

SESAME WORKSHOP

Joan Ganz Cooney Center

Using Muppets to Demystify Informed Consent

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About the authors

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When working with children and their families, researchers are required to abide by ethical guidelines to ensure that the research they are conducting does not cause any harm to its participants. A critical part of this process includes collecting informed consent from all participants, including children and their parents or caregivers.

Informed consent is when someone agrees to participate in a research study with full knowledge of the study's goals, participation expectations, and any possible risks and benefits to participating.

While a participant can provide consent through either written or verbal affirmation, research on the informed consent process shows that it often fails to provide the right level of information for a variety of reasons, including low literacy levels, inaccessible language, and lengthy, confusing consent documents. As a result, someone may agree to participate without understanding exactly what they are agreeing to, or the possible risks or benefits. A potential participant also may not fully

understand that they are not required to say yes when asked whether they consent to participate in the study. As a result, it may not be clear to them that they can refuse to participate without consequence, and that they should never feel compelled to provide consent out of fear of perceived social pressure. We were inspired by examples of research teams who used [multimedia content to support their informed consent protocols](#), especially among communities with low literacy rates.

AHLAN SIMSIM

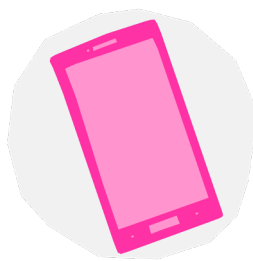
Ahlan Simsim, an Arabic-language TV show version of *Sesame Street*, represents one element of Ahlan Simsim, an initiative supported by the MacArthur Foundation and LEGO Foundation. In a partnership between Sesame Workshop and the International Rescue Committee (IRC), Ahlan Simsim seeks to deliver early childhood care and education to millions of children affected by conflict and displacement in Jordan, Lebanon, Iraq, and Syria. For more information, please visit ahlansimsim.org



Ahlan Simsim's research agenda

Research has played a critical role for both [Sesame Workshop](#) and [International Rescue Committee \(IRC\)](#) throughout each stage of Ahlan Simsim's process.

In addition to using formative research to support the development of content and programming, we are partnering with [New York University's \(NYU\) Global TIES for Children](#) as the external evaluator for Ahlan Simsim. NYU—in collaboration with the IRC and Sesame Workshop research teams—will evaluate the impact of Ahlan Simsim programming on children's learning and development, as well as on their parents' mental health and well-being. The research teams will use a variety of research methods and survey tools to measure these



changes, including in-person and phone-based interviews and surveys with parents, caregivers, and teachers as well as play-based games and activities with children.

The challenges we faced with informed consent

For impact studies the research team recruited families receiving Ahlan Simsim programming across a variety of program models. The researchers needed to collect informed consent from parents and children before collecting data. As teams began planning recruitment, however, we realized that there may be significant issues around informed consent due to low literacy levels and the significance of social pressure among participants. We observed during measurement piloting that the detailed written or spoken consent forms seemed to be a challenge for potential participants. A large number of our participants may not know how academic research works, so telling them that their data will be deidentified and kept safe may mean little to them.

In addition, prevailing social norms encourage families to welcome guests—in our case, data collectors—with courtesy. During many visits, enumerators reported that families did not thoroughly read the consent form because they felt it was not as important as welcoming their visitors, and they wanted not to offend them by refusing to participate in the study. While the courtesy is appreciated, a more effective method of sharing and conveying informed consent was needed.

How we could address that challenge

Access to smartphones and social apps, like WhatsApp, is high among the communities we work with in [Jordan](#), [Lebanon](#), and [Iraq](#). Beyond publicly available data, we have also observed that the use of multimedia and videos shared through social apps is prevalent among the families we work with. We thought we could leverage that engagement to help us convey the aims of the study, its process, and other details to the participants. In addition, most Arabic speakers working on the Ahlan Simsim research teams agreed that verbally conveying messages might be easier for families, particularly given that the consent form is provided in Modern Standard Arabic, which varies from spoken dialects.

Conversations with the field teams suggested that creating and sharing a short informative video featuring the *Ahlan Simsim* Muppets talking about the study would convey the needed information and be interesting and appealing to families. This approach seemed promising in its ability to visually inform participants about the study, the tools that would be used, the privacy and protection of all information, and the ability to refuse participation partially or completely.

Another advantage of using this method is that it would provide families time to reflect on the contents of the video before data collectors formally began their visits. Using the Muppets to represent children in this video is a fun and engaging way to share relevant information about the research project with families. Further, the video featured different Arabic dialects—Levantine and Egyptian—to allow for greater accessibility across the region.¹

Script development process

To develop an accessible informed consent video that complemented standard consent processes, we employed a collaborative process. For format, [using lessons from previous research on trusted messengers in adult-facing Ahlan Simsim videos](#), we selected that same structure: introduction from a human expert, guided by the qualities parents look for in trusted messengers. That introduction would be followed by a scene with the *Ahlan Simsim* Muppets and humans to model the experience. That Muppet scene would be followed by a short concluding statement from the human expert.

For dialogue, using the existing structure and language of informed consent, we drafted an outline, with all partners providing feedback to ensure that necessary components would be covered. We wanted the video to be long enough to cover all the relevant details but short enough to be shared via WhatsApp or another SMS application so families could view on their time, which meant a four- to six-minute video. We gave the production and education team an outline detailing the key messages we wanted to cover, which included:

- + Informed consent is when you learn about a research study, what your participation will involve, and tell the researcher if you agree to participate.
- + Participation is always voluntary and you do not have to do anything you are not comfortable doing.



¹ Levantine dialect is spoken and understood widely in Lebanon and Jordan, where our research takes place, while Egyptian dialect is widely understood because of the popularity of Egyptian media throughout the Middle East.

- + You can always change your mind about participating at any time for any reason.
- + If your child is asked to participate in a study, both you and your child will be asked to provide consent.
- + There may be times that the research team may want to use a recording device; you do not have to consent to be recorded to participate in the study.
- + The researcher will provide contact information so you can be sure your questions and concerns are addressed.

To adapt these messages for the format and to make them family-friendly, the production team drafted a script in which Researcher visits

Basma, Jad, and Salma. Researcher explains that he is conducting a study to understand the impact of an education program on learning. He explains what the study will involve, the possible benefits and risks, and offers to answer any questions they may have before providing consent. Basma and Jad model questions a young child might ask. For example, Basma asks if the questions will hurt and Jad asks what will happen if he finds Researcher's questions too hard. This modeling also shows parents that it is OK to ask questions, if they have any. Jad explains that he is not feeling comfortable and would rather not participate. Researcher accepts Jad's response in the same way he accepts Basma and Salma's responses: with no judgment or consequence.

Researcher discusses informed consent with Basma, Jad, and Salma. See the videos here: <https://bit.ly/3CShmqA>.



Informed consent video in action

The video is currently in use for an impact evaluation of children's learning after watching *Ahlan Simsim*, the TV show. So far, it has yielded positive feedback from both enumerators and caregivers.

Team enumerators say that both they and families find the video engaging. Families recruited for the impact evaluation of *Ahlan Simsim* have said they find the video motivational and that it allows them to participate more actively in the research. This is critical, as participant buy-in and support for the study is important. It can also reduce participant attrition, which helps ensure that the study remains as robust as originally designed.

The video has reduced the amount of time required to recruit families and collect consent, an unintended benefit for the research team. For a recent survey, the informed consent video saved enumerators about 15 minutes per survey. For caregivers who had watched the video, the total time for the consent process and survey was about 45 minutes, while the total time was about 1 hour for caregivers who had not watched the video. Families are sent the informed consent video via SMS message. After the video is shared, an enumerator will call a caregiver and ask, "Did you watch the informed consent video?" If the caregiver responds "yes," the enumerator then asks, "Do you provide consent for you and your child to participate in this study?" Among the recruited

sample of 4,553 households, 3,326 watched the informed consent video. Considering the size of this sub-sample, this has saved important time during the recruitment and baseline data collection process.

Some important lessons have emerged from seeing the informed consent video in action. In the case of the impact evaluation of *Ahlan Simsim*, not all families have sufficient data on their mobile devices or appropriate devices to view the video, meaning that access to the video is often determined by a household's socioeconomic status. Future implementation will consider the provision of a data stipend to ensure that viewing the video is not determined by insufficient data access.

Next steps

These lessons will be useful and relevant as we adapt this video for other contexts as well. For example, for [Takalani Sesame in South Africa](#), in preparation for an impact evaluation of [programming funded by the LEGO Foundation](#), the team has dubbed the video into English, Sesotho, Xhosa, and Zulu. We also dubbed the [video into Spanish](#) for an evaluation of video content created under [Play to Learn, programming also funded by the LEGO Foundation](#). That evaluation will test the impact of [video content](#) among displaced Venezuelan children and Colombian nationals in Barranquilla, Colombia.





Noor and Aziz are featured in videos produced in Bangla and Rohingya.

In places where Basma and Jad are less well known, or the background or human characters might not resonate, we are using lessons learned in creating this video to create similar video content. This contextualization will ensure families everywhere in the world who help us learn how to improve programming are comfortable and confident about participating in our research. In Bangladesh, for example, we have developed a video in Bangla and Rohingya that [includes our newest Muppets, Noor and Aziz](#), to model the informed consent process.

Zooming out, there are also a number of important lessons about accessibility specific to the informed consent process and we hope that other researchers will explore how this process can be made increasingly accessible for study participants. We have found that in leveraging their existing media habits, combined with the power of engaging characters and user-friendly language, families are more inclined to see their role in and value to the research process. And this speaks to a bigger goal: how to make research and evaluation a shared experience that meets communities where they are to ensure that families see themselves reflected in research designs and findings.

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