



COMMITMENT TO ACTION

# Ethics in Youth-Powered Program Design

Ethics and integrity in human-centered design for adolescent and youth sexual and reproductive health

PHOTO CREDIT: A360, TANZANIA

This Commitment to Action was developed by the HCD Exchange through the leadership of Population Services International (PSI). The HCD Exchange is a representative group of implementers, designers and funders who are committed to increasing the understanding and use of human-centered design (HCD) as an approach when working with adolescents and youth.

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*At CIFF, we fully support the integration of children and adolescent voices into structuring design thinking and development practices. Development necessitates working with youth, not just for youth, and moving forward we see this commitment as an end goal for development organisations across the board.*

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# ACRONYMS AND **ABBREVIATIONS**

AYSRH	Adolescent and Youth Sexual & Reproductive Health
FP2020	Family Planning 2020
HCD	Human-centered design
IRB	Institutional Review Board
MSI	Marie Stopes International
PSI	Population Services International
SRH	Sexual and reproductive health
UNICEF	United Nations Children's Fund
WHO	World Health Organization



# STARTING POINTS

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## WHAT DO WE MEAN BY ADOLESCENTS AND YOUTH?

This Commitment to Action refers to adolescents and youth as those ranging in age from 10-24 years old. The Commitment recognizes that this population is large and diverse, as are the needs within it. For deeper reflection on who adolescents are and the life experiences that often define them in research, see the World Health Organization’s *Guidance on Ethical Considerations in Planning and Reviewing Research Studies on Sexual and Reproductive Health in Adolescents (pages 3-11)*<sup>1</sup>.

At times we use the term “young people” in this document, interchangeably with adolescents and youth.

## WHAT DO WE MEAN BY HCD?

Human-centered design (HCD) is the process of integrating human perspectives and contexts in all steps of the problem-solving process. It is a creative, iterative, participatory and empathy-driven approach to transform insights about human needs into a range of potential design solutions that are tested and refined with the people they intend to serve.

HCD is an approach to design thinking. At times we use the term *design thinking* in this document.

For more information about HCD, see the websites for HCD Exchange partners IDEO.org<sup>2</sup>, Y-Labs<sup>3</sup> and Dalberg Design<sup>4</sup>. For examples of where HCD is being used for AYSRH, see PSI’s Adolescents 360 and Ignite projects<sup>5</sup>, MSI’s Future Fab project<sup>6</sup>, and Pathfinder’s Beyond Bias project<sup>7</sup>.

## WHO MAKES UP THE AYSRH TECHNICAL COMMUNITY?

Those people and institutions that work on adolescent and youth sexual and reproductive health (AYSRH) around the world. These include implementing organizations, donors, governments, HCD partners, design firms, evaluators, government partners and others. Adolescents and youth are key partners within all of these organizations and entities.

<sup>1</sup>Guidance on ethical considerations in planning and reviewing research studies on sexual and reproductive health in adolescents. Geneva: World Health Organization; 2018; License: CC BY-NC-SA 3.0 IGO.

<sup>2</sup>IDEO.org: <https://www.ideo.org/approach>

<sup>3</sup>Y-Labs: <http://y-labs.org/>

<sup>4</sup>Dalberg Design: <https://www.dalberg.com/human-centered-design>

<sup>5</sup>Adolescents 360: <https://www.a360learninghub.org/> and Ignite: <https://www.psi.org/special-project/ignite/>

<sup>6</sup>MSI: <https://www.maristopes-us.org/2018/factsheet-future-fab/>

<sup>7</sup>Pathfinder: <https://www.pathfinder.org/projects/beyond-bias/>





## BACKGROUND

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Over the last decade, there has been growing interest and excitement across the global health sector -- and particularly among those donors, governments and organizations working on AYSRH -- to reignite the way we design and adapt programs to better meet adolescents' and young people's needs.

One approach in the program implementer's toolbox is HCD. HCD is an approach to design-thinking. Elements that are core to HCD -- connecting with people through empathy; generating deep insights about their lives; coming up with ideas (ideation); co-creating solutions; rapidly testing rough solutions (prototyping); continually refining prototypes (iterating); and failing fast in order to pivot, among others -- have re-energized the AYSRH community for a variety of reasons, including a focus on meaningful engagement of adolescents and youth in the design of programs that serve them.

Some would say HCD has injected a magnetic hopefulness about the prospect of achieving global goals, like Family Planning 2020 (FP2020).

With this excitement and optimism, however, comes skepticism and anxiety about HCD's application to reach the best outcome for the AYSRH community at large -- and the young people we serve, specifically.

HCD methods are often used as part of other approaches (such as behavioral economics, social and behavior change communication, market research, cultural anthropology, etc.), to better understand and design for users. Together, these approaches fall under the definition of design thinking and are used to develop a deep and nuanced understanding about what matters to people -- what triggers different emotions and how that relates to the different choices they make. This approach relies upon the willingness of those people to discuss openly and honestly what they feel, hope for, aspire to, fear, love, hate, do, etc.

**When we enter an adolescent's or young person's world, we are guests in their experience. It is our responsibility, as a technical community, to ensure that they understand their rights to participate and that when they engage with HCD teams, they are not only protected and safeguarded -- physically, emotionally and psychologically -- but that their voices are amplified with authenticity and their permission.**

# This Commitment to Action is the start of a conversation.

PHOTO CREDIT: MARIE STOPES, ZAMBIA



## WHAT THIS IS

It is a shared intention to continuous and transparent improvement -- for individual organizations and as a sector -- and an invitation to discuss within our technical community the complexity and nuances of doing this work. The Commitment is intended to be generative and to provoke deep thinking and discussions based on constant reflection and learning.

The 20 principles that make up this commitment are written for the AYSRH technical community to honor and uphold when conducting HCD with adolescents and youth, throughout every stage of the design process. This includes empathy-building phases (especially when ethical review -- e.g. from an Institutional Review Board (IRB) -- is not being sought), through to insight generation, ideation, prototyping and piloting stages.

This Commitment is based on internationally recognized and validated sources that discuss the ethics -- principles and practices -- of conducting research with children and adolescents in development settings. Many of the principles are adapted specifically from [UNICEF's Ethical Research Involving Children](#)<sup>8</sup> and the [WHO's Guidance on Ethical Considerations in Planning and Reviewing Research Studies on Sexual and Reproductive Health in Adolescents](#)<sup>1</sup>.

While this Commitment is specifically written for the AYSRH technical community, we recognize the need for a common set of ethical principles that transcends disciplines and defines engagement of adolescents and youth in HCD processes writ large.

Additionally, while it is written with a specific focus on HCD, it can and should be applied across all projects that incorporate a design-thinking approach. These include those that use behavioral economics, marketing research and essential elements of HCD processes, such as empathy-building, insight generation and prototyping.

## WHAT THIS IS NOT

This Commitment to Action is not a new set of ethical guidelines for conducting research or program design. There are already validated guidelines and protocols for conducting ethical research and program design, particularly with children, which this Commitment to Action was modeled after and which this technical community upholds. This Commitment to Action does not replace current literature or practice on ethics. Those must be in place in order to begin any HCD program with adolescents and youth and must take into account the specific needs of different segments of the population related to their demographics, psychographics and behaviors. This Commitment to Action is also not a "how-to" guide or toolkit. We hope to develop such materials at a later date to complement this Commitment.

This Commitment to Action is not to be used by any one actor (e.g. donor, government, HCD partner, program implementer) as a checklist or evaluative framework. It is not a monitoring and evaluation plan nor accountability document.

This Commitment is not the end of a conversation or something that is set in stone. It is a statement of purpose and is intended to spark thinking, dialogue and action.

<sup>8</sup>Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). Ethical Research Involving Children. Florence: UNICEF Office of Research – Innocenti.





PHOTO CREDIT: A360, ETHIOPIA

### WHY THIS IS IMPORTANT

Even though protection and research ethics should permeate all of global health programming, we recognize the particular vulnerability and uniqueness of adolescents and youth -- especially in the context of SRH and especially among girls -- due to their diminished social and economic status, persistent denial of their rights and restrictive cultural, religious and gendered norms. A renewed attention is therefore needed to ensure full protection, safety and ethical approaches with and for adolescents and youth when implementing design-thinking, at the nexus where research, design and implementation meet. We hope that making this public commitment will further hold each of us accountable to ourselves, our organizations, this technical community and most importantly to the adolescents and youth that take part in our programs.

Eventually, we hope that the Commitment will lead to global tools and standards of HCD and design thinking practice that are shared and upheld by everyone working with adolescents and youth.

### Who should sign

**Everyone who is committed to upholding ethics and integrity when designing AYSRH programs, services and products -- especially those who use a design-thinking approach.**





## OUR PRINCIPLES

PHOTO CREDIT: BEYOND BIAS, BURKINA FASO

This Commitment to Action is framed around three core principles that are well understood within the research and SRH practice communities: **Respect, Justice** and **Do No Harm/ Beneficence**. Each is described in detail in the Ethical Research with Children project<sup>5</sup>, after which these principles are modelled from.

### OVERALL

#### **We are *all* responsible for upholding ethics and the dignity of adolescents and youth when conducting HCD for AYSRH.**

We, the international AYSRH technical community -- including all who participate in commissioning, funding, researching, designing, evaluating and participating in HCD processes with and for adolescents and youth -- are responsible for ensuring that the highest ethical standards are met in all HCD research and program design involving adolescents and youth, regardless of approach or whether an independent or expert ethical review is sought.

#### **Ethical considerations are vital throughout the entire HCD process, not just during the empathy-building phase.**

With HCD, we are asking adolescents and youth to share their values, insights, knowledge and personal experiences. We do this during initial consumer engagement phases (e.g. empathy-building and insight generation), design phases (e.g. ideation and co-creation), prototype testing (e.g. rapid testing and live prototyping) and pilot testing. Our work must serve adolescents' and youth's needs, and safeguard their well-being, wherever we are in that process.

#### **Ethical HCD with adolescents and youth requires ongoing reflection and action.**

Iteration is a cornerstone of HCD. Iteration allows practitioners to explore new concepts, take low-stakes risks, and follow hunches. Iteration is important because it makes feedback from adolescents and youth a critical part of finding a solution. The very nature of iteration therefore demands that we continually reflect on our practices, cultural context, and shared dialogue each and every time we are interacting with our participants. This requires ongoing attention to the assumptions, values, beliefs and practices that influence the HCD process and impact adolescents and youth.

#### **HCD plays a valuable role in a health systems approach, usually as a complement to other approaches. At times, it will not be the right approach to use.**

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The decision to use HCD should be strategic, thoughtful and collaborative. HCD works best when paired with complementary health systems approaches that can be

valuable in generating different insights, points of view and balancing out biases. These complementary approaches are critical for avoiding blind spots and potential pitfalls because they help keep HCD grounded in what is already known from the evidence-base. Health systems approaches are particularly important when making program design decisions for adolescents and youth from traumatized groups or in acute humanitarian/emergency settings. Always ensure special care and considerations are made for their experience before, during and after engaging with them. This means assessing their safety, potential risks for involvement, whether community sensitization has taken place and creating risk mitigation plans. See [Design for Health](https://www.designforhealth.org/complementary-approaches/)<sup>9</sup> for more information on complementary approaches.

### **HCD does not replace robust research when that research is needed.**

HCD is a design process that shares common principles and methods with ethnographic research. However, it is not meant to, nor does it, replace more robust research when that research is needed. For instance, HCD should not replace research for gaining an in-depth understanding of a specific audience or social phenomenon, collecting representative data from a population, attributing project interventions to program outcomes, measuring the impact of interventions, or comparing effectiveness of intervention strategies, among others.

### **HCD interventions build on what is known, in addition to adding new value.**

HCD design should take into account the existing evidence base and build on what is known as best practice, rather than beginning from scratch. This includes conducting or using existing desk reviews and landscape analyses that present up-to-date research and evidence to inform the HCD process, and building in assessments of and plans for whether and how to sustain and scale solutions beyond the prototype and pilot phases. It is part of our pact with adolescents and young people that we try to develop solutions that can generate lasting value for their lives.

## **RESPECT**

### **Respect for adolescents and young people is core to ethical HCD for AYSRH.**

Adolescents youth are persons in their own right and are worthy and capable of recognition, respect and voice in HCD research and program design. Whether they are part of our design team or participants we engage with through research and prototyping, the AYSRH community values

their lived experiences, dignity, capabilities, perspectives and emotions. To respect adolescents and youth involved in HCD -- as implementers or participants -- means to honor their privacy, confidentiality, rights, cultural context, views and experiences. It means being aware of and mitigating any potential harms from their engagement in the HCD process; and producing information that is true to their realities and their contributions to that process. This allows the AYSRH community to situate the HCD process within their lives, rather than making them step out into ours.

### **Adolescents and youth always have the right, and the opportunity, to decide whether or not to take part in HCD work.**

Adolescents' and young people's participation in any (and every) stage of the HCD process is always voluntary. Whether implementing HCD or engaging in it as a participant, adolescents and youth must be fully informed about who they are working with, what they are being asked to do, why they are being asked and what impact their participation may have on their lives. They must also know that they can stop participating at any time, at any stage of the process, for any reason and without consequences to them. It is the responsibility of the AYSRH technical community to honor this right while meaningfully engaging them to design work that is, whenever possible, beneficial to their lives and avoid work that is or could be perceived as extractive.

### **The people and organizations embedded in local contexts are the experts of those contexts and cultures, and that expertise should be leveraged.**

One of the most powerful elements of an effective HCD process is the bringing together of "unlikely teams." Teams that combine public health experts, designers, researchers, practitioners, adolescents and youth from the community, and others who bring a different expertise and perspective, are often able to unlock novel and creative ideas through collaborative processes. "Outsiders," such as those not from the country, community or profession, can lend tremendous value in bringing fresh eyes and a beginner's mindset to the process. That said, the expertise about local culture, context, practices, and customs, sits with those who are from those places. This not only means the adolescents and youth we work with, but health providers and other health systems actors. Without their involvement, solutions might not be sustained. It is important that we leverage that expertise during all stages of the HCD process.

<sup>9</sup>Design for Health: <https://www.designforhealth.org/complementary-approaches/>



PHOTO CREDIT: BEYOND BIAS, BURKINA FASO

**We foster environments that are safe, private and give adolescents and youth the power to express their voices and creativity in partnership with supportive adults.**

An underpinning of HCD for AYSRH is the ability for adolescents and youth to discover and harness their innate curiosity and creativity, while maintaining the privacy of the information that they share. This requires special attention to the collection of identifying information, including identifying images (e.g. photographs and video) and limiting the collection and use of identifying data to when it is necessary to achieve program goals. We must have consent from individuals if we are to use their identified data, internally or externally. Minors cannot give consent; usually, their parents must. Minors can only assent. We recognize that the more identifying information we have, the higher the risks. We commit to protecting privacy throughout every stage of the HCD process, with particular attention to when, how

and which types of data we collect. See WHO for more details on assent and informed consent.<sup>1</sup>

**We maintain confidentiality of people and their data.**

Confidentiality, an extension of privacy, requires a plan and system to keep confidential data and findings that result from the participation of adolescents and youth in the HCD process. We commit to maintaining confidentiality of data throughout the HCD process, limiting access to only those who need it, and storing data securely throughout the data life cycle. This commitment must be explained, in clear and understandable terms and language, to the adolescents and youth that participate in and benefit from our programs. We will follow standard research ethical guidelines for the protection of data and information beyond the life of the HCD project by means of restricting access, ensuring secure storage, safe sharing/dissemination and destruction. For more on privacy and confidentiality, see WHO's Guidelines<sup>1</sup>.

**JUSTICE**

**In HCD work, we strive for the equitable participation of adolescents and youth, across different genders and among varying levels and positions of power.**

To be just when implementing HCD for AYSRH means acknowledging and confronting the inherent power inequities between youth and adults – particularly adults who are bringing professional expertise (research, design, program implementation) to the collaborative process. These inequities also exist between youth and their communities, their families and between one another. These unequal relationships require negotiation between the youth and adults involved in the HCD process, as well as with potential gatekeepers or other adults, and must take place within the cultural context in which the HCD work is situated. Equally we recognize the rights of particularly marginalized adolescents and youth to engage in our HCD work and take steps to include them, alongside those who already have agency and privilege. We commit to paying particular attention to the equitable participation of adolescent girls. It requires deep reflection on the positioning of adolescents and youth in the local ecosystem, particularly when there are adults involved in the HCD work that come from “the outside,”

**Adolescents and youth that are part of HCD implementing and design teams are recognized and appropriately compensated for their time and work.**

To be just in our HCD work means to treat the adolescents and youth that collaborate on our implementing and design teams as equals. They should not carry undue burden of work, nor be assumed to be volunteers just because they are young. Every HCD planning process should include the meaningful recognition of adolescents' and young people's contribution and the mitigation of associated costs of their participation. It is equally important to ensure that their participation is not influenced by undue incentives.



## DO NO HARM/BENEFICENCE

### **Adolescents' and young people's emotional and physical wellbeing come before everything else.**

The imbalance of power between youth and adults must never result in emotional or physical harm to adolescents and youth. We will develop detailed plans to address the emotional and physical health needs that might result from adolescents' and young people's participation in our HCD work. This is in line with Article 3 of the [Convention on the Rights of the Child](https://www.ohchr.org/en/professionalinterest/pages/crc.aspx)<sup>10</sup>.

### **We acknowledge the integral role of safeguarding when planning, implementing and disseminating our HCD work with adolescents and youth.**

The AYSRH technical community will not allow youth to be harmed or put at risk because of their involvement in our HCD work. This means always obtaining informed consent/assent<sup>1</sup> from a young person before involving them in an HCD process and ensuring that this consent holds throughout every stage of the process. Consent needs to be based on a balanced and fair understanding of what is involved throughout the HCD process. Do no harm also means accurately describing the HCD process to the adolescents and youth involved, including the activities required, time commitment, possible risks and possible benefits. These must be communicated to the adolescents and youth as part of the informed consent process. Only then can they make an informed decision about whether to take part.

### **It is our responsibility to openly and honestly communicate expectations of the HCD process to all involved -- most importantly the communities that are engaged in prototyping.**

Prototyping is a powerful process that allows design teams and users to explore and test compelling product and service ideas together. It is a crucial and exciting part of the design process but, for a myriad of reasons, it is vital to take extra care when prototyping in the AYSRH space. It is our responsibility to ensure that when we make an idea tangible (a prototype) and then create an immersive experience in order to gain feedback (prototyping), we distinguish that from an actual program or pilot with participants. This includes considering the level of fidelity (level of detail, functionality or polish) of a prototype as it relates to provision of care and expectations of participants. The higher the fidelity, the more likely the prototype will be perceived as "real." It is important to clearly state the intention and possible outcomes of prototyping with participants, to avoid confusion, disappointment and loss of trust if the final

intervention is not implemented, or is implemented in a very different way in that community, beyond prototyping.

### **We will focus on managing expectations and communicating clearly when products, services or experiences are tested at a higher fidelity.**

We embrace the intentional discussion and planning that designers and partners may need to engage in to ensure the ethical engagement of adolescents and youth, particularly surrounding managing expectations around prototyping. Examples include ensuring participants are aware that the service is "temporary" and a "test" (and not necessarily immediately available afterwards) and that as participants, they are "co-designers" (that their honest opinions will help improve this idea in the future). This includes additional sensitivity for high-fidelity prototyping, prototyping with real health services, and those that involve sensitive information.

### **Cultivating HCD skills and confidence in young collaborators and participants is a shared opportunity and responsibility.**

For HCD, ethics is not just about discernment and protections. Ethics is also about adding value to the communities in which we work. As a technical community, we're committed to integrating explicit training and/or other skills-building into projects whenever possible. Not only does building local skills and ownership improve the quality of insight and design, but supports the ongoing implementation and refinement of HCD projects long after handoff. Beyond any single project, harnessing and refining the ingenuity of young collaborators is a way that the global HCD for AYSRH community can more broadly embody a commitment to beneficence.

### **Whether they are implementing HCD or being engaged as participants, adolescents and youth are our partners.**

Adolescents and youth are valued partners who have meaningful decision-making roles in programs and communities. Meaningful engagement not only builds connection and belonging for adolescents and youth, but also builds a sense of purpose among them, elicits new ideas, builds positive perceptions with adults and yields better programming results. This partnership takes place with caring, skilled facilitators who provide appropriate support and guidance so that adolescents and youth can formulate their views and participate in a safe and meaningful way.

<sup>10</sup>Convention on the Rights of the Child: <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

**Youth-adult partnership training is core to effective HCD for AYSRH.**

True partnership means that no one person is an absolute decision-maker, but that solutions are derived through consensus and equal value is placed on differing viewpoints. Traditionally, we do not come to this balanced position without building some skills first. In particular, age differentials introduce a power dynamic that must be addressed. Youth and adults may each need training – together or separately -- on communication, agency, how their role in HCD will affect the short and long-term outcomes in their communities, negotiation and listening skills, knowledge and values surrounding AYSRH, background, jargon and terms that will be discussed.

**OUR COMMITMENT**

**We, the signatories of this Commitment to Action, commit to putting adolescents and youth, along with their well-being and data, at the center of the design process.**

**We commit to open, nuanced and constructive dialogue about the best ways to scope, carry out and collaborate on AYSRH projects. And we stand firmly by our resolution to uphold integrity and ethics in every facet of our work.**



HCD EXCHANGE



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