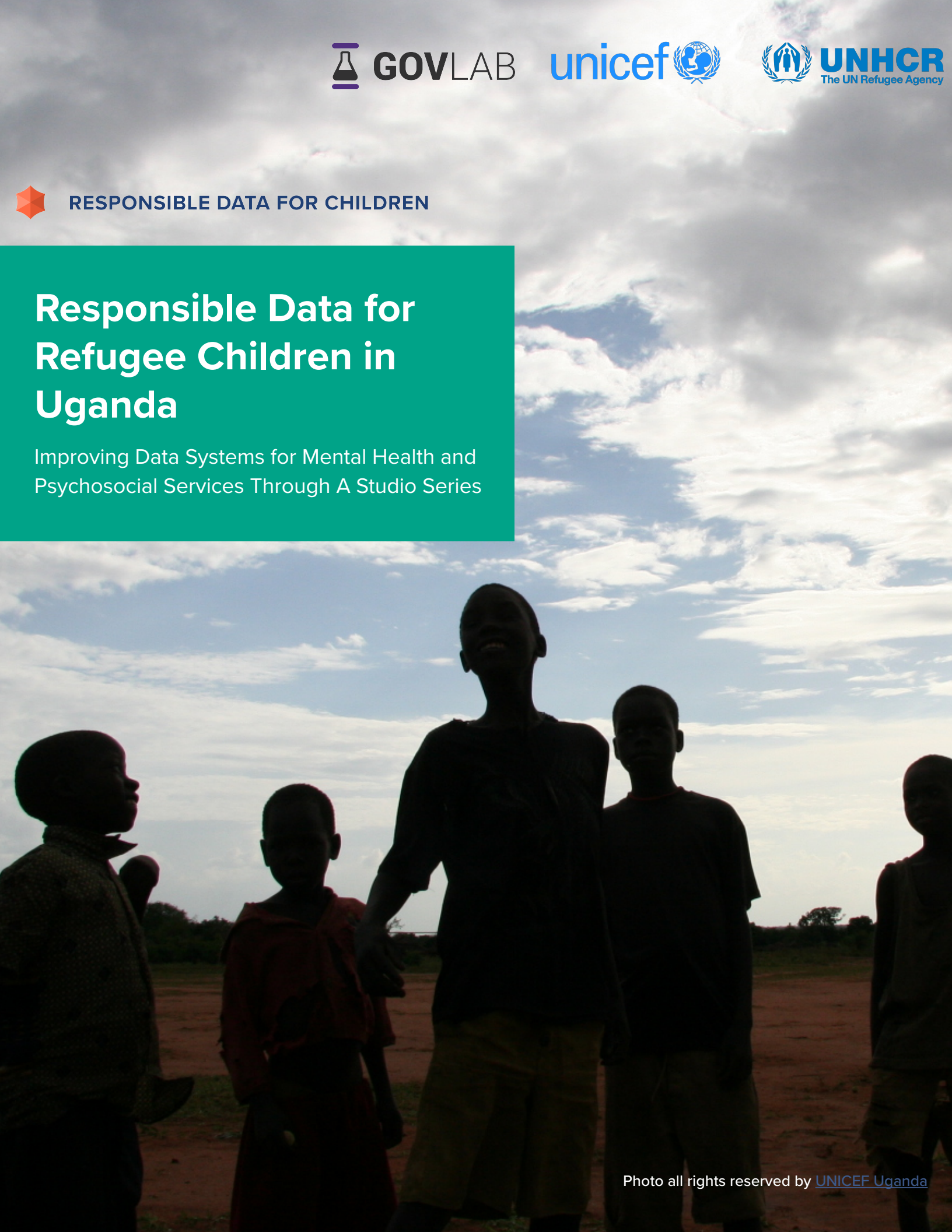
GOVLAB unicef UNHCR The UN Refugee Agency

RESPONSIBLE DATA FOR CHILDREN

Responsible Data for Refugee Children in Uganda

Improving Data Systems for Mental Health and Psychosocial Services Through A Studio Series



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1. INTRODUCTION

From 19 to 23 September, 2022, the Responsible Data for Children initiative (RD4C) team visited Uganda to map the data lifecycle of Mental Health and Psycho-Social Support (MHPSS) data about refugee children and to promote more responsible uses and reuses of such data, ultimately to improve the provision of MHPSS services in Uganda.

With over 1.5 million refugees[1]—over half of which are children—Uganda is the third-largest refugee-hosting country in the world and the largest refugee hosting country in Africa.[2] Many of these refugees report experiencing psychological distress and face challenges in accessing Mental Health and Psycho-Social Support (MHPSS), especially as a result of the COVID-19 pandemic which has exacerbated the need for MHPSS amongst refugees and host communities.[3]

Responsible Data for Children (RD4C) initiative—a partnership with The Governance Lab and UNICEF—seeks to support government officials and field practitioners to promote better management of refugee children's data related to the provision of MHPSS services in Uganda. RD4C committed itself to working with UNICEF and UNHCR in Uganda to ideate ways to responsibly harmonize and connect the various MHPSS data sources available—including those derived from cases, surveys, and Inter-Agency Feedback, Referrals, and Resolution Mechanisms and other MHPSS programme interventions—so as to improve access and effectiveness of available services.

From 19–23 September, 2022, the RD4C initiative supported by UNICEF and UNHCR Uganda hosted three workshops ("studios" in the language of the RD4C initiative) in Kampala and Isingiro District, Uganda to map common challenges regarding the responsible use and reuse of refugee children's MHPSS data and prototype a pathway forward to address these challenges through the lens of the responsible data for children principles.

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[1] UNHCR. 2022. "Uganda Comprehensive Refugee Response Portal." UNHCR Data. October 31, 2022. https://data.unhcr.org/en/country/uga.

[2] United Nations High Commissioner for Refugees. 2021. "Uganda Joins High-Level Officials Meeting amid Record Number of Refugees in the Country." UNHCR. December 14, 2021. https://www.unhcr.org/afr/news/press/2021/12/61b83c004/uganda-joins-high-level-officials-meeting-amid-record-number-of-refugees.html.

[3] UNHCR and REACH. 2021. "Uganda Refugee Operation - Participatory Assessment 2021 - National Report December 2021 - Uganda | ReliefWeb." ReliefWeb. March 21, 2021. https://reliefweb.int/report/uganda/uganda-refugee-operation-participatory-assessment-2021-national-report-december-2021.

In particular, RD4C hosted (a) one workshop with Ugandan government officials, NGOs and service providers, (b) a second workshop with regional field practitioners, and (c) a final workshop guided by the outputs of the prior engagements, with multiple key stakeholders including government officials and partners whose participation was key in ideating workable solutions to address the opportunities and challenges previously identified. These workshops were supported by focus groups discussions with refugee groups including adolescents, interviews with service providers, and meetings with government leaders.

This report summarizes the results of these engagements and describes the overarching takeaways from RD4C's week of studios in Uganda. The report identifies **action items** co-developed by national and local government officials and leaders, and key stakeholders, and we hope it can be used by UNICEF and UNHCR in Uganda as well as Government of Uganda leaders and partners to supplement their existing efforts to promote a more responsible and effective data ecosystem for MHPSS for refugee children in particular, and for the country as a whole.

2. WHAT IS THE CONTEXT OF MHPSS IN UGANDA?

Refugees and asylum seekers in Uganda—and especially child refugees and asylum seekers—face several challenges, including difficulty registering for service delivery programs, disputes with the justice system, physical insecurity, health, education, and more. One issue of notable concern for many refugees is the accessibility and effectiveness of MHPSS services in Uganda. As reported by the Uganda Refugee Operation - Participatory Assessment 2021, which relied on 882 phone surveys conducted in refugee settlements and an additional 66 phone surveys done in Kampala, 49 percent of refugee respondents reported challenges in accessing MHPSS services. The cited reasons for these challenges varied from feelings of stigma, shame, lack of treatment, and long wait time.[4] Similar surveys conducted in Uganda by UNHCR and WFP have found that refugees feel they lack adequate MHPSS support in their communities (see Figure 1).

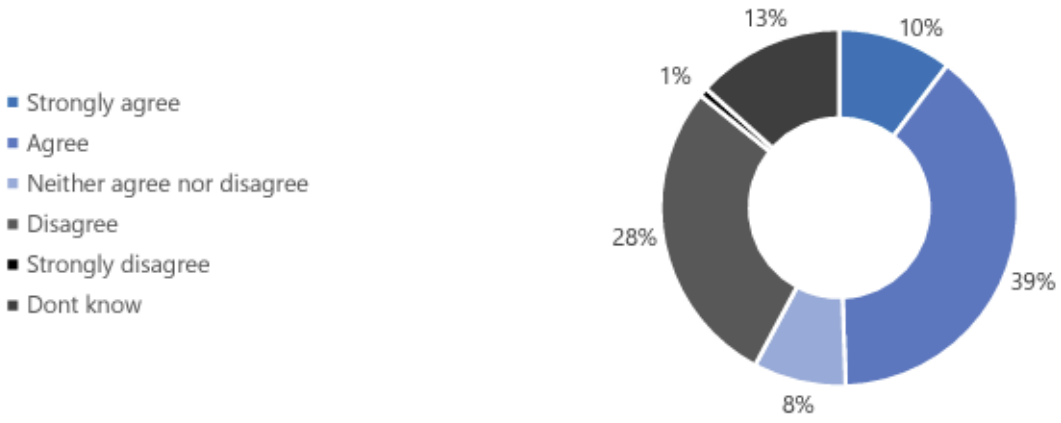

Figure 1: Extent to which refugees residing in settlements agree that MHPSS is available to meet the needs of their community.[5]

Consistent with these findings, UNICEF and UNHCR in Uganda, as well as partners such as Save the Children, have sought to expand the availability of MHPSS for children and others. This desire to support children in improving their social and

[4] Ibid.

[5] UNHCR and WFP. *JOINT STRATEGY: Enhancing Self-Reliance In Food Security And Nutrition In Protracted Refugee Situations*, 2019. https://www.unhcr.org/5c3c6d584.pdf.

psychological resilience has been heightened amid the continuing consequences of the COVID-19 pandemic. Since the World Health Organization declared the COVID-19 outbreak a pandemic on 11 March 2020, children have found themselves increasingly isolated due to school closures, freezing of transport, outlawing of mass gatherings, curfews, and lockdowns.[6]

In the effort to deliver MHPSS services to refugee children in a more accessible and effective manner, the responsible handling of relevant data is critically important. Data indeed plays a key role in allowing all stakeholders involved to have a clear understanding of what is happening as it relates to the delivery of MHPSS services to child refugees. The Inter-Agency Uganda Country Refugee Response Plan, i.e. the nationwide strategy for coordinating refugee management, notes a particularly urgent need for monitoring and evaluating refugees' access to MHPSS services in Uganda so as to be able to improve it—a goal only achievable with the aid of data.

The Government of Uganda and UNHCR note that "efforts have been made to provide clarity on impact measurement and on causal linkages from sector outcomes to impact".[7] In particular, according to input provided by our partners, data-driven efforts to address challenges related to the delivery of MHPSS services in Uganda mainly consist of surveys, participatory assessments, and other traditional data collection methods (e.g. phone-based surveys). Conducted with the support of UNHCR, the Government of Uganda, and organizations such as the REACH Initiative, these resources can be used to assess how refugee children understand their mental health and psychosocial condition, the services available to them, and potential solutions.

According to our initial fact-finding work, despite the efforts made to improve the delivery of MHPSS services to child refugees through an increasing use of data, government leaders at national, district and local levels seem to be most concerned with three main challenges:

- Difficulties in connecting and harmonizing the existing data sources mentioned above;
- Barriers limiting children's access to data-driven services;

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[6] UNHCR and Save the Children. *Concept note for home-based mobile psychosocial support provision in the COVID-19 context.* https://drive.google.com/drive/u/0/folders/1pVqz7TVx1StLJQCHPkbuUW1zKPxSNqtS.

[7] Uganda Government (OPM) and UNHCR. *Inter-Agency Uganda Country Refugee Response Plan (UCRRP) 2022-2025*, 2022. https://data.unhcr.org/en/documents/details/92447.

- Barriers to responsible data use and reuse by organizations involved in providing MHPSS for refugee children.

Thus, these served as the basis of our studios, which ultimately allowed RD4C, together with Ugandan government officials at national, district and lower local governments and local leaders and partners, to collectively identify and co-design concrete actions and policies to improve the responsible handling of child refugees' MHPSS data.

3. HOW DID WE CONDUCT THE FIELD RESEARCH?

After a variety of meetings with UNICEF and UNHCR Uganda, RD4C and its partners agreed to focus on one overall question to guide the three studios: *"How can the Government of Uganda and partners improve the responsible use of MHPSS data for and about refugee children in Uganda—particularly in ways that increase the effectiveness and reach of existing services?"*

To answer this question, RD4C first had to map the current MHPSS framework in Uganda. Conducting desk research and virtual interviews with government and key stakeholders, the RD4C team assembled a "Pre-Reader" mapping the MHPSS ecosystem across the data lifecycle (see Addendum 2). It then presented this Pre-Reader to participants at the studios and asked them to supplement this resource based on their understanding of: (a) the Data Lifecycle; and (b) the RD4C Principles.

The first of these items, the Data Lifecycle, is an abstraction that explains the opportunities and challenges in how data is translated from insight and into action. For the purposes of this research, the following data lifecycle was used:

- **PLANNING**: Defining the specific purposes/objectives of the data activity, the end-users and uses of the insights, identifying relevant partnerships, and designing a strategy to implement the data activity (*who* does *what when*, and *how*).
- **COLLECTION**: Gathering data directly from those in the field or collating it from surveys, censuses, voting or health records, business operations, web-based collections, and other relevant, accessible sources.

- **PROCESSING**: Removing irrelevant or inaccurate information, reformatting contents to be interpretable by an analytic software, and otherwise cleaning and validating the data.
- **SHARING**: Exchanging data and other information with relevant collaborators for its use and analysis (to derive insights from it).
- **ANALYZING**: Assessing the data to extract insights about the issue as well as creating a loop for (re)sharing processed data and data insights among appropriate parties.
- **USING**: Acting on insights derived. Actions can inform decisions about which data is collected, where and who, for future UNICEF/UNHCR country operations.

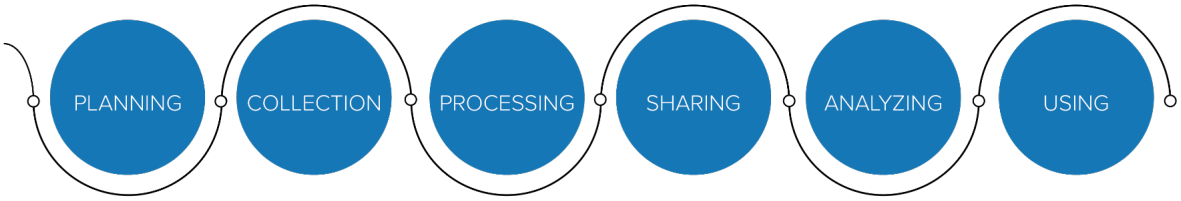

Figure 2: The Stages of the Data Lifecycle

Using the Data Lifecycle as the overarching organizing framework for discussions, RD4C and studio participants were able to map the specific steps MHPSS data goes through, thus identifying gaps and opportunities for improvement.

RD4C used the Responsible Data for Children Principles to guide our discussion and work on the Data Lifecycle, and highlight the importance of not only collecting and using data but doing so responsibly. According to the RD4C Principles, responsible data is:

- **PARTICIPATORY**: Engaging and informing individuals affected by the use of data for and about children.
- **PROFESSIONALLY ACCOUNTABLE**: Operationalizing responsible data practices and principles by establishing institutional processes, roles, and responsibilities.
- **PEOPLE-CENTRIC**: Ensuring the needs and expectations of children, their caregivers, and their communities are prioritized by actors handling data for and about them.

- **PREVENTIVE OF HARMS ACROSS THE DATA LIFE CYCLE**: Establishing end-to-end data responsibility by assessing risks in the collecting, storing, preparing, sharing, analyzing, and using stages of the data lifecycle.
- **PROPORTIONAL**: Aligning breadth of data collection and duration of data retention with the intended purpose.
- **PROTECTIVE OF CHILDREN'S RIGHTS:** Recognizing the distinct rights and requirements for helping children develop to their full potential.
- **PURPOSE-DRIVEN**: Identifying and specifying why the data is needed and how the intended or potential benefits relate to improving children's lives.

Similar concepts for responsible data management in humanitarian contexts have been developed in other fora. For example, the Inter-Agency Standing Committee (IASC) Operational Guidance on Data Responsibility in Humanitarian Action (2021) includes a list and definition of 12 principles for data responsibility.[8] As a normative guide for data activities in humanitarian contexts, these principles help promote safe, ethical and effective operational data management by individual organizations, sectors and clusters, and the humanitarian system (e.g., Humanitarian Country Team (HCT), Information Management Working Group (IMWG), Inter-Cluster Coordination Group (ICCG), etc.). Similarly, in 2015, the diverse group of organizations involved in the Protection Information Management (PIM) Initiative defined information management as a "*principled*, collaborative and systematic process". They also identified eight (8) core principles that should guide IM activities so these effectively enable evidence-informed actions that lead to quality protection outcomes for affected populations and their hosts.[9]

Framing the discussion on the data lifecycle within a responsible data approach enabled a rich exchange among participants about what currently exists in Uganda's MHPSS data systems for refugee children and what they hope to achieve in the near future.

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[8] IASC, *Operational Guidance on Data Responsibility in Humanitarian Action*, February 2021, available at: https://interagencystandingcommittee.org/operational-response/iasc-operational-guidance-data-responsibility-humanitarian-action.

[9] Protection Information Management (PIM), "PIM Principles", 2015, available at : http://pim.guide/guidance-and-products/product/principles-protection-information-management-may-2015/. For information on how the PIM Principles can be applied in practice at each step of the IM Process, see: Protection Information Management. 2017. "PIM Principles in Action." PIM Guide. February 5, 2017. http://pim.guide/guidance-and-products/product/pim-principles-action/.

4. WHAT DID WE LEARN ACROSS MEETINGS AND STUDIOS?

4.1 STUDIOS 1 AND 2: MAPPING THE DATA LIFECYCLE WITH GOVERNMENT COUNTERPARTS AND SERVICE PROVIDERS AT NATIONAL AND DISTRICT LEVELS

Participants deliberate during Studio 1 in Kampala

Opening remarks in Isingiro

On Monday, 19 September 2022, the RD4C and UNICEF and UNHCR Uganda hosted a studio in Kampala with national stakeholders including government and key service providers. On Wednesday, 21 September 2022, the RD4C and UNICEF and UNHCR Uganda team hosted a studio in Isingiro with field practitioners directly involved with providing MHPSS services to child refugees. The aim of these first two studios was to map the lifecycle of MHPSS data for and about child refugees in Uganda.

The studios each led to unique discussions about the opportunities and challenges facing the data ecosystem. At the end of the two sessions, RD4C and its partners arrived at a series of overall findings organized across the data lifecycle:

Planning

- **Need for Coordination and Cohesion in Policymaking at National and District Level:** Overall authority for MHPSS is held by the Division of Mental Health at the Ministry of Health, a body whose mandate is to promote

coordination between different MHPSS activities. However, there is a similar body at the district level, which does not include all MHPSS stakeholders, lacks the same visibility, and may complicate lines of decision-making. These facts reflect a struggle encountered by participants who expressed their concern that there often seemed to be difficulties in bringing all relevant partners together around common purposes for MHPSS data. Lines of communication were often confusing, exacerbated by institutions lacking mandates about what types of initiatives were pursued and when. Various organizations, having their own missions, pursued their own institutional goals in absence of clear guidance. In the words of one participant who was not a part of the overall decision-making body, "it can take a lot of coordination to get all of us organizations together."

- **Importance of Developing a Data Catalog and Directory:** Participants also expressed concern that there was no broad awareness of which organizations collected what data when. Given that MHPSS is often a cross-sectoral concern, organizations were not well-aware of which relevant data might exist in repositories held by others related to public health, education, gender and development, and other sectors. This lack of awareness (enabled by a lack of ecosystem mapping)[10] meant that organizations could engage in duplicative projects/interventions and duplicative collection that could lead to refugee children having to provide the same data and similar data collected in different ways. A data catalog and directory—a comprehensive listing of which data assets are held by which organizations as well as an indication of who in those organizations oversee those datasets and how to contact them—could be valuable in filling this need.[11]

- **Limited Focus on Data Governance:** Data governance was not identified by participants explicitly in any of the studios or focus groups. There was awareness of inaccuracies in the data but little focus on spotting and avoiding

[10] IASC Operational Policy and Advocacy Group. 2021. "Operational Guidance: Data Responsibility in Humanitarian Action." InterAgency Standing Committee. https://interagencystandingcommittee.org/system/files/2021-02/IASC%20Operational%20Guidance%20on%20Data%20Responsibility%20in%20Humanitarian%20Action-%20February%202021.pdf.

[11] We distinguish a data catalog and directory from a data inventory in that the former spans across organizations and is as much about facilitating communication and collaboration among them as it is about providing an overview of data assets. Data inventories, typically, merely lists the data assets held by one organization along with information about that data (e.g. owner, frequency of update, and file owner). See: GovEx Labs. 2022. "Data Inventory Guide." Johns Hopkins University Center for Government Excellence. April 2022. https://labs.centerforgov.org/data-governance/data-inventory/.

biases that may result from them. In terms of proportionality of collection, one participant spoke about how, "I will collect as much data as I can to satisfy whomever will need it, even if I don't know who will." In the view of the RD4C team, instilling responsible data practices, including principles of data minimization, is critical to avoid potential harm across the data life cycle.

Collecting

- I**mportance of a Unique Identifier:** Participants spoke about how their organizations created their own unique identifiers for each child. Each organization can track child refugees that have been identified by their own organization, but there are sometimes challenges in understanding how the same child could be represented differently within different organizations and service providers. While UNHCR has generated one unique identifier for refugees during registration, it is rarely ever used when other, individual organizations start providing services as they have developed their own, unique identifiers for their organizations. It may be beneficial to connect identifiers or promote a common identifier, provided that data protection standards can also be upheld, so that organizations can better coordinate to address the needs of children. As one participant noted, "we try to bring in other organizations [...] but does the data match? Do other partners know about this child?"

- **Need for Social License Beyond Individual Consent:** Individual consent seems to be prioritized over a more general social license—that is acceptance granted to an organization by a community—as the main legal basis for personal data processing. However, based on our conversations, individual consent as deployed is rarely informed; moreover, individual consent does not seem to be sufficient to ensure ongoing approval and social awareness and acceptance by the local community. To achieve that, achieving group consent through public discussions seems a key element to develop. This can indeed increase legitimacy, credibility and trust of the data management and governance processes in place.

Processing

- **Importance of Having a MHPSS Taxonomy and Common Tools:** In the studios, participants expressed concerns about the lack of common

categories, terms, and definitions across institutions as well as differences in the tools they use to process MHPSS data. There were additional concerns that the same individual could have their case logged in different ways, at varying levels of quality, which could make analysis difficult or unreliable. Participants across the two studios agreed on the importance of developing a clear distinction between the classification of mental health (MH) versus psychosocial well-being. In the current system, these two categories often overlap, leaving space for potential confusion and missed treatment opportunities.

- **Value of Streamlining Case Management and System Design:** Participants indicated that data is often processed by different organizations who each have their own data management systems to collect, store, analyze and report. It is reported back according to the needs of each individual organization as opposed to a common set standard. This fact complicates efforts to compile and aggregate data. Even within single organizations, different departments and teams organize and categorize data in their own way, leading to potential information loss, decontextualization, and misinterpretation. One participant noted that while they submit data to the UNHCR and other actors, the data systems they use "are totally different" from organization to organization.

- **Need to Produce Both Clinical and Community Setting Screening:** Participants observed it is hard to understand what really is the state of mental health and psychosocial well-being for child refugees if only current health and clinical data is analyzed and used. While some challenges may stem from an inability to develop appropriate research questions and indicators needed to answer it, the focus of many discussions was on information that *did* exist but could not be meaningfully processed, combined, and aggregated for regional and national insights. Participants noted that many communities collect their own data but that this is not processed nor shared or used at the national level. This gap, in turn, leaves state-wide analyses only to clinical data-based insights and, even then, not all clinical cases are reported.

Sharing

- **Value of Incentives to Share Data:** Participants expressed concerns that there are few incentives to share data across government ministries, partners and organizations. Actors working with MHPSS data on refugee children often collect data with the aim of (a) keeping track of their own specific context; and

(b) providing services to the specific individuals they interact with. District facility-based data is collected and sent to the national level. However, little is done to share data across districts and regions to address issues at the national level or to inform each other's work. When sharing did come up, there did not seem to be focus given to the distinctions between personal and non-personal data and the obligations involved in handling, data protection, and data security. Few organizations are focused on trying to assess the broader scope of challenges. Few also seemed ready to answer what the purpose of the data was; what was available but not shared that could help; why was it not shared; and were those reasons legitimate.

- **Desire for Common Platforms, Systems and Points of Contact:** Participants identified the need for common systems and platforms for data entering and sharing to be developed and employed. In particular, participants highlighted their desire for the Ugandan Government to develop a unified national system with support from partners, agreeing on a single set of standards. Many participants also agreed that it would be important to involve communities and consult them when designing the system, as they are ultimately the beneficiaries of data sharing practices. However, the RD4C team would emphasize that such systems are not easily established and that organizations need to be cautious in establishing them so as to guarantee the proper protections for personal and non-personal data. Before any common platform can exist, a comprehensive system for data protection and data security must be in place. Otherwise, organizations risk exposing and endangering those most vulnerable to harm.

Analysis

- **Importance of Exploratory and Descriptive Analysis:** Information and insights from the data collected could help organizations understand both individual and group cases. However, there seem to be significant challenges in compiling/aggregating data so that it can be used to understand the situation around MHPSS for refugee children on a regional or national scale (that is, answering questions about "What is there?" as well as "Who? What? Where? When? And How many?). Data is often siloed and gaining a comprehensive picture of the current situation is consequently hard.

- **Value of Diagnostic and Prescriptive Analysis:** Participants agreed that there is an overarching need to expand capacity for identifying root causes of what

doesn't work (diagnostic analysis) and ultimately what works (prescriptive analysis). Indeed, the data collected often seems to be left unanalyzed and unused when it comes to making evidence-informed decisions on how to improve the design, delivery and effective monitoring of MHPSS services provided to child refugees. Instead, data is often used by private NGOs to inform donor activity and by hospitals to meet national reporting requirements.

- **Opportunity of Integrating Lived Experience:** In all projects involving data for and about the MHPSS needs of refugee children participants highlighted the importance of keeping in mind the context in which data was generated, collected, and analyzed. Decontextualized data presents the risk of generating incomplete and/or biased analytical findings, and obfuscating lived experiences, which are ultimately key to understanding the state of the situation at stake. In focus groups with refugee community members, the need to understand how volunteers collected data and the environments in which they operated came up repeatedly.

Using

- **Value of Translating Data into Meaningful Decisions:** During both workshops, participants expressed their concerns about data not being used to make meaningful decisions. Indeed, many noted how often there are no insights stemming from the data, and how—when insights were available—they did not bring about clear, identifiable actions or policies. Such difficulties may point to problems early on in the data lifecycle (e.g. planning and collection) where organizations determine what it is they want to accomplish and what they need to do so. The studios highlighted the risk of investing time and resources in data collection, without having a concrete or meaningful outcome at the end of it. It is also important to note that the lack of clear outcomes and decisions stemming from the data gathered is a result of how this data is collected individually by singular organizations and thus siloed, leaving little room for collective identification of problems, solutions, and responsibilities.[12]

[12] Organizations such as the Joint Internal Displacement Profiling Service have developed guides for joint analytic processes that might be useful in addressing this need. *See*: Schelhorn, Svend-Jonas, Caryn Saslow, Margharita Lundkvist-Houndoumadi, and Wilhelmina Welsch. 2021. "Joint Analysis Guide (2021) - JIPS - Joint IDP Profiling Service." Joint Internal Displacement Profiling Service. https://www.jips.org/jips-publication/joint-analysis-guide-2021/.

- **Lack of Feedback Loops:** Participants expressed concern that they were not informed of how data and insights were used to address needs. On an individual case level, community members spoke about how they didn't hear about what happened to refugee children after their referral and whether a child's needs were met despite considering themselves "responsible" for them.[13] Those who were the target of services were unaware of why enumerators were collecting information on them and what benefits and risks there were associated with different forms.

- **Importance of Sharing Insights:** One of the major concerns expressed for the "Using" stage was the lack of insights shared across organizations involved. To have a useful picture of what the condition of MHPSS service delivery for refugee children is (that is, understanding the "*Who* is doing *what where*"), it is essential that insights be made available and understandable among stakeholders. Indeed, while NGOs operating in the Nakivale Refugee Settlement, for instance, do share This indeed avoids duplication of efforts and enables greater richness of the information.

- **Relevance of Community Awareness:** The first two studios identified community awareness as a key factor in using data to improve MHPSS service delivery. As per our RD4C Principle on being "Participatory", data-based processes are more effective and responsible when the community is aware of how data is used by the Government and other partners. The UN Inter-Agency Standing Committee's concept of Accountability to Affected Populations similarly calls for humanitarian actors to "enable affected communities to play an active role in the decision-making processes that affect them through the establishment of clear guidelines and practices to engage them."[14] This will indeed allow trust-building and co-design processes, which will increase the quality of the data shared and ultimately of the services delivered.

[13] Organizations might want to reflect on this concern and how a desire for information among volunteers intersects with children's rights to privacy and confidentiality.

[14] Inter-Agency Standing Committee. 2015. "The Essential Linkages between Accountability to Affected Populations (AAP) and Prevention of Sexual Exploitation and Abuse (PSEA)." United Nations Office for the Coordination of Humanitarian Affairs Services. https://interagencystandingcommittee.org/system/files/aap_psea_2-pager.pdf.

4.2 FOCUS GROUPS: OUR VISIT TO THE NAKIVALE REFUGEE SETTLEMENT

Following the second studio, the RD4C team traveled to Nakivale, a refugee settlement in southwest Uganda near the country's border with the Democratic Republic of Congo. There, the RD4C team, UNICEF and UNHCR hoped to understand how MHPSS data systems are understood by those directly implementing them and receiving them on an individual level. These groups included village health teams, child protection committee members, and adolescent refugees themselves.

Adolescent Refugee Girls

As part of our visit to the Nakivale refugee settlement, the team held a focus group with a small group of adolescent refugee girls aged from 14 to 18 years. The overall aim of the focus group was to understand how refugee children and adolescents understand the processes of data collection, whether they are aware and supportive of them, and if they know what happens with the information they share. Major takeaways from the engagement include:

- **Lack of Information**: Adolescent refugee girls participating in the focus group indicated that they don't know why information about them and their mental health is collected. They expressed concerns that sharing details about their mental health challenges does not seem to be useful in getting the support they need. Indeed, they do not see their engagement leading to meaningful support or services, which could indicate a major problem if a common experience across refugee settlements.
- **Lack of Trust:** The participants said that the constant requests to divulge information and the absence of necessary support leads them to have a lack of trust toward professionals and systems more broadly. Furthermore, the adolescents argued that if they knew what happens with the information they share (e.g. why it is collected, who uses it, how it is used, why it is sometimes not used), they would trust the institutions and organizations working on the settlement more.

MHPSS Service Providers, VHTs and Child Protection Committee Members

In addition to the meeting with adolescent refugee girls, the team hosted two focus groups with 17 (5 female and 12 male) MHPSS service providers, VHTs and Child Protection committee members operating in the Nakivale refugee settlement. The first category met were the MHPSS service providers, which included clinical psychologists, community-based psychotherapists, and volunteer psychosocial support assistants. The second category were members of the Village Health Teams

(VHTs), a set of volunteers elected from within their refugee communities who work with service providers to identify, work with and refer children who may be suffering from various challenges, mental health or otherwise and the third category were the Child Protection Committee members who work specifically in handling child protection issues.

The aim of the discussion was to get a direct understanding of how the settlement works, specifically as it relates to the handling of MHPSS data about and for refugee children.

Major takeaways from these engagements include:

- **Feedback Loops:** MHPSS and child protection professionals (often volunteers from civil society and refugee settlements themselves) expressed concerns that they did not know how cases they reported were dealt with by service providers. They were not "looped in" on basic reporting on the results of specific cases nor overall reporting (e.g. number of cases referred or number of services provided). Individuals could talk to parents (mostly the father) and could independently ask about cases at monthly meetings with service providers but otherwise received little information about children after referral. Individuals also expressed concern they did not receive feedback on their work.
- **Morale and Support:** The VHTs emphasized that they worked in difficult contexts on a volunteer basis, often with few resources available to them. While many participants found motivation in their desire to help children in their community, focus group participants spoke about how it was easy to become dejected and disengage from their child protection responsibilities. They emphasized the need for more personnel and more resources available to each individual to ensure that child protection cases could be identified early and addressed fully.
- **Training**: There seems to be an urgent need to train all VHTs on MHPSS, so that they are able to integrate it in "general health" issues and resources. Out of the 87 villages in the settlement, only 25 have VHTs trained on MHPSS. Many recognized the importance of having enumerators trained to handle the data they collect. Moreover, while many of the VHTs were able to use a paper-based form to track cases and expressed their confidence in identifying extreme behavioral and mental health challenges (e.g. addiction), the RD4C team noted that the VHTs might encounter difficulties in identifying less acute mental health and psychosocial conditions (e.g. anxiety, depression).

4.3 STUDIO 3: CO-DEVELOPING SOLUTIONS WITH NATIONAL STAKEHOLDERS

Stefaan presents the findings from the previous week of activities

Participants report back from their breakout groups in Isingiro

On Friday, 23 September, RD4C and its partners, UNICEF and UNHCR, hosted its final workshop focused on ideating solutions to the most pressing challenges identified in the previous studios, interviews, and community focus groups. After some internal deliberation and validating the decision with the studio participants, the partners identified the following three priorities as being the most important and feasible to address within the next 3–6 months:

- **The Need for a Taxonomy for MHPSS Data**: How can data be more consistently categorized, collected, analyzed, stored and used, particularly one that distinguishes MH from PSS in a useful fashion?

- **The Value of a Data Catalog and Directory:** How can MHPSS service providers datasets be accessed, used or re(used) more responsibly as per the principles of responsible data for children and requirements around personal data protection?

- **Responsible Data Governance**: How can data be more responsibly managed to promote the rights and welfare of child refugees?

After a presentation and brief discussion, the studio broke into small groups—each consisting of stakeholders across sectors—to identify ways to address these needs and promote more responsible, effective, and far-reaching MHPSS data systems for refugee children. These deliberations arrived at the following action items to be achieved over the next three to six months.

Group #1: The Need for a Taxonomy for MHPSS Data

1. ***Bring Together the Working Groups Operating at Different Levels of Response:***
    a. Participants discussed how there was a MHPSS working group at the refugee response level, a technical mental health unit at the Ministry of Health, a National Mental Health and Psychosocial Support Working Group and other coordinating bodies involved in issues relevant to the mental health and psychosocial well-being of refugee children. For the participants, a natural first step in developing harmonized standards and practices would be to bring these groups together under one umbrella.[15] In addition to these national policymakers, participants also recommended this group include field practitioners familiar with conditions "on the ground," such as representatives from the Uganda Counselors Association.

    b. This consolidated working group would subsequently be tasked by the national government to develop specific criteria for both MH and PS diagnoses, breaking down existing standards found in the "Diagnostic and Statistical Manual of Mental Disorders," the current basis of existing databases, into more particularized categories broken down by severity (e.g. mild anxiety, moderate anxiety, and acute anxiety). The working group would also be tasked with identifying specific, usable categories (and diagnosis criteria) for PS disorders.

    c. These standards, once agreed upon by the consolidated working group, would then be developed into a report for use by the working group and partners.

2. ***Socialize Standards Within Service Provider Organizations:***
    a. Upon completing the report, the representatives of each organization included in the working group would be tasked with disseminating the standards within their organizations' leadership and integrating it into existing practice.

    b. Participants believed that these representatives, often high placed within their own institutional hierarchies, would be best positioned both

[15] A participant in the plenary session subsequently noted that such a group might already exist, but participants were unaware of this fact. If this is the case, it may be beneficial to take steps to improve this group's (and its products') visibility and to strengthen its capacity to contact and lead organizations.

to understand the issues under discussion and how to embed the new, common standard into their institution. These leaders would support work to address the large, system-level challenges inhibiting collaboration among institutions. Participants noted that it may be beneficial for these representatives to make themselves available to their staff for questions and to provide information.

3. ***Prioritize Training Staff to be Familiar with New Standard:***
    a. Once the institutions are familiar with the new standards and what each category or data type entails, the next step would be to train field practitioners and other individuals likely to make contact with children how to use them.

    b. Participants emphasized the vital importance of integrating the standards into existing training and re-training health and social workers to ensure these standards took hold. Only by making sure people use the standards is it possible for them to persist and meaningfully support coordination.

4. ***Further Disseminate Standard Within Communities With Training and Information:***
    a. Finally, once standards have been adopted institutionally—from senior leadership to those social workers engaging directly with children—participants spoke about their hope of making them common knowledge among parents, teachers, and anyone else who might be a "point of first contact" for a child suffering from MH or PS challenges.

    b. In addition to providing generalized training, participants spoke highly about the value of common, easily understandable materials (e.g. signs, posters, brochures) explaining how to identify and categorize a child's potential struggles as well as who to contact. Participants particularly focused on the value of common "checklists" that could be used by teachers and village health teams to track specific symptoms and understand when to refer cases up the chain. Such a checklist would need to span the length of the system, containing information relevant from the beginning of the process to the end. Participants further noted how several organizations, such as War Child, have already developed these checklists but that these need greater visibility and adoption by other institutions.

Group #2: The Value of a Data Catalog and Directory

1. ***Map the Ecosystem:***
    a. Before stakeholders can know which organizations hold which data, group participants argued that it made sense to understand which actors were involved in which topics—formally and informally. As such, the participants centered much of their conversation on ways they could conduct a comprehensive mapping of MHPSS data holders and data users in Uganda, who might have a role to play in child refugee well-being. To this end, it seems important to note that there is in fact an ongoing process by the Ministry of Gender Labour & Social Development (MGLSD) aimed to conduct a comprehensive data needs assessment for child care and protection. This effort could indeed be beneficial and make it easier to map the ecosystem.

    b. There were various suggestions on who would be best positioned to lead any kind of mapping effort about MHPSS data for and about refugee children. Participants noted that the Ministry of Health, the Office of the Prime Minister, the Ministry of Gender, Labour and Social Development, the Ugandan Bureau of Statistics, as well as UNHCR and UNICEF and Civil Society Organizations (at national and local levels) had a role to play and encouraged them to be deeply involved in the process. However, the most obvious authority (for participants) was one of the existing national MHPSS working groups.

2. ***Develop a Summary Report or Directory:***
    a. After the working group conducts its mapping in consultation with relevant stakeholders, the group would be called to summarize its information in a way that could be usable by different organizations.

    b. Given data often exists in different repositories and is controlled by different organizations, a directory could “tag” which datasets contain data for which issue as well as a contact at an organization responsible for coordinating with external parties about data sharing and data collaboration. Organizations might designate an individual particularly capable of responding to and submitting requests for data.

Group #3: The Importance of Responsible Data Governance

1. ***Create a Dedicated Expert Group to Identify Best Practices:***
    a. As a necessary first step to understand what constitutes good data governance, the group focused on the concept of an expert group that would be tasked with developing best practices for others to follow. This group would include senior professionals across sectors and agencies.

    b. To ensure adoption of these best practices for MHPSS data systems affecting child refugees, this expert working group would be developed under the auspices of the national MHPSS working group. The experts would be charged with developing a draft report and presentation for the working group to review and discuss.

2. ***Develop a Manual or Standard Operating Procedure:***
    a. Based on the material provided, the National MHPSS working group would then work on developing a common data governance framework for responsible data management that could be adopted and implemented across government and service providers. Toward that end the participants focused on what it would take to develop a manual or standard operating procedures around MHPSS governance.

    b. Among the topics such a manual would cover include managing access to data; data storage (including data archiving and destruction); data security; data protection and privacy; data quality; among other areas. This manual, when complete, would be made available to data-holding and data-using organizations that provide services to refugee children in Uganda.

5. CONCLUSION: SHORT-TERM ACTIONS

During the three studios in Uganda, the RD4C initiative and its partners attempted to both identify the challenges facing MHPSS data systems affecting refugee children and co-develop possible solutions to these challenges. Both the challenges and actions are outlined above. As immediate first steps toward accomplishing these actions, stakeholders in Uganda might:

- Convene the MHPSS Working Group and Other Stakeholders: At the next meeting of the MHPSS Working Group, participants might discuss the actions identified in Section 4.3, including those involved in developing a taxonomy for MHPSS data, a data catalog and directory, and data governance framework. The working group might think, particularly, about *who* specifically can serve as the point of contact on these efforts, who they might be relevant to work with them on these issues, and what timetable might be useful for keeping groups engaged and motivated.

- Circulate Guidance and Regular Updates: To ensure a common understanding of the next steps among relevant stakeholders, the MHPSS Working Group might develop a summary of the results of these discussions on an easily accessible public platform such as a website or the communication channel used within the MHPSS Working Group (e.g. newsletter). It might then provide regular updates on the progress it has made toward achieving its goals and who is involved in these efforts to ensure there is accountability.

- Solicit Input From Recognized Stakeholders: Throughout this work, officials might want to keep channels open with community groups and aid providers so they can provide their input and expertise. These channels could include in-person meetings and sub-groups to the MHPSS working group, email engagement, forms and surveys.

While this work can only be a first step in improving the responsible management of data for and about refugee children, we hope that this document can identify a few potential avenues that the Government of Uganda can pursue together with UNICEF and UNHCR Uganda. Until then, we will continue to work in Uganda and around the world to promote responsible data.

Addendum I: Studio Schedule

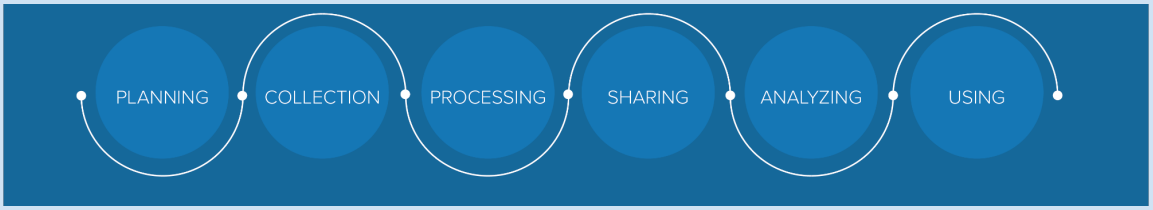
Date	Activity
Monday 19 September 2022	Meeting with UNICEF & UNHCR senior management
	Studio #1: Consultation with MGLSD, OPM, MoH, Butabika, CP/MHPSS partners and other national stakeholders
Tuesday 20 September 2022	Meeting with Refugee Desk Officer OPM in Mbarara
	Meeting at Mbarara Regional Referral Hospital
Wednesday 21 September 2022	Meeting with OPM commandant
	Studio #2: Consultation with MHPSS and CP partners
	Focus group consultation with refugee community, volunteer health teams, and adolescents
Thursday 22 September 2022	Discussion of prior engagements with UNICEF and UNHCR Uganda
Friday 23 September 2022	Studio #3: Consultation with MGLSD, OPM, MoH and MHPSS/CP partners on ideating solutions

Addendum 2: Pre-Reader

- **WHY WE ARE HERE:** With over 1.5 million refugees— over half of which are children—Uganda is the third-largest refugee-hosting country in the world and the largest refugee hosting country in Africa. Many of these refugees report experiencing psychological distress and face challenges in accessing **Mental Health and Psycho-Social Support (MHPSS)**. COVID-19, increased isolation and abuse/violence exacerbate the need for MHPSS amongst refugees and host communities.

- **WHAT WE ARE DOING:** UNHCR, UNICEF and the Responsible Data for Children (RD4C) initiative—a partnership with The Governance Lab—seeks to support *government officials* and *field practitioners* to promote better management of refugee children's data related to the provision of MHPSS services in Uganda. Particularly, it seeks to ideate ways to harmonize and connect the various MHPSS data sources available—including those generated through cases, surveys, and Inter-Agency Feedback, Referrals, and Resolution Mechanisms and other MHPSS programme interventions—so as to improve access and effectiveness of available services.

- **HOW WE WILL DO THIS:** From 19–23 September, we will host three studio workshops to map common challenges and concerns regarding the responsible use and reuse of refugee children's MHPSS data and prototype a pathway forward to address these challenges through the lens of the responsible data for children principles. To organize the existing and emerging MHPSS work in Uganda, we rely on the **Data Lifecycle**—an abstraction that explains the opportunities and challenges in how data is translated from insight and into action. It includes:
    - **PLANNING:** Defining objectives and partnerships and designing an implementation strategy.
    - **COLLECTION**: Gathering data from surveys, censuses, voting or health records, business operations, web-based collections, and other relevant, accessible sources.
    - **PROCESSING**: Removing irrelevant or inaccurate information, reformatting contents to be interpretable by an analytic software, and otherwise validating the data collection.
    - **SHARING**: Accessing data with relevant collaborators to derive insights from it.
    - **ANALYZING**: Assessing the data collection to extract insights about the issue as well as creating a loop for (re)sharing processed data and data insights among appropriate parties.
    - **USING**: Acting on insights derived. Actions can affect data collected for future operations.



- Further, we present the Responsible Data for Children principles that can guide responsible (re)use of MHPSS data:
  - **PARTICIPATORY**: Engaging and informing individuals affected by the use of data for and about children.
  - **PROFESSIONALLY ACCOUNTABLE**: Operationalizing responsible data practices and principles by establishing institutional processes, roles, and responsibilities.
  - **PEOPLE-CENTRIC**: Ensuring the needs and expectations of children, their caregivers, and their communities are prioritized by actors handling data for and about them.
  - **PREVENTION OF HARMS ACROSS THE DATA LIFE CYCLE**: Establishing end-to-end data responsibility by assessing risks in the collecting, storing, preparing, sharing, analyzing, and using stages of the data lifecycle.
  - **PROPORTIONAL**: Aligning breadth of data collection and duration of data retention with the intended purpose.
  - **PROTECTIVE OF CHILDREN'S RIGHTS**: Recognizing the distinct rights and requirements for helping children develop to their full potential.
  - **PURPOSE-DRIVEN**: Identifying and specifying why the data is needed and how the intended or potential benefits relate to improving children's lives.

Planning: Defining objectives and partnerships and designing an implementation strategy.

Defining the Problem	The Uganda Country Refugee Response Plan (UCRRP) 2022–2026 notes an **urgent need for improved monitoring and evaluation as it relates to refugee MHPSS in Uganda**, including providing "clarity on impact measurement and on causal linkages from sector outcomes to impact." Issues stem from a lack of funding for MHPSS strategy and service delivery, coordination between stakeholders, and challenges in creating participatory and community-based initiatives. Thus, work is needed to assess the level of engagement of beneficiaries, promote accountability, and promote "peaceful co-existence."
Forging Partnerships and Designing Mechanisms	Examples of existing data collection mechanisms in Uganda include: ● The REACH Initiative provides "granular data, timely information and in-depth analysis from contexts of crisis, disaster and displacement." It is a joint initiative of IMPACT Initiatives, ACTED, and the United Nations Operational Satellite Applications Programme (UNOSAT). ● The Inter-Agency Feedback, Referral and Resolution Mechanism (FRRM) launched in Uganda in October 2018 by the UNHCR, Office of the Prime Minister of Uganda, and several other partner agencies provides a centralized, toll-free call center for refugees seeking advice. ● ProGres v4, UNHCR's "corporate, centralized, web-based case management software application" allows for collection of data about individuals to facilitate the protection of people of concern. It is used for collection of refugee and IDP data, biometric data, cash assistance programs, and other assistance programs. UNHCR uses ProGres globally.
Key Considerations:	***Actor collaboration?*** ***Funding?***

Collection: Gathering data from surveys, censuses, voting or health records, business operations, web-based collections, and other relevant, accessible sources.

Current Practices	There are a variety of mechanisms that organizations in Uganda use to collect MHPSS data. Several notable mechanisms include: 1. Organizations have various surveys, participatory assessments, and other traditional data collection methods (e.g. phone-based surveys) used to collect data about refugee situations in Uganda. 2. The FRRM is a specialized helpline for refugees to "augment the existing **information sharing system in refugee settlements and provide safe, accessible and reliable communication channels to refugees and asylum seekers**." Its main service is a centralized call center reachable via a toll-free number. It is a tool to share feedback and file complaints or queries. 3. UNICEF and Save the Children also run "Child Friendly Spaces" to provide psychosocial support to children in schools. **Facilitators of the program collect various data on** names, age groups, sex, school attendance, and disabilities of children enrolled. **Donors use this "registration and attendance data" to verify programs.** 4. UNHCR, through its implementing partner, keeps an **Excel database of clients (children and adults) receiving mental health support.** More detailed files are maintained for clients receiving advanced mental health support. While there are various sources available on the general well-being of refugees through this avenue, **few of these sources or techniques are harmonized as it pertains to MHPSS and children**.
Evaluating Data Assets	These assets are considered important sources of information but have limitations: 1. Surveys, participatory assessments, and other traditional data collection methods are often not harmonized as it relates to MHPSS and children. 2. **Data related to MHPSS programming and service provision is often done by hand, on paper, with no common tools for collection,** which can present challenges for secure management of sensitive data. 3. FRRM has tried to become more accessible by also allowing complaints to be received through protection desks, suggestion and complaint boxes, and face-to-face communication. However, practitioners believe that the **FRRM is underutilized in the field by children because of the need to access a phone.** 4. Information collected on "Child Friendly Spaces" is often collected on paper by hand in different formats with different standards, when what is needed is a common guidance and a single tool used by all agencies. In addition, as the data is collected regularly, community members use it to monitor child absences or reduced attendance which could be flagged to case workers.
Key Considerations:	***Widespread accessibility?*** ***Standardization of data collection practices/techniques?***

Processing: Removing irrelevant or inaccurate information, reformatting contents to be interpretable by an analytic software, and otherwise validating the data collection.

Developing Storage Guidelines	To be useful, data collected from surveys and traditional data collection methods, FRRM, and "Child Friendly Spaces" and from other MHPSS programmes/ interventions needs to be stored in a safe way for responsible data use and reuse and to maintain confidentiality of personal/identifying information. However, the RD4C team was not able to verify ***how*** data collected on MHPSS was stored by UNICEF, UNHCR, partners and the Government of Uganda. **Little knowledge is available on whether there were backup systems, deletion practices, or reviews of storage procedures.**
Building Robust Security	The RD4C team was not able to verify whether there were **policies or procedures in place to prevent unauthorized access, data breaches, data loss, and data misuse.** Interviews with key stakeholders did not reveal any specialized training on data handling and data security.
Establishing Internal Access & Security Protocols	The RD4C team was not able to verify whether there were **particular restrictions regarding data access**—including tiered access to raw data, password protocols, secure server rooms, change history and audit trails , and internal processing safeguards.
Categorizing and Taxonomizing Data	The RD4C team did not find any indication that there was **active tracking of data provenance, mapping of data**, or documentation of the assumptions involved in processing.
Key Considerations:	***Information on data storage governance and practices?***

Sharing: Accessing data with relevant collaborators to derive insights from it.

Establishing Cross-Partner Trust	One of the goals of the national MHPSS working group is to "foster stronger links" between different offices and organizations. The UNHCR MHPSS strategy notes "a need for enhanced coordination between actors, enhancement of clinical/specialized services, further community engagement, integration of MHPSS across sectors, strengthened referral pathways, guidance and minimum standards for MHPSS, prevention activities and also enhanced welfare and staff care for staff working on MHPSS activities." **Yet how this coordination can be achieved**, especially in a child refugee data context, among national refugee authorities, the Office of the Prime Minister, and 68 humanitarian partners involved in refugee management is **unclear**.
Collaborating to Achieve Goals	The RD4C team was unable to identify any documents or concerted efforts to address operational differences, coordination and interoperability among stakeholders involved in MHPSS for refugee children. In fact, a **lack of coordination and interoperability has been a major challenge to the responsible use and reuse of this data to help child refugees.**

Key Considerations:	***Actor collaboration?*** ***Interoperability of data collection and collation to allow for cross-sectoral sharing?***

Analyzing: Assessing the data collection to extract insights about the issue as well as creating a loop for (re)sharing processed data and data insights among appropriate parties.

Conducting Targeted Analysis	The Uganda National MHPSS working group in Kampala oversees MHPSS data analysis collected from traditional data collection, FRRM, and "Child Friendly Spaces". It has about 20 members and consists of several local and international NGOs working on MHPSS in both humanitarian and development settings. It provides a platform for technical and strategic coordination to "share learnings and approaches, ensure that partners implementation is based on the IASC guidelines on MHPSS and consolidate the Uganda MHPSS 4Ws matrix from different MHPSS partners."
Considering Algorithmic Implications	The RD4C team **could not identify any particular practices to explicitly and systematically vet data that might be used to train algorithms,** consider blind spots and biases, assess inferred personal data, assess inequities, ensure algorithmic interpretability, and test model predictions.
Keeping Humans in the Loop	Improving evaluation of MHPSS data for refugee children is a major priority in Uganda. The RD4C team **did not identify any specific practices to avoid monolithic evaluation**, educate engaged parties on algorithmic techniques, or transform results into action.
Key Considerations:	***Critical data examination to spot and avoid biases?***

Using: Acting on insights derived. Actions can affect data collected for future operations.

Preparing Findings for Release	Partners are aligned in their purpose to expand the reach, access, and effectiveness of MHPSS services to refugee children. Insights derived from individual data sources are communicated to leaders from UNICEF, UNHCR, OPM and others with support of the MHPSS Working Group. **However, the RD4C team could not identify specific preparation techniques.**
Releasing Findings	Findings from data can be used to assess how refugees (and subsets of refugees, such as children) understand their condition, the services available to them, and potential solutions. While they may not necessarily focus on MHPSS, the findings can inform problems that may *contribute* to MHPSS concerns (e.g. surveys on gender-based violence).
Planning for Data Aftermath	The RD4C team **could not verify specific strategies pertaining to data retention and destruction** or how organizations ensure compliance with privacy regulations and retrain models.

Reflecting on Implementation	The RD4C team **could not verify specific evaluation techniques or how organizations consider missed uses of data**—that is, reflection on other ways to analyze or contribute the data for better understanding of MHPSS problems.
Key Points:	***Standardized presentation of data findings (i.e. monthly/annual reports)?*** ***Data disposal governance and practices?*** ***Critical data (re)evaluation?***