I. Historical and Current Issues Regarding Research Population

A. Focus of this Toolkit

As discussed below, both urban and youth can have many meanings and definitions. Investigators should carefully consider the various definitions in order to explicitly define the population they wish to investigate.

This toolkit focuses on increasing research participation among teenagers and young adults living in urban areas who face disadvantage because of the race/ethnicity and/or low socioeconomic status. This group faces the dual hardship of experiencing health disparities and lower participation in research, and as increasing research participation from groups like this is a primary goal of the toolkits, that is why we have defined our population like this.

B. Contested Definitions

The terms "urban" and "youth" deserve consideration before thinking about how to research this group. Some thoughts are offered below, though they are not exhaustive explorations of these topics. Researchers using these terms should provide further clarity about how they are defining their population of interest.

Recent economic, technological, and demographic changes have altered the distinction between urban spaces and their closest counterpart, the suburban. Implicit in this distinction is that, "the urban is invariably the location of all manner of social pathologies, the suburban is largely marked (or classically unmarked) as a trouble-free zone."[1] Whereas in the mid-20th Century, wealthy (and typically white) people often fled the cities, the last few decades have seen them return to urban centers. This has pushed people of color, immigrants, and less wealthy residents farther out, with the term "inner-ring suburb" emerging to describe the area between the concentrations of wealth in the urban core and outer suburbs.[2] In other words, urban residents vary widely in terms of wealth, race/ethnicity, education level, access to resources, and many other factors.

The term youth is also an oversimplification of a complex situation. It emerged in the early 20th Century as both a focus of academic study, and a distinct market to which products could be aimed—at first, fantasy and adventure entertainment. The latter also produced one of the first widespread moral panics about the state of contemporary youth, a theme that has continued through music, drugs, video games, etc. Another aspect is the idea of transitioning towards independence from one's family. Rather than being universal, this aspect is actually more limited to middle- and upper-class households, as working-class youth often continue living at home and contribute to the household's income.[3] When looking beyond the borders of the United States, it becomes clear that the qualifications for being a youth, and the characteristics of youth, depend greatly on many factors, such as socioeconomic status and culture as well as age.[4]

At times, however, it is necessary to define youth in terms of ages, especially for statistical purpose and/or eligibility for studies. In the United States, the legal definition of adulthood (and thus when one is no longer a youth) is reaching the age of 18 in most circumstances. In some circumstances, this can be lower, as in the case of emancipated minors. Other definitions exist, however. The United Nations defines youth as people between the ages of 15 and 24 years old.[5] The Centers for Disease Control and Prevention's Violence Prevention programs define youth violence as acts committed by young people between the ages of 10 and 24.[6] For the National Institutes of Health, including grants, children are defined as anyone under the age of 18.[7] Other definitions exist as well. The job of the researcher is to make it clear how they are defining youth, whether by age range, cultural factors, youths' own definitions, and/or other factors.

B. Multiple Sources of Identity

Working with youth requires understanding the multiple sources of identity acting on youth, and the consequences those can have. While it may seem obvious, being a young person is just one aspect in creating person's identity: their nationality, citizenship status, race/ethnicity, sexual orientation, gender identity, class, and many other aspects contribute to their identity. Moreover, some (but not all) of these identities are not fixed but fluid; they may also be emphasized or toned down in different situations.[8] This can substantially impact the research process. Assuming that youth can effectively engage with others of a similar age underestimates the social positioning other sources of identity can impose. For example, in one study, youth researchers from a secular background had difficult establishing rapport and understanding with youth who were fervently religious.[9] Thus, it is important to consider youths' multiple identities when engaging them in research.

C. Participatory Research

Participatory research is not a singular approach, and several models exist to describe participatory research with youth. Shier suggests various levels of engagement can occur, ranging from merely listening to youth as part of the research process, to taking those views into account, to having youth share power and responsibility for decision-making with adult researchers.[10] McLaughlin proposes a different spectrum, with projects being adult-led, co-researched, or youth-led.[11] In all participatory models, however, the issue of power is key. How much say do youth have over the choice of topic, the methods to be used, the analysis of data, and the dissemination of findings? How much do adults constrain the choices available to youth and the avenues for them to express themselves?[12]

Working with youth presents unique challenges and opportunities for participatory research. One challenge is that youth researchers often do not have the technical skills that more experienced researchers with years of postsecondary education possess. Power dynamics can also impact interactions. Youth researchers with privilege or those who are more extroverted may talk over or otherwise constrain the voices of other youth researchers. Similarly, as mentioned in section C above, social dynamics can undermine their ability to connect with young people participating in the research.

At the same time, involving youth can bring many opportunities. One is that youth often have deep knowledge of the issue the research project is investigating, which can be helpful in designing the overall project, as well as interpreting the data. When issues of privilege are less of a factor or are mitigated, youth researchers can be expert recruiters of other participants and can help to create a more comfortable environment, leading to richer data collection.[13] These connections can also ensure that dissemination gets back to other youth, boosting awareness of the issue and improving the prospects for involvement in future projects.[14] The youth researchers themselves can also benefit from learning new skills and confidence development. Ideally, youth should be involved as early as possible, and they should collaboratively shape their involvement.[15]

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[1] Dimitriadis, p. 115.

[2] Dimitriadis, pp. 114-119.

[3] Dimitriadis, pp. 8-13.

[4] Dunne, M., Durrani, N., Crossouard, B., & Fincham, K. (2015). Youth Researching Youth: Reflections from a multi-country study of youth claiming rights to education and sexual reproductive health. In Bastien, S. & Holmarsdottir, H.B. (Eds.), *Youth 'At the Margins': Critical perspectives and experiences of engaging youth in research worldwide*. Rotterdam, The Netherlands: Sense Publishers, pp. 302-303.

[5] United Nations Educational, Scientific, and Cultural Organization. (2017). *What do we mean by "youth"?* Retrieved from http://www.unesco.org/new/en/social-and-human-sciences/themes/youth/youth-definition/.

[6] Centers for Disease Control and Prevention. (2017 June 23). *Youth Violence: Definitions*. Retrieved from https://www.cdc.gov/violenceprevention/youthviolence/definitions.html.

[7] National Institutes of Health. (2015 October 13). Inclusion of Children in Clinical Research: Change in NIH Definition. Retrieved from https://grants.nih.gov/grants/guide/notice-files/NOT-OD-16-010.html.

[8] Dimitriadis, p. 110.

[9] Dunne et al., p. 312.

[10] Groundwater-Smith, S., Dockett, S., & Bottrell, D. (2015). *Participatory Research with Children and Young People*. London, United Kingdom: Sage Publications, p. 10.

[11] Dunne et al., p. 303.

[12] Groundwater-Smith, Dockett, & Bottrell, p. 12.

[13] Dunne et al., pp. 307-313.

[14] National Children's Bureau (UK). (2010). *Young People in Research: How to involve us*. London, United Kingdom. Retrieved from http://www.participationworks.org.uk/files/webfm/files/resources/k-items/ncb/Pear%20Leaflet_final_lores/index.pdf.

[15] INVOLVE Support Unit. (2004). *A Guide to Actively Involving Young People in Research: For researchers, research commissioners, and managers*. Eastleigh, United Kingdom: Kirby, P. Retrieved from http://www.invo.org.uk/wp-content/uploads/2012/01/InvolvingYoungPeople2004.pdf.

II. Health and Research Practice

A. Best Practices and Interventions

Centers for Disease Control and Prevention School Health Practices

     School Health Policies and Practices Study (SHPPS)
     https://www.cdc.gov/healthyyouth/data/shpps/index.htm

     School Health Profiles
     https://www.cdc.gov/healthyyouth/data/profiles/index.htm

Healthy People 2020 Evidence-Based Practice for Adolescents and Young Adults

     Alcohol Misuse: Screening and Counseling
     http://www.uspreventiveservicestaskforce.org/uspstf/uspsdrin.htm

     Asthma: Home-Based Multi-Trigger, Multicomponent Environmental Interventions –
     Children and Adolescents with Asthma
     https://www.thecommunityguide.org/findings/asthma-home-based-multi-trigger-
     multicomponent-environmental-interventions-children-and

     Birth Defects: Community-Wide Campaigns to Promote the Use of Folic Acid
     Supplements
     https://www.thecommunityguide.org/findings/birth-defects-community-wide-campaigns-
     promote-use-folic-acid-supplements

     Cervical Cancer: Screening – HPV Testing in Women Younger Than Age 30 (Clinical
     Guide Recommendation)
     http://www.uspreventiveservicestaskforce.org/uspstf11/cervcancer/cervcancerrs.htm

     Gonorrhea and Chlamydia: Screening
     http://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStateme
     ntFinal/chlamydia-and-gonorrhea-screening

     Health Equity: High School Completion Programs
     https://www.thecommunityguide.org/findings/health-equity-high-school-completion-
     programs

     Health Equity: Out-of-School-Time Academic Programs – General
     https://www.thecommunityguide.org/content/health-equity-out-school-time-academic-
     programs-general

     Health Equity: School-Based Health Centers

https://www.thecommunityguide.org/findings/promoting-health-equity-through-education-programs-and-policies-school-based-health-centers

Human Immunodeficiency Virus (HIV) Infection: Screening – Non-pregnant Adolescents and Adults
http://www.uspreventiveservicestaskforce.org/uspstf13/hiv/hivfinalrs.htm

Preventing Tobacco Use Among Youth and Young Adults: A Report of the Surgeon General
https://www.surgeongeneral.gov/library/reports/preventing-youth-tobacco-use/full-report.pdf

Testicular Cancer: Screening – Adolescent and Adult Men (Clinical Guide Recommendation)
http://www.uspreventiveservicestaskforce.org/uspstf10/testicular/testicuprs.htm

Vaccination Programs: Requirements for Child Care, School, and College Attendance
https://www.thecommunityguide.org/findings/vaccination-programs-requirements-child-care-school-and-college-attendance

Violence: School-Based Programs
https://www.thecommunityguide.org/content/violence-school-based-programs

Violence: Therapeutic Foster Care – for Chronically Delinquent Juveniles
https://www.thecommunityguide.org/content/violence-therapeutic-foster-care-chronically-delinquent-juveniles

B. Searchable Resource

Healthy People 2020 Search
https://www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources

III. National and Local Data

A. General Data

Add Health: The National Longitudinal Study of Adolescent to Adult Health
http://www.cpc.unc.edu/projects/addhealth

Centers for Disease Control and Prevention

> National Center for Health Statistics (broad range of health statistics)
> https://www.cdc.gov/nchs/

> National Survey of Family Growth (information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's and women's health)
> https://www.cdc.gov/nchs/nsfg/index.htm

> National Youth Physical Activity and Nutrition Study (NYPANS)
> https://www.cdc.gov/healthyyouth/data/yrbs/nypans.htm

> Youth Risk Behavior Surveillance System (YRBSS – data on behaviors leading to injury or violence, sexual behaviors, drug use, and health-related habits)
> https://www.cdc.gov/healthyYouth/data/yrbs/index.htm

> Web-based Injury Statistics Query and Reporting System
> https://www.cdc.gov/injury/wisqars/index.html

Census of Juveniles in Residential Placements (data on offenders in custody under the age of 21)
https://www.ojjdp.gov/ojstatbb/ezacjrp/

ChildStats.gov: America's Children, Key National Indicators of Well-Being
https://www.childstats.gov/americaschildren/tables.asp

Data Resource Center for Child & Adolescent Health

> Interactive Data Query (broad range of data on health)
> http://www.childhealthdata.org/browse/survey

> National Survey of Children with Special Health Care Needs
> http://www.childhealthdata.org/learn/NS-CSHCN

Department of Justice, Office of Juvenile Justice and Delinquency Prevention:
National Survey of Children's Exposure to Violence
https://www.ncjrs.gov/pdffiles1/ojjdp/227744.pdf

The Health and Well-Being of Children: A Portrait of States and the Nation 2007
https://mchb.hrsa.gov/nsch/07main/

Monitoring the Future: Study of Youth Drug, Alcohol, and Nicotine Use
http://www.monitoringthefuture.org/

National Center for Education Statistics

      Assessments
      https://nces.ed.gov/surveys/SurveyGroups.asp?Group=4

      Data Lab
      https://nces.ed.gov/datalab/

      Elementary & Secondary Surveys
      https://nces.ed.gov/surveys/SurveyGroups.asp?Group=1

      Indicators of School Crime and Safety Report
      https://nces.ed.gov/programs/crimeindicators/

National Data Archive on Child Abuse and Neglect
https://www.ndacan.cornell.edu/

SAMHSA: National Survey on Drug Use and Health
https://nsduhweb.rti.org/respweb/homepage.cfm

B. State and Local Data

Chicago Data Portal
Births to mothers aged 15-19 years old in Chicago, by year, 1999-2009
https://data.cityofchicago.org/Health-Human-Services/Public-Health-Statistics-Births-to-mothers-aged-15/9kva-bt6k/data

Heartland Alliance: Social Impact Research Center, State & Local Datasets
https://www.heartlandalliance.org/research/data-heartland-alliance/

Illinois Criminal Justice Information Authority: Crime & Risk Factor Data Tools
http://www.icjia.state.il.us/research/overview#tab_research-tools

Illinois Department of Public Health: Vital Health Statistics
http://www.idph.state.il.us/health/statshome.htm

Illinois Youth Survey: Health and Social Indicators
https://iys.cprd.illinois.edu/

IV. Ethical and Regulatory Issues

A. Federal and UIC Policies

The U.S. Department of Health and Human Services provides guidance for research involving children, defined as those under 18 in most circumstances, in 45 CFR 46 Subpart D. Special situations include emancipated or mature minors. See https://www.hhs.gov/ohrp/regulations-and-policy/guidance/special-protections-for-children/index.html for a summary and https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html#46.401 for the full regulation.

The UIC policy on Research Involving Children (Including Wards of the State) is available at http://research.uic.edu/node/762. Subpart D of 45 CFR 46 applies to most research at UIC: "It should be noted that the Department of Education and Defense have adopted Subpart D, but the National Science Foundation has not; however, UIC policy affords the same protections to children regardless of the funding source and parallels the additional protections afforded to children as codified in Subpart D to all research involving children."

B. Consent and Assent

This section is intended as a starting point. Researchers should consult the UIC policy on Research Involving Children at http://research.uic.edu/node/762 before designing their project and submitting materials to the IRB.

In most cases, individuals under the age of 18 cannot provide consent to participate in research. Typically, at least one parent or guardian must consent on behalf of the young person. In higher-risk research, the consent of both parents is typically required unless there are extenuating circumstances (such as: one parent is deceased, unknown, incompetent, not reasonably available, or only one parent has legal responsibility for care and custody of the child). The limited circumstances where parental consent may not be required include an emancipated or mature minor, and situations where the IRB determines parental or guardian permission can be waived in order to protect the subjects, such as in the case of abused or neglected children. See http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=1539&ChapterID=35 for the relevant Illinois statute related to minors consenting to medical treatment.

Even when they are not able to legally consent for themselves, young people should not be kept in the dark about research in which they are being asked to participate. For children who are at least seven (7) years old, assent is typically required, and assent documents should be written in an age-appropriate manner. If the IRB has not waived the requirements of parental consent and child assent, both are required for the young person to participate: the failure to obtain either one means the child cannot participate in the research.[16] Forms can be found at http://research.uic.edu/sites/default/files/form/files/assent.doc and http://research.uic.edu/compliance/human-subjects-irb/forms.

In some cases a child's assent to participate in research may not be required, for example, if the child is not able to provide consent because of their age, maturity, or psychological state; or if the research intervention has the potential for direct benefit but is only available in the context of the research. In these circumstances, youth should still be informed about the research with an information sheet and/or discussion. Additionally, if individuals who began the study as children reach the age of majority (typically 18) during the course of the study, there must be procedures in place to get the consent of the now-adult participants.

Some additional dynamics beyond the policy guidance bear consideration. Assent typically follows parental consent. Youth may feel overt or subtle pressure to participate as a consequence, and researchers should be attuned to this. Additionally, the social position of the youth should be considered. As Groundwater-Smith, Dockett, & Bottrell point out, "Have their social, religious, economic, gendered and cultural conditions provided them with the necessary background and understandings to reflect upon that which they are giving consent to?"[17] One important potential source of pressure can be the child's parents or guardians. Research on the consenting process shows that parents can have a strong influence on youths' willingness to participate in research, though this does diminish as youth get older.[18] One possible solution is having part of the assent process take place without the parent(s) present, allowing the youth the opportunity to ask questions or voice concerns without worrying about how they look in front of their parents. However, this must be balanced against parental rights. Researchers should also consider their own social position, and whether this allows them to have open, honest communication with the youth. While there is no set of best practices to address these concerns, researchers should keep them in mind and think about how to navigate them throughout the research process.

C. Framing Research with Marginalized Communities

Research with marginalized communities has often portrayed them negatively. Section I provides some examples of this. Additionally, in a study of family practices in African-American families, the researchers were repeatedly asked, "Please, don't *just* say bad things."[19] In another study, families emphasized the need to focus not just on individual behavior, but also on public policies that can have destructive effects on their communities.[20] Negative portrayals bring up an ethical question: although ethical frameworks tend to focus on individual risks, should group stigmatization be another factor in determining research risk? Some ethicists have argued that unchecked group stigmatization might place undue research burdens on politically disadvantaged members of society.[21] Changing the framework is an appropriate response to these concerns.

Framing the study in a more complete light and including strengths-based measures are two ways to bring more balance to how research portrays communities. When done well, research can actually be a cathartic experience for marginalized individuals and communities. One study found that homeless youth were extending their interviews because they were enjoying the interaction and having the interviewer's undivided attention.[22] Parents of inner-city youth as well have shown their appreciation for research that they believe gives them a greater voice than they would have otherwise.[23] Achieving these results will take careful planning and, usually, the involvement of the community from the start of the research.

D. Forthcoming Changes to the Common Rule

Recent revisions to the Common Rule (the Final Rule, published January 19, 2017 in the Federal Register (https://www.hhs.gov/ohrp/regulations-and-policy/regulations/finalized-revisions-common-rule/index.html) allow more research with children to be classified as exempt, such as research conducted in educational settings involving normal educational practices, limited types of educational testing, certain types of secondary research, and program evaluations of federally-supported projects.[24] Some provisions of the Final Rule went into effect in 2018. Researchers should consult with their IRB for further guidance on these regulations.

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[16] US Department of Health and Human Services, Office for Human Research Protections. (n.d.). *Research with Children FAQs.* Retrieved from https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/children-research/index.html.

[17] Groundwater-Smith, S., Dockett, S., & Bottrell, D. (2015). Participatory Research with Children and Young People. London, United Kingdom: Sage Publications, p. 46.

[18] Institute of Medicine (US) Committee on Clinical Research Involving Children. (2004). Chapter 5: Understanding and Agreeing to Children's Participation in Clinical Research. *Ethical Conduct of Clinical Research Involving Children*. Washington (DC): National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK25560/

[19] Cauce, A.M & Nobles, R.H. (2011). With All Due Respect: Ethical Issues in the Study of Vulnerable Adolescents. In Trimble, J.E. & Fisher, C.B., eds. *The Handbook of Ethical Research with Ethnocultural Populations and Communities.* Thousand Oaks, CA: Sage Publications, p. 17.

[20] Fisher, C.B. & Wallace, S.A. (2000). Through the Community Looking Glass: Reevaluating the Ethical and Policy Implications of Research on Adolescent Risk and Psychopathology. *Ethics and Behavior*, Vol. 10, No. 2, p. 107.

[21] Fisher & Wallace, p. 112.

[22] Cuace & Nobles, pp. 18-19.

[23] Cuace & Nobles, p. 17.

[24] Federal Policy for the Protection of Human Subjects, Final Rule; 82 Fed. Reg. 12 (2017 January 19) (to be codified at 45 CFR pt. 46).

V. Recruitment and Retention Best Practices

A. Settings for Research

The setting for any research is important, but this become heightened when working with youth. Many of the places where the recruitment and/or data collection occur, such as schools, community centers, youth centers, juvenile justice centers, and places of worship are typically not focused on research. This brings up four issues: gatekeeping, privacy, access, and biased sampling.

Gatekeeping describes the way that administrators, clinicians, social workers, and others may limit access to potential research participants. While that may be obvious, it actually brings up several considerations that sometimes pull in different directions. As many gatekeepers are responsible for the well-being of those in their facility or program, they can be overly cautious about letting researchers in. They may also limit the types of research, even when their own participants come up with them: in California, school and parental authorities limited the ability of a student team to research condom access. At the same time, some gatekeepers may unduly pressure youth to participate, in the hopes of increasing access to resources. Though there is no way to prevent any of these situations entirely, involving gatekeepers early in relationship-building can be an important step towards their honest cooperation.[25]

Privacy also becomes an important consideration when performing research in these settings, particularly when researching sensitive topics. For instance, if youth at a school are recruited to participate in a focus group about living with HIV, care should be taken in the outreach materials, recruitment, and logistics for the event so that others do not see who participates. Additionally, there should be extra reminders that information shared in the group is not discussed outside.

Access to the research encompasses many dimensions. Potential participants should be able to get from where they live to the research site, which could mean finding a nearby site, providing transportation support, or both. Once at the location, they should be able to use it: that may mean selecting a location that is stair-free or has signs in braille. Finally, the timing of the research should be adjustable to meet participants' needs. For example, evening or weekend times may need to be provided in place of or in addition to weekday times.

Finally, researchers should be aware of the potential bias introduced when working in these settings. Many youth drop out of school, particularly in high school: in the Chicago Public Schools, the class of 2016 had more than 1 in 5 students drop out (http://cps.edu/SchoolData/Pages/SchoolData.aspx). Thus, simply recruiting high schoolers and expecting them to represent all adolescents would be inaccurate. People who engage in high-risk behaviors, such as drug use or prostitution, may be less willing to visit institutions voluntarily. Youth may not access community centers, even if they are within walking distance, if it means crossing a gang border. Many other factors may limit the representativeness of the youth in these

places. That is not to say researchers should not use them, but that they should acknowledge these barriers and find ways to limit and/or mitigate the effects of this bias.[26]

B. Retention: Keeping Youth Engaged

With all of the other demands on youths' time and interest, keeping them engaged is critical for retention. Checking in with participants lets them know their voice is being heard and increases the chances that problems can be identified and solved before they result in attrition. Where possible, introducing variety into the research can be beneficial. In one study, youth switched between being interviewed, interviewing others, and operating a camera. This not only reduced boredom but gave them the opportunity to experience the situation from multiple perspectives, deepening their understanding. Making connections between the study and larger forces, such as health equity or representation for marginalized communities, can also boost motivation and interest. Enacting these practices should improve retention rates.[27]

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[25] Groundwater-Smith, S., Dockett, S., & Bottrell, D. (2015). Participatory Research with Children and Young People. London, United Kingdom: Sage Publications, pp. 37-54.
[26] Groundwater-Smith et al., pp. 37-54.
[27] Groundwater-Smith et al., pp. 37-54.

VI. Recruitment Templates

FDA Research Volunteer Brochure
http://go.uic.edu/FDA_Research_Volunteer_Brochure

Flyers Aimed at Children and Youth

African American Girl
http://www.ccts.uic.edu/sites/default/files/res_flyer__AFR_F_child_1.doc

African American Girls
http://www.ccts.uic.edu/sites/default/files/res_flyer__AFR_F_child_2.doc

African American Boy
http://www.ccts.uic.edu/sites/default/files/res_flyer__AFR_M_child_1.doc

Latina Girl
http://www.ccts.uic.edu/sites/default/files/res_flyer__HISP_F_child.doc

Latino Boy
http://www.ccts.uic.edu/sites/default/files/res_flyer__HISP_M_child.doc

Simplified Recruitment Language
http://go.uic.edu/Simplified_Recruitment_Language

VII. Community Engagement Resources

A. Local Organizations

Active Transportation Alliance
http://activetrans.org/

Alivio Medical Center
http://aliviomedicalcenter.org/

Alternatives
https://www.alternativesyouth.org/

Casa Central: Youth Opportunities Unlimited
http://www.casacentral.org/our-programs/youth-opportunities-unlimited/

Center on Halsted Youth Programs
http://www.centeronhalsted.org/youth.html

Chicago Public Library: Teen Programs
https://www.chipublib.org/browse/teens/

Chicago Women's Health Center
http://www.chicagowomenshealthcenter.org/

Children's Home and Aid Society of Illinois
https://www.childrenshomeandaid.org/

Consortium to Lower Obesity in Chicago Children
http://www.clocc.net/

Corazon Community Services
http://www.corazon-chicago.com/

Healthcare Alternative Systems
http://www.hascares.org/

Howard Brown Health: Broadway Youth Center
http://howardbrown.org/wp/byc/

Illinois Action for Children
http://www.actforchildren.org/

Metropolitan Family Services
https://www.metrofamily.org/

YMCA of Metro Chicago
http://www.ymcachicago.org/

B. National Organizations

Aspira
http://www.aspira.org/

Boys & Girls Clubs of America
https://www.bgca.org/

Child Welfare League of America
http://www.cwla.org/

Children's Defense Fund
http://www.childrensdefense.org/

GLSEN
http://www.glsen.org/

National Council of Juvenile and Family Court Judges
http://www.ncjfcj.org/

National Education Association
http://www.nea.org/

National Institute on Out-of-School Time
https://www.niost.org/

YMCA of the USA
http://www.ymca.net/

YWCA USA
http://www.ywca.org/

VIII. Researchers at UIC and C3 Working on the Issue

Please note: This list is intended to be illustrative rather than exhaustive. Resources to find additional researchers include https://projectreporter.nih.gov/reporter.cfm, https://clinicaltrials.gov/, https://www.researchgate.net/, and https://scholar.google.com/.

A. UIC

Jaleel Abdul-Adil, PhD & Liza Suarez, PhD, Co-Directors, Urban Youth Trauma Center
https://www.psych.uic.edu/research/urban-youth-trauma-center/our-team

Frank J. Chaloupka, PhD
https://www.ihrp.uic.edu/researcher/frank-j-chaloupka-phd

Geri Donenberg, PhD
http://publichealth.uic.edu/global-health-program/geri-donenberg

Otima Doyle, PhD, MSW, MHS
https://socialwork.uic.edu/facultyandstaff/otima-doyle/

Institute for Juvenile Research
http://www.psych.uic.edu/ijr

Jennifer Hebert-Beirne, PhD
https://oceanhp.uic.edu/jennifer-hebert-beirne-phd-mph/

Stacey S. Horn, PhD
https://education.uic.edu/personnel/faculty/stacey-horn-phd

Michele Kelley, ScD, MSW, MA
https://coeinmch.uic.edu/about/faculty-staff/michele-kelley-scd-msw-ma/

Sonya J. Leathers, PhD
https://socialwork.uic.edu/facultyandstaff/sonya-j-leathers/

Henrika McCoy, MSW, MJ, PhD, LCSW
https://www.henrikamccoy.com/

Robin Mermelstein, PhD
https://www.ihrp.uic.edu/researcher/robin-j-mermelstein-phd

Mariann Piano, PhD, FAAN, FAHA
https://www.nursing.uic.edu/faculty-staff/mariann-r-piano-phd-faan-faha

Lisa M. Powell, PhD
https://www.ihrp.uic.edu/researcher/lisa-m-powell-phd

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Linda A Teplin, PhD
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C. University of Chicago

Chicago Center for Youth Violence Prevention
https://voices.uchicago.edu/ccyvp/

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Harold Pollack, PhD
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Dexter R. Voisin, PhD
https://www.ssa.uchicago.edu/ssascholars/d-voisin

IX. Measuring Instruments

A. Surveys for Use with Youth

Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer
http://proxy.cc.uic.edu/login?url=http://onlinelibrary.wiley.com/doi/10.1002/pbc.25358/full

Adolescent Reinforcement Survey Schedule – Alcohol Use Version
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4956412/

Boston Youth Survey (measures violence exposure, safety, weapons carrying, and bullying)
https://www.hsph.harvard.edu/hyvpc/boston-youth-survey/

Bureau of Justice Statistics: National Survey Of Youth In Custody
https://www.bjs.gov/index.cfm?ty=dcdetail&iid=321

Centers for Disease Control and Prevention

> Measuring Bullying Victimization, Perpetration, and Bystander Experiences: A Compendium of Assessment Tools
> https://www.cdc.gov/violenceprevention/pdf/bullycompendium-a.pdf

> Measuring Violence-Related Attitudes, Behaviors, and Influences Among Youths: A Compendium of Assessment Tools
> https://www.cdc.gov/violenceprevention/pdf/yv_compendium.pdf

> National Youth Tobacco Survey (NYTS)
> https://www.cdc.gov/tobacco/data_statistics/surveys/nyts/index.htm

> Youth Risk Behavioral Surveillance System (YRBSS)
> https://www.cdc.gov/healthyyouth/data/yrbs/index.htm

Communities That Care Youth Survey (measures multiple risk and protective factors)
http://proxy.cc.uic.edu/login?url=https://link.springer.com/article/10.1007%2Fs10940-004-1788-1

Denver Youth Survey (measures delinquency, drug use, victimization, and mental health)
http://www.icpsr.umich.edu/icpsrweb/NACJD/studies/36473

Healthful Eating Attitudes Scale, Youth Version
http://proxy.cc.uic.edu/login?url=https://ijbnpa.biomedcentral.com/articles/10.1186/1479-5868-10-125

National Comorbidity Survey: Adolescent Supplement (measures mental health disorder history)
http://www.icpsr.umich.edu/icpsrweb/HMCA/studies/28581

National Survey of Youth and Religion
http://youthandreligion.nd.edu/announcements/nsyr-releases-survey-instrument/

Pennsylvania Youth Survey (measures behavior, attitudes and knowledge concerning alcohol, tobacco, other drugs and violence)
http://www.pccd.pa.gov/Juvenile-Justice/Pages/Pennsylvania-Youth-Survey-(PAYS).aspx

Sexual Health Information Seeking: A Survey of Adolescent Practices
http://proxy.cc.uic.edu/login?url=http://onlinelibrary.wiley.com/doi/10.1111/jocn.12192/full

Strengths & Difficulties Questionnaire (behavioral screening tool)
http://www.sdqinfo.com/

VIA Youth Survey (measures character strengths)
http://www.viacharacter.org/www/Research-Old2/Psychometric-Data-VIA-Youth-Survey

Youth and Parental Attitudes Toward Fighting
http://proxy.cc.uic.edu/login?url=http://journals.sagepub.com/doi/pdf/10.1177/0886260507312947

Youth Development Study, G2 (measures attitudes towards school and work)
http://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/24881

B. Tools for Parents and Professionals

Healthful Eating Attitudes Scale, Parent Version
http://proxy.cc.uic.edu/login?url=https://ijbnpa.biomedcentral.com/articles/10.1186/1479-5868-10-125

Knowledge, Skills, and Abilities Assessment for Practitioners
http://www.ncwd-youth.info/sites/default/files/KSA-Assessment_for_Professionals.pdf

Parent Attitudes toward Youth Sexual Behavior
http://proxy.cc.uic.edu/login?url=http://www.jstor.org/stable/1132083

Parent-Reported Reasons for Nonreceipt of Recommended Adolescent Vaccinations
http://proxy.cc.uic.edu/login?url=http://journals.sagepub.com/doi/pdf/10.1177/0009922811415104

Youth Development Study, G1 (measures adult attitudes towards teen employment)
http://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/24881

Youth and Parental Attitudes Toward Fighting
http://proxy.cc.uic.edu/login?url=http://journals.sagepub.com/doi/pdf/10.1177/0886260507312947

X. Program Announcements for Grants

National Institutes of Health (note: Smaller grant opportunities may have an associated R01 grant. The R03/R21/R34 opportunities were prioritized here. Each grant closes no earlier than 2019.)

Basic Mechanisms of Brain Development Mediating Substance Use and Dependence (R01)
https://grants.nih.gov/grants/guide/pa-files/PA-17-119.html

Characterization of the Adolescent Reproductive Transition (R03)
https://grants.nih.gov/grants/guide/pa-files/PA-16-316.html

Characterization of the Adolescent Reproductive Transition (R21)
https://grants.nih.gov/grants/guide/pa-files/PA-16-315.html

Chronic Condition Self-Management in Children and Adolescents (R21)
https://grants.nih.gov/grants/guide/pa-files/PA-17-116.html

End-of-Life and Palliative Needs of Adolescents and Young Adults (AYA) with Serious Illnesses (R21)
https://grants.nih.gov/grants/guide/pa-files/PA-15-325.html

Linking the Provider Recommendation to Adolescent HPV Vaccine Uptake (R03)
https://grants.nih.gov/grants/guide/pa-files/PAR-16-337.html

Linking the Provider Recommendation to Adolescent HPV Vaccine Uptake (R21)
https://grants.nih.gov/grants/guide/pa-files/PAR-16-336.html

Oral Anticancer Agents: Utilization, Adherence, and Health Care Delivery (R21)
https://grants.nih.gov/grants/guide/pa-files/PA-17-061.html

Reducing the Duration of Untreated Psychosis in the United States (R34)
https://grants.nih.gov/grants/guide/pa-files/PAR-16-264.html

Screening and Brief Alcohol Interventions in Underage and Young Adult Populations (R03)
https://grants.nih.gov/grants/guide/pa-files/PA-15-296.html

Screening and Brief Alcohol Interventions in Underage and Young Adult Populations (R21)
https://grants.nih.gov/grants/guide/pa-files/PA-15-294.html

Ford Foundation
https://www.fordfoundation.org/work/challenging-inequality/

Jacobs Foundation Research Fellowships
http://jacobsfoundation.org/what-we-do/research-funding/jacobs-research-fellowship-program/

The Joyce Foundation
http://www.joycefdn.org/apply/what-we-fund

Robert Wood Johnson Foundation Research, Evaluation, and Learning Grants
http://www.rwjf.org/en/how-we-work/rel.html

William T Grant Foundation Research Grants
http://wtgrantfoundation.org/grants/research-grants

XI. Community Stakeholder Involvement

A. Urban Youth Specific Resources

Healthy City Collaborative Youth Council Advisory Council
Sabrina Nelson
sabrina1@uic.edu
Angela Ellison
aellison@uic.edu

B. General Resources for Individuals

National Institutes of Health – Clinical Research Trials & You
https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics

Research Fundamentals for Activists
http://www.treatmentactiongroup.org/sites/default/files/201305/RFA%20FINAL.pdf

Research Match (search for clinical trials to join)
https://www.researchmatch.org/

C. General Resources for Organizations

Alliance for Research in Chicagoland Communities, Northwestern University

   Assessing your Organization's Research Environment and Capacity
   http://arccresources.net/wp-content/uploads/2013/08/Assessing-your-Organizations-Research-Environment-Capacity.pdf

   Community-Based Participatory Research 101
   http://arccresources.net/wp-content/uploads/2014/01/CBPR-101-2014expanded.pdf

   Community-Engaged Research Funding & Grantwriting Tips and Strategies
   http://arccresources.net/wp-content/uploads/2015/01/CEnRFunding.GrantwritingTips.Strategies.pdf

   Community Partner Resources
   http://arccresources.net/category/community-partners/

   Considering and Developing Your Organization's Research Purpose
   http://arccresources.net/wp-content/uploads/2013/08/Considering.Developing-Your-Organization%E2%80%99s-Research-Purpose.pdf

   Introduction to Qualitative Research Methods

http://arccresources.net/wp-content/uploads/2015/09/Intro-to-Qualitative-Research-Methods.pdf

Introduction to Research Design
http://arccresources.net/wp-content/uploads/2013/08/Intro-to-Research-Design.pdf

NIH Biosketch for Community Partner
http://arccresources.net/wp-content/uploads/2015/06/NIH-Biosketch-for-Community-Partner.pdf

Patient and Stakeholder Engagement (PCORI)
http://arccresources.net/wp-content/uploads/2013/12/Patient-and-Stakeholder-Engagement-in-Patient-Centered-Outcomes-Research-PCORI.pdf

University 101
http://arccresources.net/wp-content/uploads/2014/12/University-101full.pdf

Center for Clinical and Translational Sciences
http://www.ccts.uic.edu/

Recruitment, Retention, and Community Engagement Program
http://www.ccts.uic.edu/content/recruitment-retention

Clinical Trials Database
https://clinicaltrials.gov/

Community Based Participatory Research 101: From a Community Partner Perspective
Harlem Community & Academic Partnership
https://ccph.memberclicks.net/assets/Documents/CNREI/cbpr%20101%20presentation.pdf

A Quick Start Guide to Conducting Community-Engaged Research
Southern California Clinical and Translational Science Institute, Office of Community Engagement
http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf

UIC Office of Community Engaged Research and Implementation Science
https://cancer.uillinois.edu/outreach-program

UIC Office of Community Engagement and Neighborhood Health Partnerships
https://oceanhp.uic.edu/

XII. Team Readiness to Work with Special Populations

A. Cultural competency training

Cultural Competence Assessment Instrument (CCAI)
http://ccbmdr.ahslabs.uic.edu/wp-content/uploads/sites/5/2014/04/CCAI.pdf

Cultural Competence with LGBTQ Clients
Cultural Competence in HIV Care
http://www.matec.info/programs/illinois

National Research and Training Center (NRTC) Training and Education: Toolkit and Training
on Assessing Cultural Competency in Peer-Run Mental Health Programs
http://www.cmhsrp.uic.edu/nrtc/starcenter.asp

B. Team diversity representation

Making sure that the research team has some representation of the target special population
group helps establish trust, understanding, and credibility. For example, having a person who
identifies as LGBT when needing to recruit participants among the LBGT community, or having
an African-American person on the research team when surveying other African-American
individuals, can make for a more effective study.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

Implicit Association Test (IAT)
http://projectimplicit.net/nosek/iat/

Look Different's Implicit Association Tests
http://www.lookdifferent.org/what-can-i-do/implicit-association-test

Project Implicit
https://implicit.harvard.edu/implicit/

*D. LH-STEP – Helps assess an individual's capabilities by measuring skills, abilities, and
potential for success.*

http://www.creativeorgdesign.com/tests_page.php?id=477

E. Resources to Evaluate Attitudes and Train Skills Necessary for Working with Urban Youth

3 Basic Counseling Skills for Working with Teens
http://centerforadolescentstudies.com/3-basic-counseling-skills-working-teens/

Competencies for Professional Child & Youth Work Practitioners
http://www.cyc-net.org/pdf/2010_Competencies_for_Professional_CYW_Practitioners%20(1).pdf

Youth Service Professionals' Knowledge, Skills, & Abilities Training Modules
http://www.ncwd-youth.info/ksa/training-modules/

Citing the CCTS's Target Population Toolkit

The LGBT Target Population Toolkit was developed by the UIC Center for Clinical and Translational Science's Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

"The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health."

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