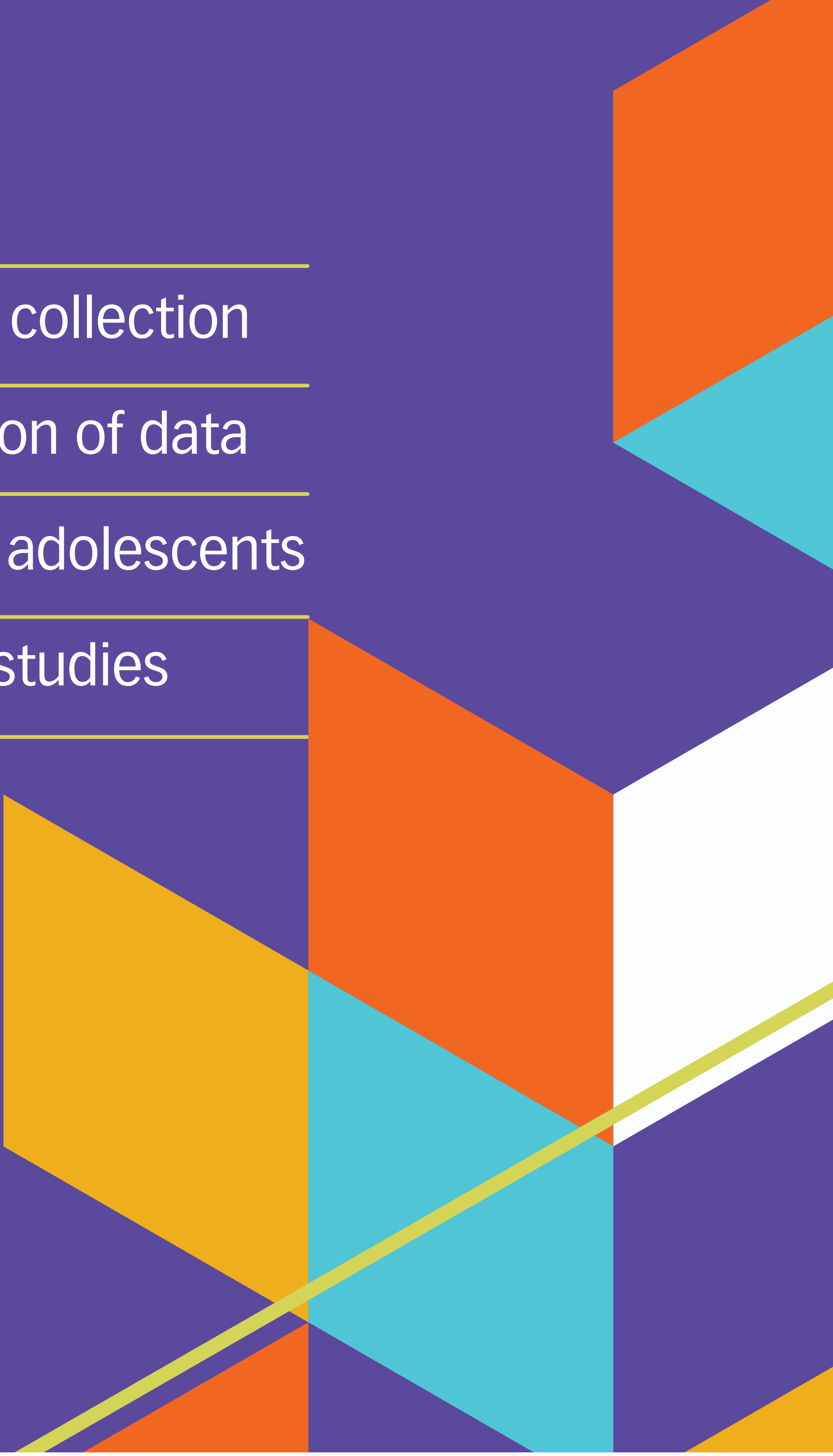
Protocol for the collection and dissemination of data on children and adolescents participating in studies



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Assent: UNICEF (2015) defines this as “the willingness to participate in research, evaluations or data collection by persons who are by legal definition too young to give informed consent according to prevailing local law but who are old enough to understand the proposed research in general, its expected risks and possible benefits, and the activities expected of them as subjects”. The World Health Organization (2019) states that: “Assent may be expressed (e.g. indicated verbally or in writing) or implied or tacit (unspoken or implied through the individual’s actions, for example by not making eye contact with the researcher or by remaining unresponsive to the researcher’s questions)”

Ethics committee: A group of individuals unrelated to the research to be reviewed. The committee is an advisory body tasked mainly with ensuring that research involving children and adolescents abides by a set of ethical standards. It must review the research designs and approve, reject or provide feedback. It must consist of at least three members who are free from conflicts of interest.

Confidentiality: According to the Ethical Research Involving Children (ERIC) project, the concept of confidentiality means that “The researcher and all staff involved in the research are ethically obliged to treat information acquired during the research process carefully, in confidence, and to not allow this to be revealed to others. Researchers must securely store, protect and dispose of information/data that has been collected. They must also be prepared to breach confidentiality if a child or others are at risk” (Graham and others, 2013).

Informed consent: According to the definition provided in ERIC, “Informed consent refers to the process of fully informing children and their parents/carers as to the purpose of the research and what their involvement will be, prior to their decision as to whether or not they participate in the research. Informed consent is an explicit agreement which requires participants to be informed about and have an understanding of the research. It must be given voluntarily and be renegotiable, so that children may withdraw at any stage of the research process” (Graham and others, 2013).

Caregivers: all persons who fulfil the role of father or mother and are responsible for the care of children and adolescents.

Harm: in the research setting, harm or damage refers to physical punishment or other sanctions inflicted by another person as a result of participation or non-participation in the research activities, in addition to physical harm, emotional suffering, anxiety or loss of self-esteem caused directly by the research study itself (Graham and others, 2013).

Participation rights: as enshrined in the Convention on the Rights of the Child, these rights underpin the obligation