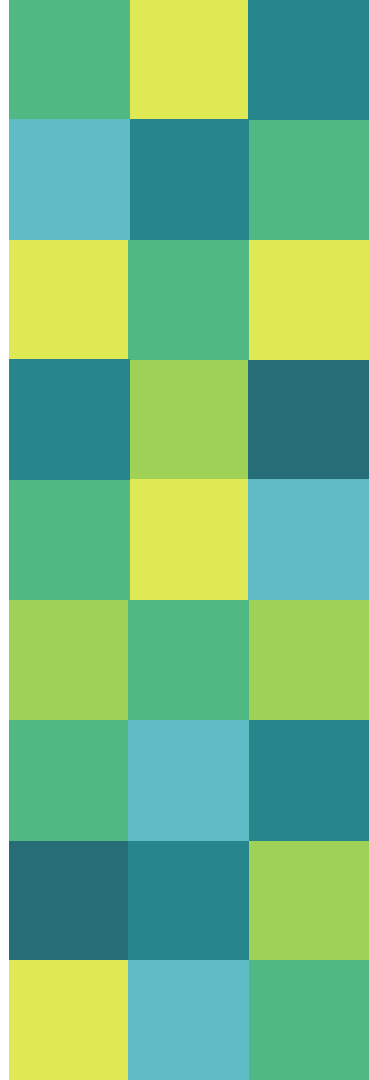
- All advantages listed for venue sampling
- The probability of selecting a member of the population of interest can be calculated—approximates a probability sample
- Statistical methods are available to produce unbiased estimates



# Time Location

## Weaknesses

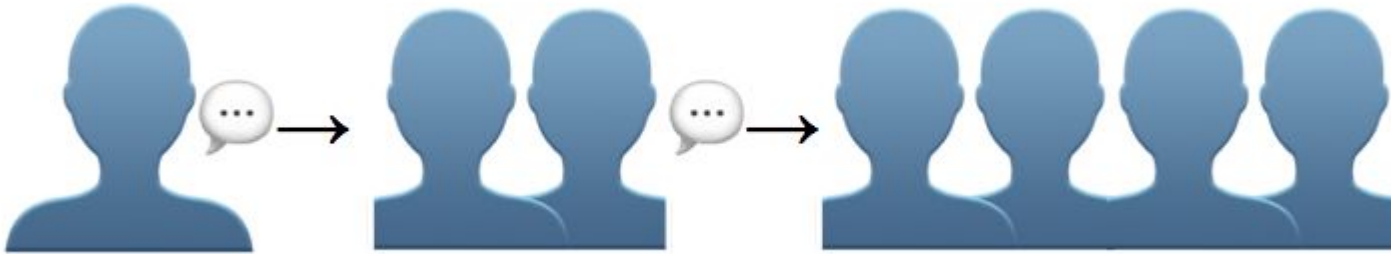
- Leaves out those who do not attend venues
- Over-represents venue-goers
- Hard to statistically adjust
- Labor intensive
- May require difficult hours of operation
- Safety of staff and of population may be an issue



# Snowball Sampling

Sampling people through their social connections or networks.

Adolescents recruited by research staff are requested to recruit their eligible social contacts to the study.



# Snowball Sampling

## Strengths

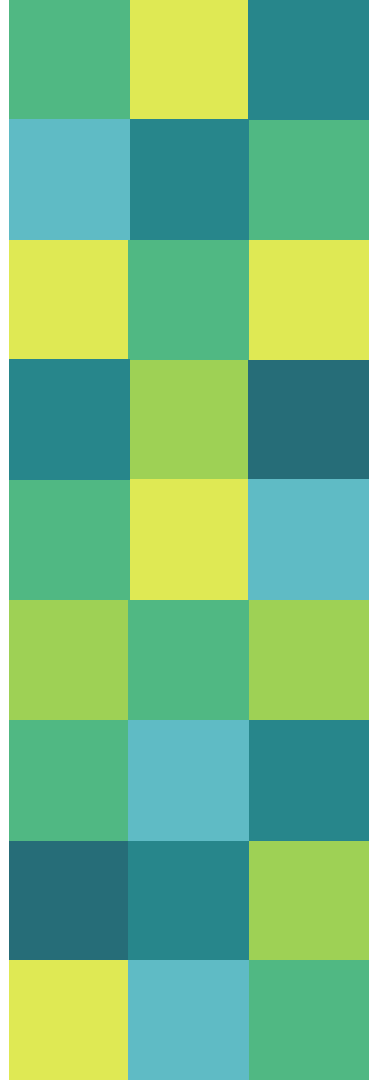
- Targets hidden population
- May be best available option for some populations
- May be faster and less expensive than locating and recruiting people with research staff
- Peers know each other better than researchers
- Peer recruiters can also recruit people for interventions



# Snowball Sampling

## Weaknesses

- Non-probability sample
- Biased towards the socially well connected; leaves out the socially isolated
- The probability of selecting a members of the population of interest is unknown
- There is no statistical method to produce unbiased estimates

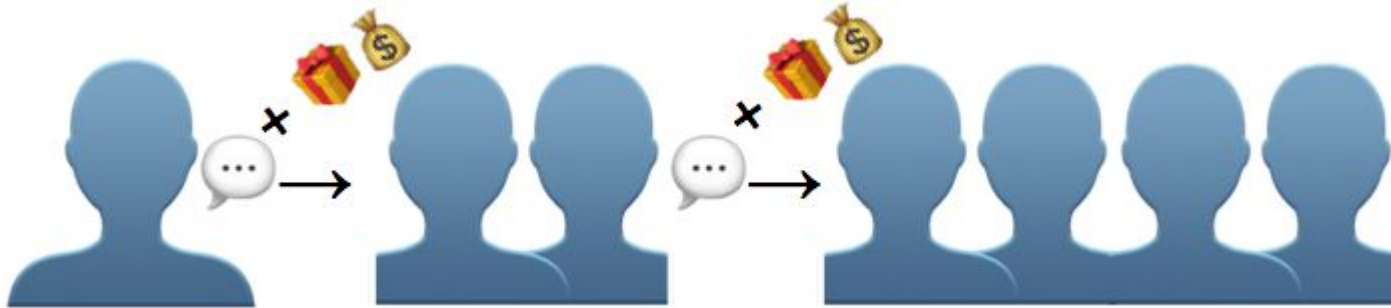


# Respondent-Driven Sampling (RDS)

A modified form of snowball sampling: adolescents recruited by research staff ('seeds') are incentivized to recruit their eligible social contacts to the study.

Social contacts are incentivized to recruit eligible individuals from their social network, who are in turn incentivized, and so on...

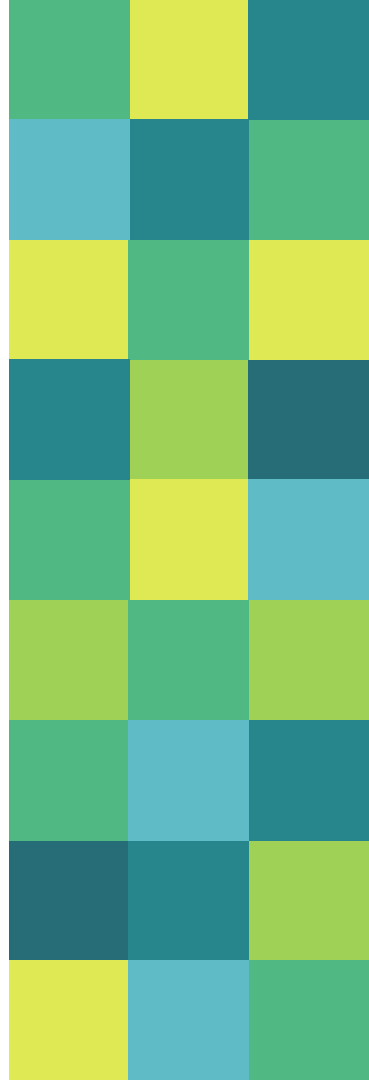
Data are used to estimate the characteristics of the population as a whole.



# Respondent-Driven Sampling (RDS)

## Strengths

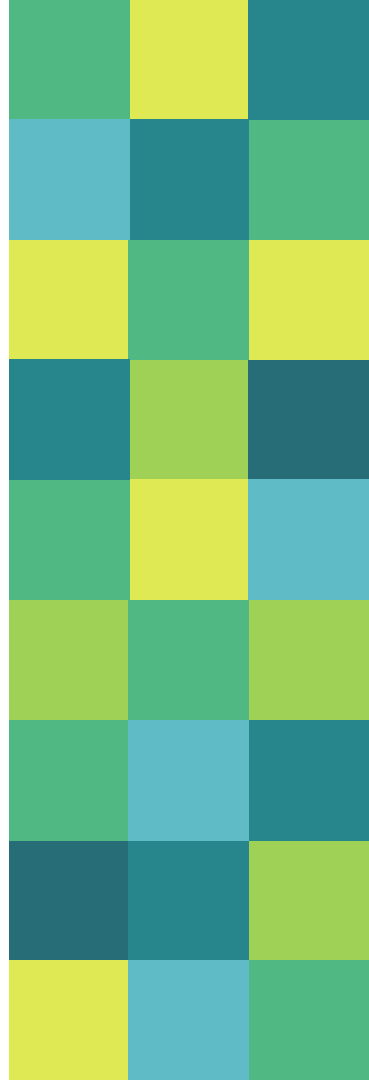
- All advantages of snowball sampling
- Probability of selecting a member of population of interest can be calculated; it approximates a probability sample
- Statistical methods available to produce unbiased estimates
- High-quality formative research can maximize validity



# Respondent-Driven Sampling (RDS)

## Weaknesses

- Inaccurate estimates in communities with sub-networks
- Bias towards to socially well connected; leaves out the socially isolated
- Statics for analysis difficult and debated
- Findings sometimes inconsistent with qualitative research
- Theoretical assumptions hard to meet and to verify
- Sometimes peers fail to recruit others
- Secondary incentives may be coercive or commoditized

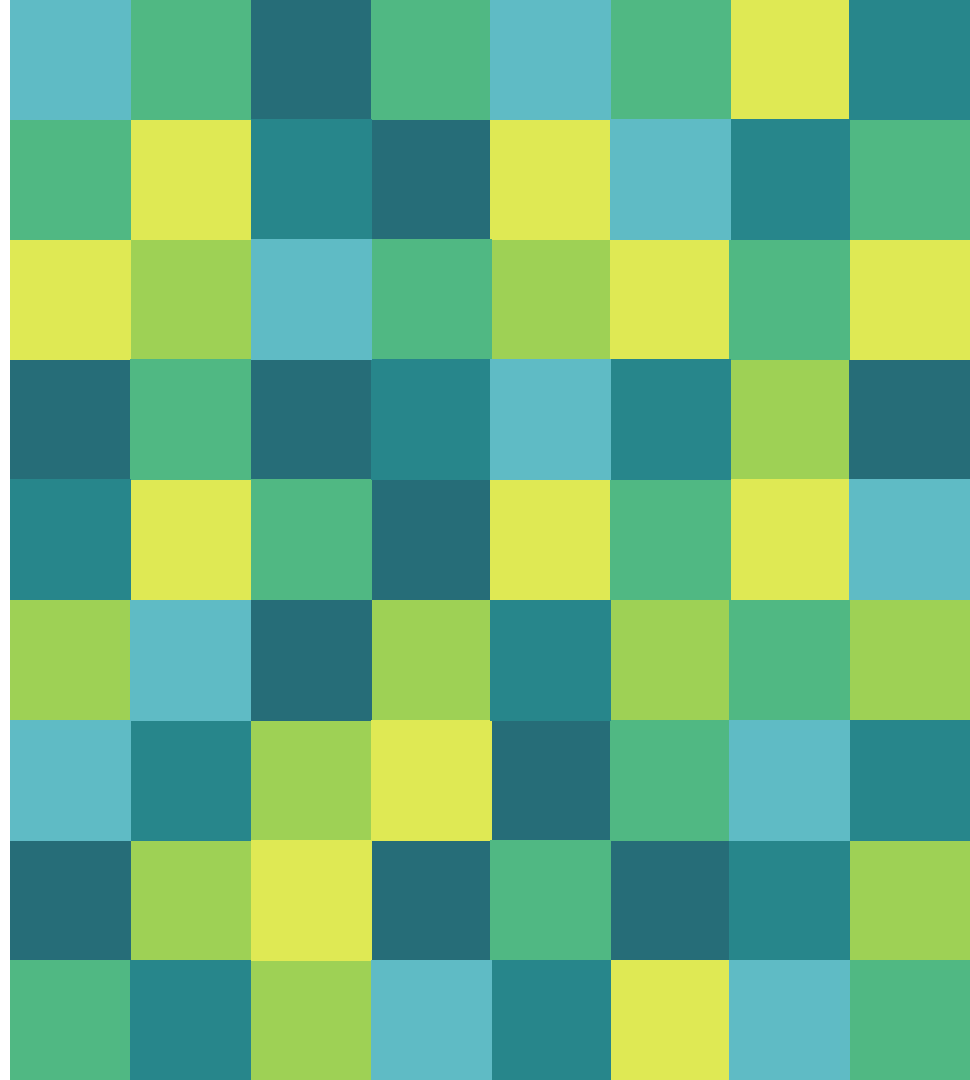




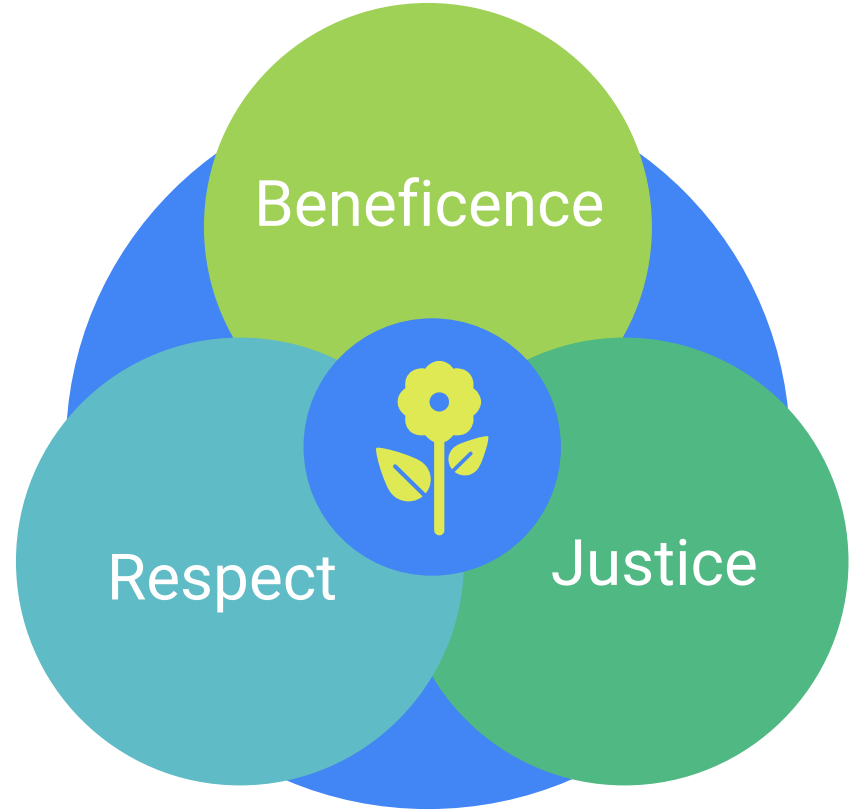
Who? Why? What? When? **How?**

# Dissemination

Challenges & Opportunities



# Ethical principles



# Thank you!

**Any questions?**

You can find me and learn more:

- [coco.auerswald@berkeley.edu](mailto:coco.auerswald@berkeley.edu)
- [i4Y.berkeley.edu](http://i4Y.berkeley.edu)
- [yparhub.berkeley.edu/](http://yparhub.berkeley.edu/)





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