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# How to Conduct Research with Adolescents in Low- and Middle-Income Countries?

YouthPower Learning Webinar

with Speakers from UNICEF, Office of Research - Innocenti and Columbia University

November 16, 2017



*Advancing solutions to transform the lives of young people*



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# YouthPower Learning

## Advancing solutions to improve young lives

- **YouthPower Learning** advances solutions through integrated research and development programs to improve the capacity of youth-led and youth-serving institutions.
- *By engaging youth, their families, communities, and governments in innovative programs, we build young people's skills, assets, and competencies; foster healthy relationships; strengthen the enabling environment; and transform systems.*

### What is Positive Youth Development (PYD)?

PYD programs recognize youth's inherent rights and result in youth who have **assets**, the ability to leverage those assets (**agency**), and the ability to **contribute** to positive change for themselves and their communities, surrounded by an **enabling environment** that supports them

<http://www.youthpower.org/positive-youth-development>



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## How can you benefit from and work with YouthPower Learning?

- Learning from [What Works](#)
- Measuring PYD: [PYD Measurement Toolkit/Indicators](#)
- Sharing and Accessing Webinar Recordings, Resources, Events, Information: Learning Hub [YouthPower.org](#)
- Joining [Communities of Practice](#):
  - Youth in Peace and Security
  - Gender and PYD
  - Youth Engagement
  - Cross-Sectoral Skills
- Leveraging Learnings from YouthPower Projects: [YouthPower Projects](#)
- Applying for an Upcoming [Grant](#)





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## Speakers



Dr. John Santelli, Columbia  
University



Dr. Nikola Balvin, UNICEF, Office  
of Research- Innocenti



# How to Conduct Research with Adolescents in Low- and Middle-Income Countries?

**Dr. John Santelli, Columbia University**

**Dr. Nikola Balvin, UNICEF, Office of Research- Innocenti**



# Introduction: Adolescence a critical period of development



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- 1.2 billion adolescents—the largest cohort in history
- 90 percent live in LMICs
- Adolescence: a critical period of cognitive, emotional, physical and sexual development
- Increased prominence in the international arena:
  - Sustainable Development Goals (SDGs)
  - Global Strategy on Women's, Children's and Adolescents' Health
- Limited comprehensive data collection systems and evidence base for interventions





# Who's in the audience?

## POLL: Your turn

1. Do you conduct research on or with adolescents?
2. Do you commission research on or with adolescents?
3. Do you participate in policy advocacy and programme design to improve adolescent well-being?



# Background: UNICEF Research Programme on the Social and Structural Determinants of Adolescent Well-being

**CASH TRANSFERS** *Identifying pathways through which cash impacts on a safe transition to adulthood* Cross country and program analysis; Testing affects of violence, HIV risk, hope, mental health, work, fertility, education, among others

**CHILD MARRIAGE** *Finding the methodology for multi-sectoral scale-up and operationalizing a determinants approach* Analyzing the policy environment; system and service mapping. Linked to ECM scale up programmes

**FAMILY & PARENTING SUPPORT** *Assessing how parent's characteristics can predict adolescent outcomes* Literature review; Parenting program: RCT + qualitative + process evaluation

**MULTI-COUNTRY STUDY ON VIOLENCE** *Discovering what drives violence against children and solutions for prevention* Establishing an etiology of violence; action research. Multi-country comparative study, developing how to manuals

**ICT** Child Rights in the digital age. *Unpacking how children's rights are being enhanced or undermined through information and communication technologies.* Cross national study - Global Kids Online.

**CROSS – CUTTING**, Gallup World Poll *Determining prevalence and correlation between determinants and youth wellbeing outcomes across the globe (food insecurity focus);* Handbook on Adolescent Development Research *Edited book in collaboration with the Society for Research in Child Development.*

**RESEARCH METHODS, UPTAKE & SYNTHESIS** Gender socialization review, adolescent research digest, research method briefs, Adolescent Gap Map. **GLORI** Global Network of Longitudinal and Cohort Studies

**ADOLESCENT SCORE CARD** *Identifying a core set of globally comparable indicators and guidance* - score card piloting; linking to CRC General Comment and state accountability mechanisms

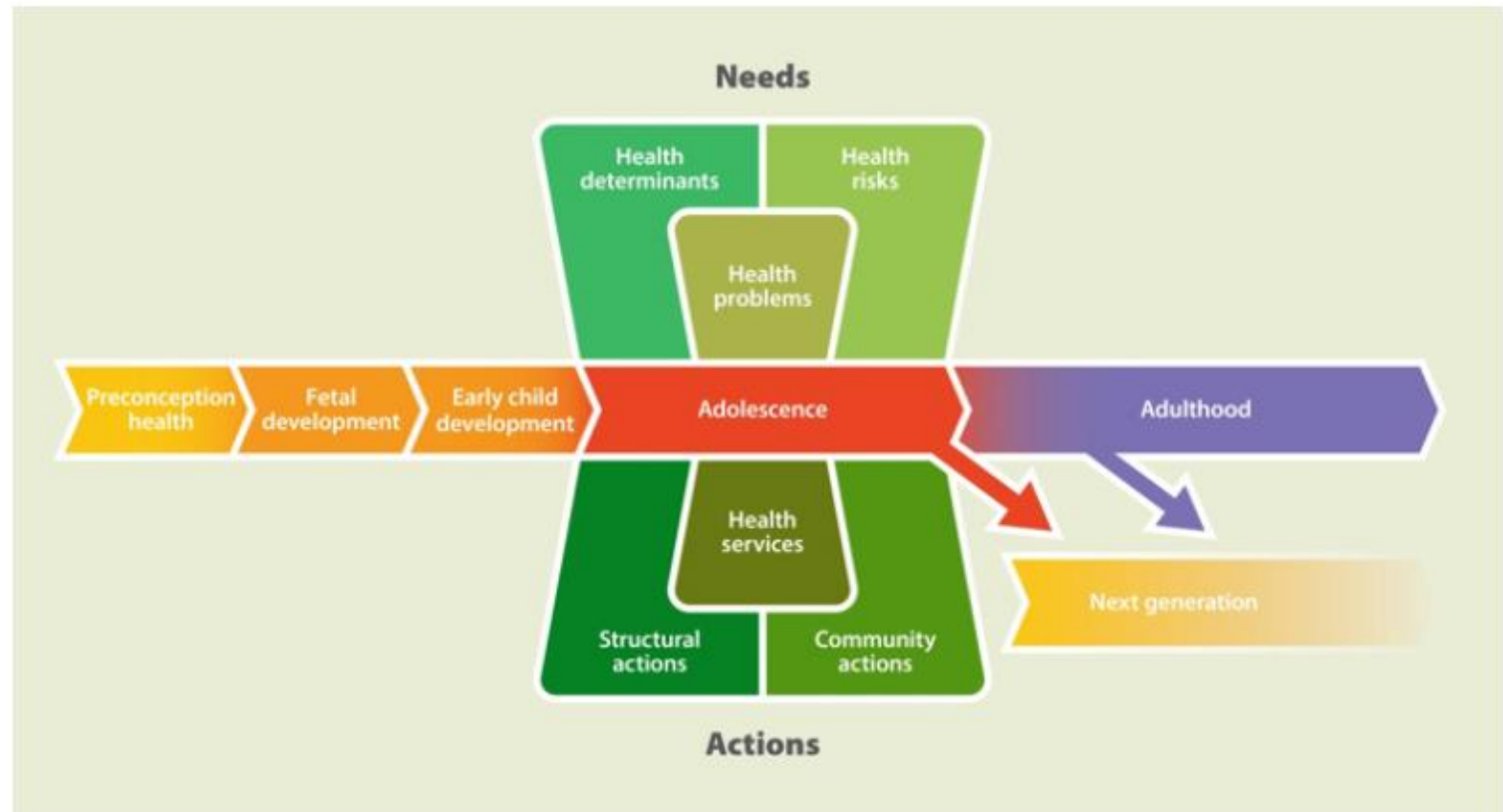
Research Projects in LMICs

Data & Methods  
Measurement





# Background: Lancet Commission on Adolescent Health and Wellbeing



Source: Reproduced with permission from Patton et al., 'Our Future'

A holistic approach to examining adolescent health and well-being across the life-course - by looking at the social and structural determinants

Comprehensive  
data collection systems  
and research on adolescent  
well-being are lacking

The world is  
home to 1.2 billion  
adolescents – the  
largest cohort in  
history

# How to conduct RESEARCH with ADOLESCENTS in Low- and Middle-Income Countries

download  
here

**Adolescence**  
is a critical period of  
cognitive, emotional,  
physical, and sexual  
development with  
consequences across  
the life course

## 7 RESEARCH BRIEFS:

**The importance of  
better research  
methods**  
on adolescent health and  
well-being



Brief  
**1**

**Indicators for  
adolescent health  
and social  
development**  
and global sources of data  
to monitor adolescent  
well-being



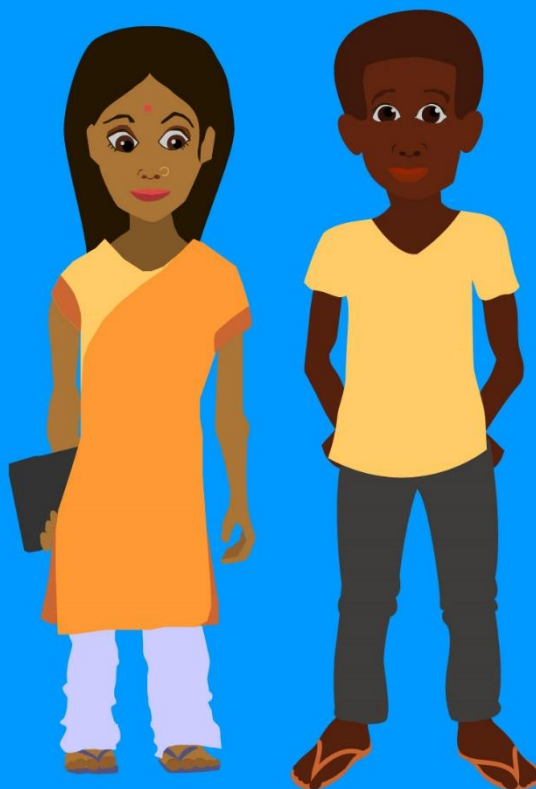
Brief  
**2**

**Ethical principles**  
for involving adolescent  
minors in research



Brief  
**3**

The briefs provide  
guidance on how to  
collect rigorous  
evidence for  
programmes and  
policies to improve  
adolescent health  
and well-being



Brief  
**4**



Research with  
**disadvantaged,  
vulnerable and  
marginalized**  
adolescents

Brief  
**5**



**Adolescent  
participation  
in research**

Brief  
**6**



Research on  
**enabling &  
protective  
systems** for  
adolescents

Brief  
**7**



Methods to evaluate  
**economic  
strengthening  
programmes**



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This series of seven briefs was  
developed in collaboration between  
UNICEF's Office of Research – Innocenti,  
Columbia University and the Lancet  
Commission on Adolescent Health and  
Wellbeing

**unicef-irc.org/**  
adolescent-research-methods



# Methodological Briefs on Conducting Research with Adolescents from Low- and Middle-Income Countries (LMICs)

## Objectives:

- Improve understanding of how to conduct research with adolescents and measure adolescent health and well-being
- Provide an overview of different methodological approaches used in research with adolescents
- Identify what is unique about research with adolescents living in LMICs
- Guide practitioners and decision-makers through established practices and key knowledge gaps in accessible language and format

Link to briefs: <https://www.unicef-irc.org/adolescent-research-methods/>



# Methodological Briefs on Conducting Research with Adolescents from LMICs: Topics and Authors

No.	Title	Authors and Affiliation
1	Improving the methodological quality of research in adolescent well-being	Nicola Reavley and Susan Sawyer (University of Melbourne)
2	Data and indicators to measure adolescent health, social development and well-being	Peter Azzopardi, Elissa Kennedy, George Patton, (University of Melbourne)
3	Inclusion with protection: Obtaining informed consent when conducting research with adolescents	John Santelli, Sonia Haerizadeh and Terry McGovern (Columbia University)
4	Research with disadvantaged, vulnerable and/or marginalized adolescents	Colette L. Auerswald, Amber Akemi Piatt, Ali Mirzazadeh (UC Berkeley School of Public Health; Innovations for Youth (I4Y) )
5	Adolescent participation in research: Innovation, rationale and next steps	Emily J. Ozer & Amber Akemi Piatt (UC Berkeley School of Public Health; Innovations for Youth (I4Y) )
6	How to measure enabling and protective systems for adolescent health	Russell Viner (University College London)
7	Methodologies to capture the multidimensional effects of economic strengthening interventions	Fred Ssewamala and Laura Gauer Bermudez (Columbia University)



## A deeper dive into two briefs ...

Brief 1: Improving the Methodological Quality of Research in Adolescent Well-being

Brief 3: Inclusion with Protection: Obtaining Informed Consent When Conducting Research With Adolescents

Link to briefs: <https://www.unicef-irc.org/adolescent-research-methods/>





# Brief 1: Improving the Methodological Quality of Research in Adolescent Well-being



- **Authors: Nicola Reavley and Susan Sawyer, University of Melbourne**
- Adolescence is a:
  - critical phase within the life course
  - period of biological and social transition that is itself undergoing change (Transitions in transitions)
  - longer period within the life course
  - covered by the Convention on the Rights of the Child
- Definitions:
  - Adolescent: 10-19 years
  - Youth: 15-24 years
  - Young people: 10-24 years





## Brief 1: Improving the Methodological Quality of Research in Adolescent Well-being

- A period of **opportunity and vulnerability**
  - Maturing brain
  - Onset of risk behaviors
  - Determinant of outcomes across the life course
- **Limited evidence**
  - On interventions that work and how to scale up
  - Data collection systems and longitudinal studies
  - Early adolescence
  - From LMICs
  - Age disaggregation is necessary. (E.g. early adolescence=10-14 years, late adolescence = 15-19 years, young adulthood = 20–24 years)



## Brief 1: Improving the Methodological Quality of Research in Adolescent Well-being

- New understanding from **neuroscience** can have important implications for programming
  - 2<sup>nd</sup> biggest set of changes after infancy
  - Most dynamic growth in Pre-frontal Cortex (reasoning, decision-making, planning, self-awareness, etc.), increasing connectivity and sculpting.
  - Emotions and motivation: increases in importance of sense of belonging, social status, motivation for immediate rewards. Difficulty overriding ‘hot emotions’.
- Addressing **social and structural determinants** is crucial to improving adolescent well-being
  - Economic and social conditions in which people are born, grow, develop, live, work and age



# Brief 1: Improving the Methodological Quality of Research in Adolescent Well-being



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- **Inter-sectoral** and comprehensive **multi-component** action is required
  - Structural interventions
  - Media and social marketing interventions
  - Online interventions
  - School and health service-based interventions
  - Community and family-based interventions
- **Gender and equity** (including a focus on disadvantaged, vulnerable and marginalized adolescents) should always be considered



# Brief 3: Inclusion with Protection: Obtaining Informed Consent When Conducting Research With Adolescents

**Authors: John Santelli, Sonia Haerizadeh; Terry McGovern, Columbia University**

## **Brief 3 focuses on:**

- The value of research with adolescents
- The importance of balancing inclusion and protection
- The evolution in social thinking about adolescents' human rights and legal protections
- Ethical principles and research ethical guidelines
- Current scientific understandings about adolescents' decisional capacity and their capability to provide informed consent
- What to do when parents/guardians are not able to act in the best interests of the adolescent
- Ethical and practical recommendations for conducting research with adolescents



# Ethical Concepts and Definitions

## Key concepts

- Inclusion – the right of individual or groups to participate in research & to receive benefit
- Protection – safeguards to prevent harm

## Ethical principles

- Respect for persons– the right of autonomous individuals to make free decisions and protection for vulnerable persons
- Justice/Equity – a fair distribution of the benefits and burdens of research
- Beneficence – the obligation to do good and to avoid harm

## **Informed Consent** – *information, comprehension, voluntary participation*

- Assent – a child's affirmative agreement to participate in research
- Parental Permission – the agreement of parent(s) to their child's participation in research

**Minimal Risk** – ‘the probability and magnitude of harm or discomfort anticipated are not greater...than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.’<sup>1</sup>

1. US Department of Health and Human Services 2007.



# Legal and Human Rights Definitions

## Legal Concepts

- Age of majority – the age at which adolescents become adults and attain the legal rights and privileges of adulthood, commonly age 18
- Child – a person below the age of 18 years
- Emancipation – achievement of adult legal status before the age of majority
  - (e.g., by marriage, motherhood, military service)
- Minor Consent Laws – allow access health care independently before the age of majority
- Mature Minor – derives from common law, the capacity to make independent judgements when faced with specific life decisions

## Human Rights Concepts

- Evolving Capacities –capacities for autonomous decision-making develop with age and maturity; related to the ability of an adolescent to provide informed consent
- Best Interests – recognizes the personhood of the child, the need to provide protection, and promote the human rights of the child





# Barriers to Conducting Research

- Misunderstandings about adolescents' decision-making abilities
- An overzealous valuing of protection over inclusion
- Institutional self-protection
- Antiquated attitudes about adolescents



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# Convention on the Rights of the Child

- *The Committee recognizes that children's evolving capacities have a bearing on their independent decision-making on their health issues*
- *In accordance with their evolving capacities, children should have access to confidential counseling and advice without parental or legal guardian consent, where this is assessed by the professionals working with the child to be in the child's best interests*
- *States should review and consider allowing children to consent to certain medical treatments and interventions without the permission of a parent, caregiver, or guardian*



# Decisional Capacity

## **Adolescents display cognitive abilities for agency, judgment, and self-protection**

- These are fundamental to the capacity to provide informed consent and to make decisions themselves about research participation
- Early adolescents are generally able to make sensible decisions about research and health care - in the absence of coercion and unhealthy influences such as peer pressure
- 14-year-olds are as capable as adults in understanding multiple viewpoints and considering conflicting information
- Adolescents may want the advice of support of parents or adults in making decisions

## **Brain science is rapidly evolving**

- Adolescents' decision-making is influenced by age, social context, experience, emotional states, and the risk and complexity of a particular study
- Research ethics committees should include a professional who works with adolescents and understands adolescent development



# Decisional Capacity

- Capacity is linked to previous life experiences of the adolescent:
  - Illness and self-care
  - Adverse social events and environments and risk behaviors
  - Use of the healthcare system
- Steinberg on adolescents' decision-making and executive functioning:
  - Hot Cognition: Involves affectively charged social interactions with peers such as drinking or engaging in risk taking behaviors
  - Cold Cognition: Adolescents' decision-making is similar to that of adults in controlled, non-emotional settings



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# When Guardians and Parents May Not Be Able to Act in the Best Interests of the Child

- Parents - essential in protecting children from harm in research and other important realms
- However, parents may be unable to fulfill their duty to protect
- Laws around child abuse, child labor, and child marriage are designed to address this failure to protect
- Laws allowing adolescent to seek health care independently from parents recognize the potential for conflicts of interest between parents and adolescents
- Parents may coerce adolescents to make decisions contrary to their best interests:
  - to marry; to continue or abort a pregnancy; to work instead of attending school; to use contraception or to forbid contraceptive use; to participate in research or to forbid participate



# Waiver of Parental Permission in Research with Adolescents

- Parental permission is problematic and a waiver should be considered where:
  - A conflict exists between the best interests of the adolescent and the parent
  - An adolescent is capable of making independent decisions about medical or mental healthcare or social services and/or is legally empowered to make these decisions
  - The adolescent is legally emancipated because of age or status, or is functionally emancipated
  - Parents are functionally incapacitated, unavailable, or otherwise unable to provide permission
  - The adolescent is estranged from their parents
  - The adolescent is capable of providing informed consent for the research, based on the principle of evolving capacity





# Informed Consent from the Adolescent

- Informed consent can often be obtained directly from adolescents, particularly for:
  - Minimal risk studies,
  - Studies that present the possibility of direct benefit,
  - Studies that involve procedures commensurate with adolescent's experience.
- For studies involving considerable risk and the potential for direct benefit, the capacity of adolescents to consent can be assessed by a social or health professional
- Where informed consent is obtained directly from the adolescent, adolescents should be encouraged to seek the advice of parents, other family members, or trusted adults
- Governments should consider removing rigid age restrictions and unnecessary parental consent requirements that impede adolescents' access to research



# Case Study 1

- Adolescent girls at high risk of HIV infection in sub-Saharan Africa
- Investigators in Kenya are planning an in-school RCT of gender-based sexuality education, supports to stay in school (fees, uniforms)
- Students (13-18 years) will be followed for 3 years
- Periodic KAB questionnaires and HIV testing

## Ethical decisions:

- Risks and benefits? Best interests?
- Who can provide informed consent? Evolving capacity? Legal status?
- Special circumstances?



## Case Study 2

- South Africa- very high HIV incidence among young women, occupation migrants, sex workers, others
- Investigators in South Africa are planning a trial of PrEP (pre-exposure prophylaxis) to prevent HIV transmission
- Young women would be followed for 2 years with 3 month HIV testing, STI tests, behavioral measures

### Ethical decisions:

- Risks and benefits?
- Should adolescents be included?
- Certain adolescents excluded?
- Who can provide informed consent?



# Recommendations when Conducting Research with Adolescents

## Research ethics committees and researchers should:

- Shift their thinking about adolescents: from subjects of research to agents in research
- Move from inclusion vs. protection to inclusion with protection
- Work to harmonize laws and regulations influencing research participation by adolescents
- Respect adolescents as persons and rights holders
- Build on science



# Take home messages

- Research with adolescents has unique challenges and methodologies: no longer children, not yet adults.
- Protection and inclusion are compatible.
- Unique indicators are required for certain outcomes.
- Where possible, research should be participatory and empowering to adolescents.
- Disadvantaged, vulnerable and/or marginalized adolescents need to be represented in research and programmes.
- The briefs ask many relevant questions about the way we interact with adolescents. Read them before your next stakeholder meeting, course, etc.





# Q & A

## YOUR TURN: Questions from the audience

- Please type your questions and comments into the side panel.
- Indicate who your question is for.



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# THANK YOU!

- Any questions? Please email [nbalvin@unicef.org](mailto:nbalvin@unicef.org) or John Santelli [js2637@cumc.columbia.edu](mailto:js2637@cumc.columbia.edu)



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# Thank you!

Thank you for participating in the YouthPower Learning event.

The recording and presentation will be sent to all registrants and posted on [YouthPower.org](https://www.youthpower.org).



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