

FINAL TECHNICAL REPORT_UNIVERSITY OF OSLO

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Research teams in Jordan and Palesting

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REPRODUCTIVE, MATERNAL, NEWBORN AND CHILD HEALTH SERVICES DELIVERY IN FRAGILE SETTINGS*

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Introduction

This technical report covers a period from November 2019 to April 2023 funded by the International Development Research Centre (IDRC). The project is titled “Governing Digital Personal Data to Strengthen Reproductive, Maternal, Newborn and Child Health (RMNCH) Services Delivery in Fragile Settings in Palestine and Jordan”.

The focus of this project has been to increase our understanding of the use of digital technologies for digital personal data DPD in the provision of RMNCH services in Palestine and Jordan and the opportunities and challenges associated with their application in relations to human rights and gender equality.

The aim was to produce a body of evidence which could be used by other researchers to identify further research avenues, and for civil society organization to use to develop key recommendations and demands for a variety of stakeholders.

The research problem

While there is a rapid increase in digital health initiatives focusing on the processing of personal data for strengthening the delivery of reproductive, maternal, newborn and child health (RMNCH) services in fragile settings, these are often unaccompanied at both the policy and operational levels with adequate legal and regulatory protections for data governance that impact human rights and gender equality. The failure to consider these elements makes beneficiaries of RMNCH services vulnerable to exploitation and exclusion while rendering the potential benefits from these digital initiatives to improve services delivery sub-optimal in terms of reach, coverage, scale and sustainability.

The project started with three main outcomes with each having two research objectives. The team has prepared a list of activities to achieve the proposed outcomes. The list of activities prepared was more detailed to facilitate the fieldwork and data collection.

The outcomes are:

- OUTCOME 1: Increased understanding of the existing policies, strategies and regulatory and legal frameworks governing the use of digital personal data for digital RMNCH services in Jordan and Palestine and the implications for human rights and gender equality
- OUTCOME 2: Improved capacity of drivers and implementers of digital health initiatives to assess maturity levels and leverage points of existing digital health strategies and systems in Palestine and Jordan to optimize gender equality and human rights.
- OUTCOME 3: Improved understanding of the experience of beneficiaries in accessing digitally-enabled RMNCH services using digital personal data (DPD), and whether there is a direct impact [positive or negative] on rights and gender equality to inform policy development and further research.

The data was collected at the regional, national and individual levels. In the first year of the project, we have completed the collection and analysis of the data at the national level in both Palestine and Jordan. This included mapping of the digital health initiatives and policy analysis.

Research methodology and findings

This project is the first in Palestine and Jordan that looks at digital health initiatives utilizing a comprehensive approach. This was evident when we started formulating the advisory committees and mapping the digital health initiatives.

This meant that at the onset of the project the focus was on undertaking the stakeholder analysis to understand the stakeholder ecosystem around ongoing DPD initiatives and analysis of existing policy and legal frameworks, and the development of the research methodology and tools to collect the needed information to make progress with the research planned under this project.

Mapping of DPD initiatives in Palestine and Jordan

Over the course of the project, the project team undertook a mapping of the DPD initiatives in Palestine and Jordan using a variety of methods for identifying the initiatives and collecting information on these initiatives, including:

1. Online search: We conducted a literature review using MEDLINE, Web of Knowledge, POPLINE, and ACM databases for studies in English published between 1 January 2000 and 30 September 2020. Searches incorporated medical subject heading terms, keywords and free text using the following search terms: “reproductive health”, “sexual”, “maternal”, “newborn”, “child/child health service”, “pregnant”, “neonatal”. We also searched for human rights and gender equality aspects of maternal and neonatal health care system using the following search terms “human rights”, “gender equality/discrimination”, “humanitarian”, and “refugee” under another string. The Boolean operator “OR” was used for the terms under each search string and “AND” was used to combine the two strings. The searches were broad, and all titles/abstracts were read to identify relevant papers.
2. Looking into the privacy policy for each initiative (if available) and retrieving these data (especially the ones related to data privacy).
3. Personal communications in a form of phone calls and face to face meeting with stakeholders.

A total of 12 initiatives were identified in Palestine and 9 initiatives in Jordan. The developed tool was used to extract detailed information on each identified initiative, with a main focus on objectives, level of the service, ownership of the initiative and the data, data flow, maturity level of the initiatives, and policies regulating these initiatives.

The literature review showed that limited availability of maternal and child health data has hindered progress in reducing mortality and morbidity among pregnant women and children in Palestine. Moreover, due to an unresolved and unpredictable political situation, Palestine is still in the process of establishing and implementing an eRegistry for maternal and child health in the

absence of formal legislation. Documentation and reporting consume considerable time for care providers in primary care maternal and child health clinics in Palestinian. Literature also showed significant data driven benefits for the health care system when utilizing automatically extracted data from a digital registry, however, multiple barriers exist to its dissemination and implementation including fragile political situation and overlapping legal traditions. The review also highlighted that there is a great demand for communication and service delivery tools in community-based maternity health workers.

In Jordan, the use of electronic medical records is also still quite in its infancy and the level of adoption of electronic health records (EHRs) is relatively low. However, significant steps are being taken to implement EHRs in hospitals, including, incentives to purchase EHRs, the availability of technical assistance, and additional reimbursement for the use of EHRs. The review also helped us to point out some of the challenges and barriers that hinder the development of e-health initiative in Jordan, such as economic burden of purchasing EHRs, lack of a centralized database for compiling audit results, lack of information technology staff, disruption to clinical care, and policies that support the e-health development.

The results of the mapping part were very important, as this is the first document that compiled all digital health initiatives related to RMNCH in Palestine and Jordan. It provides information about where these initiatives are, how they were developed, by whom, who funded it, the target population served, data sharing, data accessibility, and data flows. The results of the mapping part were shared with the advisory committee in Palestine for feedback and as a first dissemination activity. The tool developed will be shared with researchers interested in following similar methodologies and focusing on other digital health initiatives.

The results of the mapping and the literature review were published in [the Frontiers in Digital Health](#) in May 2023 with the following citation: Nemer M., Khader Y., Alyahya M., de Corbion A., Sahay S., Abu-Rmeileh N., **“Personal Data Governance and Privacy in Digital Reproductive, Maternal, Newborn, and Child Health Initiatives in Palestine and Jordan: A mapping exercise”**, April 2023

Micro and macro mapping of the policy landscape

During the mapping exercise, we also gathered literature data on reproductive health human rights that helped us to understand the assessment of knowledge, perceptions, attitudes, and practices of reproductive health rights among women of reproductive age in Palestine and Jordan. We also gathered data on data governance related to RMNCH in the two countries. The aim was to understand the legal, regulatory, and ethical landscape and to identify gaps, opportunities, and actions necessary to ensure an ethical and lawful framework for an eRegistry.

A systematic policy/document analysis approach was developed to facilitate the policy analysis. Based on the developed approach, a tool for gathering data was developed. The tool has two main parts; the first is the Desk-based Document Analysis part and the second part includes Key Informant Interview Questions. The two parts were made complementary to comprehensively cover all the aspects related to the policy documents to understand how these policies regulate

digital RMNCH initiatives, and how they incorporate data governance concerns of human rights, gender equality, and privacy within contexts of fragility.

The data collection and the key informants' interviews were challenged by the COVID-19 lockdown and interruption of work in Palestine and Jordan. We had planned to have more field visits to the stakeholders, but we restricted our visits to the minimum and according to the movement ability, and used phone calls and zoom interviews in many cases instead. For the desk-based document analysis, data were collected based on websites, documents and personal communications. Furthermore, it is important to note that the searching process for the policy document was a challenge. The documents were not easily accessible for the researchers and hence the wider community. It required several permissions to reach the policy documents.

In Jordan, eight different documents (policies and strategies) were identified and analyzed; the first three policies were health related documents, and the other five strategies/ policies were mainly focusing on the information and communication technology sector. In Palestine, four strategies and policies were identified; national health and reproductive health strategies, and two policies related to information technology and information security. The integrated findings of policy analysis from both countries provided comprehensive knowledge and deeper insights into policy development, monitoring, and evaluation.

Based on the findings from the mapping and the data analysis of both Policy/Documents Analysis and Key Individual Interviews undertaken, we undertook a wider macro analysis of legal, policy and regulatory developments in the region in relations to the digital transformation and digital health.

The findings revealed weak policies and governance environment to optimize human rights, women's rights, gender equality, and data protections, and the policies are implemented without adequate legal and regulatory frameworks, and in particular highlighted the following:

- in both countries, there is a piecemeal approach to the regulation and governance of personal data including health data and the processing of personal data in the health sector;
- in both countries, there is a lack of comprehensive and holistic approach to ensure that health-related regulations and the governance of the digital transformation integrates a rights-based approach
- policies and strategies are not multidisciplinary. For example, health strategies and policies do not cover digital or IT aspects such as data governance and data privacy issues, and on the other hand, the digital or IT strategies do not include health aspects, women's issues, gender equality, and human right aspects.

The final analytical piece is currently being reviewed and will be published shortly in the first half of 2023. It will then be shared with civil society organisations and academics working in the region and on related issues through social media channels.

The findings of this research informed two pieces on digital health published by Privacy International which showcased the work being undertaken in Palestine and Jordan:

- A resource/background on digital health which provides an overview of what digital health initiatives have been rolled out, for what purpose, where and by who, as well as some of the concerns they raise for the enjoyment of fundamental rights and freedoms. See: <https://privacyinternational.org/long-read/4671/digital-health-what-does-it-mean-your-rights-and-freedoms>
- In a long-read piece we present main discussions and measures we need to see being systematically adopted to inform decision-making about digital solutions in the health sector, and provide examples of where these were not integrated in decision-making processes and with what consequences. See: <https://privacyinternational.org/long-read/4674/why-we-need-talk-about-digital-health>

Assessments of maturity levels: data governance/interoperability and gender/human rights

Through this project, we developed maturity tools and FGDs guideline (Annex 1 includes the tools) to assess the maturity levels in relations to (i) data governance and interoperability and (ii) gender and human rights. The tool includes the maturity level checklist and levels of incorporation of human rights and gender concerns in digital infrastructure, in addition to data governance and interoperability.

The maturity assessment tools and FGDs guidelines were used in both countries as follows for data gathering and to support with analytical process.

In Jordan

- 2 DPD initiatives were selected for empirical analysis: i) The EMCH at UNRWA in the primary care sector; and ii) The Perinatal and Neonatal Mortality Surveillance and Auditing System “J-SANDS” in the hospital sector.
- Maturity level assessment approaches in Jordan involved identifying key stakeholders (developers, system designers, IT support persons, implementers, and end-users engaged in the collection and use of data) of each of the two DPDs selected.
- A total of 4 FGDs with key stakeholders were held in Jordan; 2 for JSANDS and the other 2 for the EMCH.
- To better understand the context of the maturity level of these selected digital solutions, we held two online group meetings using zoom application: one for each selected initiative.

In Palestine

- We have assessed the maturity level for three initiatives: Avicenna, a hospital-based initiative, MCH e-registry, a primary health care initiative, and the e-MCH mobile application introduced by the UNRWA to be used in their MCH clinics.
- We selected a variety of stakeholders who are involved in the selected initiatives, and who could answer parts or all of the aspects included in the maturity assessment tool.
- We used snowballing to identify additional key respondents to interview. The total number of stakeholders who participated in this assessment was 37; 13 for the Avicenna, 11 for the MCH e-Registry, and 13 for the e-MCH Application.

- Each stakeholder was interviewed individually with questions relevant to his/her position and qualifications.
- After all were interviewed, 2 focus group discussions were conducted and they included some of the interviewed stakeholders of each initiative.

Below we outline our main findings.

i. **Maturity assessments of data governance and interoperability**

Overall, the digital infrastructure and technological readiness components are more advanced and show higher maturity levels compared to data governance and interoperability components in Jordan and Palestine. In Jordan, the overall JSANDS initiative maturity indicators are somehow less advanced than those of the EMCH-J application. In Palestine, the MCH e-registry initiative maturity indicators are more advanced than both Avicenna and EMCH-P initiatives. Table 1 summarizes the maturity level ratings for the five RNMCH digital initiatives in the two countries.

The findings of the digital maturity assessment tool and focus group discussions with stakeholders highlighted several challenges and opportunities around the application and implementation of selected digital health initiatives in the provision of RMNCH in Jordan and Palestine. Our findings shed light on the maturity level of these initiatives within fragile contexts. The maturity level of the five RNMCH initiatives in both countries is inadequate and require further advancement before it can be scaled up and scaled out.

Amid all the heightened interest, several recommendations that we adopted were shared as WHO reports and suggested from several studies reporting on best practices in scaling digital health in LMICs through practical experiences from real-life case studies of scaling and sustaining digital health initiatives that became fully integrated in healthcare systems. Taking these recommendations into account when developing, implementing, and scaling digital health initiative in Low- or Middle-Income Countries (LMICs) can result in successful and sustainable initiatives, thus meet health needs and improve healthcare of individuals especially those living in fragile contexts.

Table 1: Maturity level ratings for selected RNMCH digital initiatives in Jordan and Palestine

Category 1: Digital infrastructure in place for RMNCH						
Dimension	Components	JSANDS	Avicenna	EMCH-J	EMCH-P	MCH-e registry
ICT Infrastructure (Techn	Reliable power/electricity	2.5	2	3	3	2
	Hardware	3	2	2.5	2	3

	Reliable networks and Internet connectivity	2.5	2	2.5	2	2
	Operations and maintenance (for computer technology)	2	2	3	2	2
	Training and education (includes continuous professional development)	2	1	3	2.5	2
Category 2: Data governance and interoperability						
Dimension	Components	JSANDS	Avicenna	EMCH-J	EMCH-P	MCH-e-registry
Governance	Drivers for Data Governance Planning	0	0	2	NA	1
	Data Governance Planning	1	0	2.5	NA	0
	Governance structure	1	0	2	NA	1
Legislation, Policy, and Compliance	Data ethics and human rights	2	2	2.5	3	2
Standards and Interoperability	Data and exchange standards	1	1	2.5	2	2
	Personal data exchange	0	0	2.5	2	0
	Aggregate data exchange	2	0	2	2	1
Data Quality and Use	Data management	1	0	3	NA	2
	Data use availability strategy	2	0	3	0	0
	Data synthesis and communication	1	1	2	NA	2
	Reporting and analytics features	2	1	1	NA	2

The manuscript was [published in the journal of Methods of Information in Medicine](#) as follows: Alyahya, Mohammad S., Niveen ME Abu-Rmeileh, Yousef S. Khader, Maysaa Nemer, Nihaya A. Al-Sheyab, Alexandrine Pirlot de Corbion, Laura Lazaro Cabrera, and Sundeep Sahay. "Maturity Level of Digital Reproductive, Maternal, Newborn, and Child Health Initiatives in Jordan and Palestine." *Methods of Information in Medicine* 61, no. 05/06 (2022): 139-154.

ii. Maturity assessments of human rights and gender

Our findings show that there is a lack of systemic and comprehensive approach and consistency to how issues related to gender and human rights within DPD initiatives are addressed and how these considerations inform the design and implementation of such initiatives for the five digital initiatives in the provision of RMNCH in both Jordan and Palestine. In particular we would like to highlight the following:

- There is a need for further advocacy and capacity building at all levels on issues related to gender and human rights within DPD initiatives targeting the different actors involved in the design, implementation, and use of these systems, including developers, system designers, IT or technical support persons, policymakers and high-level stakeholders, implementers, and end users engaged in the collection and use of data.
- There is a general lack of systematic and meaningful approach to understanding the needs of patients i.e. the beneficiaries of the systems, in the context of ensuring that the services they are offered adequately incorporate gender and human rights considerations.
- There is not only a lack of understanding amongst all stakeholders of how digital initiatives in reproductive and maternal healthcare settings have the potential to implicate an array of rights of patients and the importance of ensuring that such systems are built with the needs and rights of the patients at the center, but this understanding is different amongst stakeholders in terms of how DPD initiatives are designed and implemented.
- There is a need for frameworks and policies that are specific to the respect, promotion and protection of human rights, and there is a need to undertake awareness raising about their existence and where they can be accessed.
- There is a lack of systemic approach to risk assessments, and the purpose these serve to inform the design and implementation of systems.
- There is an inconsistent approach to seeking consent from patients prior to data processing.
- Mechanisms for patients to report any concerns in relations to human rights and gender are currently not in place.
- There is an inconsistency in terms of how gender and human rights are considered between State-run initiatives and initiatives deployed by third party such as humanitarian agencies.

The manuscript has been finalized and will be presented to various journals covering human rights and health and/or technology issues in the first half of 2023 under the title: **“Women’s perceptions of using Digital RMNCH Initiatives – the UNRWA’s e-MCH application in Jordan and Palestine”**.

Understanding experience of beneficiaries

To better understand the experience of beneficiaries in accessing digitally enabled RMNCH services using DPD, we conducted observations and individual interviews with women attending the health center. In order to do so, we developed a checklist for observations and an interview guide (Annex 2 contains these tools).

The Jordan team conducted 55 individual interviews (with beneficiaries) and observation sessions as follows:

- For JSANDS, 20 interviews and observation sessions were conducted.
- For EMCH, data was collected from three UNRWA healthcare centers: Irbid (10 interviews), Alzarqa (15 interviews), and Albaqa (10 interviews)

The Palestine team conducted 46 individual interviews (with beneficiaries) and 21 observation sessions at the health facilities as follows:

- For Avicenna, 9 interviews and 5 observation sessions.
- For MCH e-registry, 12 interviews and 6 observation sessions.
- For eMCH application, 25 interviews and 10 observation sessions.

Our findings highlighted the experiences of women who were using the e-MCH application in Jordan and Palestine. Women in both countries appreciated the usefulness of this application as a credible source of information related to their pregnancy and child care. This improved access to information through mobile application has proved to be effective during pandemics, as it provided them with continuous access to necessary information and instructions related to their pregnancies and their child care, when physical access was not possible. In addition, the women talked about the instructions that they received which was relevant for protecting themselves and their families during COVID-19.

Women highlighted another advantage in terms of reduced waiting time, which enhanced the frequency of contact with healthcare providers, improved their satisfaction levels, and helped overcome time barriers for receiving such care, especially in busy clinics. One prominent function of the e-MCH is that it provides women with a remote access to their and their children's health records and helped mothers to track their data in real real-time and continuously review their progress. Likewise, providers could review past progress notes, vitals, immunizations, family history, and much more. This mobile application helped the providers stay up to date on all patients' health information and helped patients stay educated on their health as well as their engagement and interactions with their healthcare providers.

Women saw the initiative as useful in alerting them about their appointments and reminders at the clinic, which helped to improve health outcomes. Appointment reminders helped increase attendance regardless of the type of appointment. Automated reminders targeted at modifying behaviours were also shown to be effective as they increased attendance rates and potentially decreased clinic costs due to missed appointments.

Almost all of the participants did not have any concerns about disclosing their personal information using this digital initiative in both countries. Many women considered the initiative safe because it was recommended by their healthcare providers, whom they trusted deeply. It is worth mentioning that while online users increasingly relied on smart mobile devices, the processing of personal data through such tools was not always transparent or controllable by the users. It is important to note that many beneficiaries indicated they had not read the privacy policy and some were even unaware of it because the health care providers downloaded the app

for them. This raises further questions about beneficiaries' understanding and ensuring that they have clear access to information about how their data is being processed, by whom and for what purpose, in particular in light of the findings outlined in the gender and human rights assessment which indicated concerns about obtaining meaningful consent, and generally a lack of consideration for gender, human rights and risk in relations to Digital RMNCH Initiatives.

In conclusion, the e-MCH mobile application was perceived by women in Jordan and Palestine as beneficial, user-friendly, and safe because it was recommended by their healthcare providers, whom they trusted most but they are still some issues and questions to explore further on how to empower beneficiaries to make informed decisions about how their data is processed, by whom and for what purpose, and the implications this may have on them and their rights.

The analysis has been completed and the findings been presented in a manuscript by the project teams at JUST and Birzeit University which was reviewed by Privacy International. The manuscript is in the final stages of drafting and peer review. It will be presented to various journals covering human rights and health and/or technology issues in 2023 under the title: **“Women’s perceptions of using Digital RMNCH Initiatives – the UNRWA’s e-MCH application in Jordan and Palestine”**.

Research methods and analytical techniques

The methodology used to complete outcome one included desk research, and interviews. The research team identified key stakeholders around each initiative using the mapping tool. The development of the mapping tool was based on international literature and research team experience. Desk-based Document Analysis part and the second part includes Key Informant Interview Questions

The team has also developed a tool for document review and key informant interview guide for the policy analysis. The tool was based on several international tools focusing on gender equality and human rights integration within health policies.

The process of tools development started at the national level, where the Palestinian and Jordanian teams searched for the different tools. Then the tools were shared with the rest of the team from University of Oslo and Privacy International for feedback. Special sub-group was formed to further develop the policy analysis tool to ensure the integration of gender and human rights based issues. The tool was further shared with gender and human rights experts from Palestine and Norway for feedback.

The tool development process was challenging because of the limited number of studies conducted in the region and the team had to rely on international literature. Another challenge was the accessibility of policy documents. The researchers could not find the policy document directly and needed to talk to several stakeholders to get them. There was delays due to the lockdown when mobility was limited.

Partnership development

The research team has formulated two advisory committees; one in Palestine and the other one in Jordan. The role for the advisory committee was to support the implementation of the research and provide guidance and feedback throughout the process. There was some delay in formulating the committees due to the lockdown. However, the Palestinian team has managed to conduct a meeting with the advisory committee remotely using Zoom. The committee was pleased with the project in general and has provided productive feedback on the mapping part. The advisory committee has agreed to have a major role in disseminating and advocating for the research findings during and after completing the implementation of the project.

Progress towards Goal and Outcomes

Building on the results reported in Year 1 and Year 2, this report demonstrates that over the course of the project we have made significant progress toward achieving the aim of this project to identify and assess the use of digital technologies for DPD in the provision of RMNCH services in Palestine and Jordan in order to understand the opportunities and challenges associated with their application in relations to human rights and gender equality as well as to understand the stakeholders in this ecosystem as well as their respective obligations and responsibilities.

OUTCOME 1: Increased understanding of the existing policies, strategies and regulatory and legal frameworks governing the use of digital personal data for digital RMNCH services in Jordan and Palestine and the implications for human rights and gender equality

Working within the framework of an interdisciplinary project team we have been able to incorporate diverse perspectives in documenting the implications for human rights and gender equality of digital RMNCH services in Jordan and Palestine.

Over the course of the project we have made significant progress towards this objective. As a result of primary research we undertook through the use of tailored-made tools and other data gathering activities including interviews and FGDs and secondary research analysing policy documentation and other materials, we have been able to present a strong evidence base on the current use of digital personal data for digital RMNCH services in Jordan and Palestine through the identification of the main programmes and systems in place, how they are implemented and operate, and to assess their implications for human rights and gender equality.

Increased research skills

This project contributed to an emergence of a multidisciplinary research team from different countries who started collaborating and working in an efficient manner. Thanks to this research project as a project team, we have built our own understanding of the existing policies, strategies and regulatory and legal frameworks governing the use of digital personal data for digital RMNCH services in Jordan and Palestine and the implications for human rights and gender equality. We have a clearer understanding of the actors involved in digital RMNCH interventions in both countries having had to identify who they were ahead of the data collection phase. We also have a better grasp on the current legal and regulatory framework as well as voids in which these interventions are deployed, and as outlined in our research findings above we have been

able to assess if and how human rights and gender equality are considered in the design, and deployment of digital RMNCH interventions which has enabled us to identify further areas of research and to articulate some initial advocacy and policy demands.

Beyond the substance of the findings, it is important to note here that the project resulted in the project team building and developing the analytical skills, including collecting, visualizing and analyzing information to see the bigger picture or trend behind facts, as well as the systematic trends or links. Analytical skills were mainly obtained because of the need for the project members to develop tools and research methodologies to undertake the data collection including the policy analysis, maturity level assessment, and analysis of beneficiary's perceptions around use of digital RMNCH services and DPD. We became, as researchers, more knowledgeable in understanding different DPD maturity levels and dimensions and the required infrastructures and capacities of digital health solutions.

Knowledge sharing

With the aim of building the understanding of other researchers and academics in this field, the research findings from the different parts of the projects have been presented into 4 manuscripts of which 1 has been published (an assessment of maturity levels with regards to data governance/interoperability which was published in *Methods of Information in Medicine*), one has been accepted for publication in the *Frontiers in Digital Health* (mapping exercise of digital health interventions), and two are pending including the assessment of maturity levels with regards to gender and human rights, and are pending publication and study of beneficiaries' perceptions of using digital RMNCH Initiatives in Jordan and Palestine. The latter two will also be published in leading academic journals.

Furthermore, we trust that the tools we developed for policy analysis which cover issues of data governance, human rights and gender equality will help future researchers to study other initiatives in their countries, especially in fragile settings. In fact, another project team, inspired by this project, is also initiating a similar research effort in India.

Content produced on digital health by Privacy International which presented some of the main governance, gender and human rights issues around digital health were shared widely with the Privacy International Network, as well as key actors in the space of digital health. Furthermore, Privacy International was invited by the University of Oslo's Informatics Department to deliver a seminar on: "A Human Rights Approach to Digital Health", which took place in April 2021, which referred to the approach adopted by this project to consider the governance, gender and human rights issues around RMNCH.

Advocacy and strategic dissemination

Over the course of the project, we have taken steps to ensure that these newly available findings and increased understanding of digital MNCHC initiatives emerging from our research were shared with a variety of stakeholders so they could also increase their own understanding of the issues explored in this project.

We have done this by making the findings accessible to others thanks to our pro-active outreach and participation in national and international events and consultations both in the health and human rights spaces targeting other researchers and academics as well as civil society, government authorities and global development and humanitarian organisations.

The policy analysis exercise informed the Higher Population Council in Jordan to revise and enhance their latest strategy “National Population Strategy 2021-2030) which was issued recently. In the West Bank, stakeholder involved in reproductive health were interested in learning more to include in the newly developed Reproductive Health Strategy for the years 2023-2026.

The project team was represented to join discussions as part of The Future of Digital Work: The Challenge of Inequality “IFIPJWC2020” international conference as part of the research in progress track. It served to bring attention to the issue of digital RMNCH services in Jordan and Palestine to an international audience, and to connect with other experts in the field. Similarly, PI delivered a lecture to the University of Oslo’s Informatics Department to deliver a seminar on: “A Human Rights Approach to Digital Health” in April 2021, and colleagues from JUST participated in a scientific workshop titled “Integrating Scientific Research in Big Data Tools” that was held by Hashemite University.

The issues and concerns being addressed by this project were also included in a submission presented by Privacy International to the UN Working Group on discrimination against women and girls regarding the “women’s and girls’ sexual and reproductive health and rights in situations of crisis” to inform the Working Group’s thematic report to the 47th session of the UN Human Rights Council in June 2021.

In November 2023, PI made two submissions to the UNSR on health as part of her consultation for [her upcoming thematic report on digital innovation, technologies, and the right to health](#), which she will be presenting at 50th Human Rights Council session: a [free-standing submission](#) and a joint submission co-signed with STOPAIDS, the Global Fund Advocates Network, and others with contributions from Women’s Link Worldwide, DRF and Action for Global Health. Both included extensive references to the issue of the use of new technologies and data for the provision and management of maternal, sexual and reproductive health services and information. The joint submission was developed based on information collected during a consultation event run by the UNSR on health on the topic of digital health, which was co-hosted by PI and STOPAIDS, to encourage CSOs to join our submission or make their own. There were around 25 participants including organisations PI had invited such as some of its global partners (Karisma, DRF), project partners (Birzeit University) and allies in the reproductive rights space. We are pleased to report that an early version published by the UNSR includes a section on “Digital innovation and technologies and the right to sexual and reproductive health” which highlights the risks associated with such developments and the need for safeguards.

Over the course of the project, we have also shared our project findings in a variety of spaces where organisations work on issues around digital rights and exploring issues around health and the use of new technologies were engaging including Digital Health Week, Bread & Net Conference, as well as with fellow organisations of the IDRC’s Digital Health & Data

Governance Research Cohort through our participation in the joint learning and collective action workshops.

Finally, with the aim of building capacity with a wider audience, we developed some publicly accessible content, including a series of pieces on digital health and privacy published by PI, an episode for PI's Technology Pill podcast, and a blog post on "Context, gender, power, and choices" co-authored by Professor Yousef Khader from JUST.

OUTCOME 2: Improved capacity of drivers and implementers of digital health initiatives to assess maturity levels and leverage points of existing digital health strategies and systems in Palestine and Jordan to optimize gender equality and human rights.

The policy analysis and the mapping of digital RMNCH initiatives in Jordan and Palestine in Year 1 provided the necessary process to identify the main stakeholders the project partners needed to be engaging with and reaching out to over the course of the project.

Through the research process of assessing the maturity of systems in relations to data governance, interoperability, ICT infrastructure and technological readiness, and gender and human rights, the research teams were able to engage directly with drivers and implementers of digital health initiatives around these issues. The research methodology was customised to ensure that respondents understood the questions in relation to issues they may need to be more familiar with. For example, this came up during the assessment on gender and human rights where questions for the survey and the FGDs were drafted in a way that the respondents would understand the questions, and further detailed and explained during the data-gathering process. This process served to raise awareness on these issues. We are pleased to be able to report some concrete examples of such increased awareness with UNRWA who noted that this project *"opened their eyes and minds on very important but neglected issues such as data governance, women's rights, and others"* and decided to translate their privacy policy into Arabic following their involvement in the research project.

At the same time there were some respondents who were unable to answer some questions either because they did not have the information and/or did not know how to respond to the question posed by the research teams. This highlighted that further work is needed to raise awareness and the understanding of the implications of digital health initiatives on beneficiaries and their rights, as well as in relations to the policies and frameworks required to oversee the design, implementation and maintenance of these systems to ensure they protect, promote and respect human rights.

We are also happy to report that over the course of the project we have engaged more widely with drivers and implementers of digital health interventions. For example, the project team at JUST in Jordan led trainings for medical staff of Princess Basma Health Center as well as a workshop organised by WHO, UNFPA, and UNICEF, and the Dr. Nemer and Professor Abu-Rmeileh from Birzeit University participated in AI and D4D meetings, conducted by the [A2K4D Center at the AUC](#).

OUTCOME 3: Improved understanding of the experience of beneficiaries in accessing digitally-enabled RMNCH services using digital personal data (DPD), and whether there is a direct impact [positive or negative] on rights and gender equality to inform policy development and further research.

The primary research we undertook to visit health facilities and interview beneficiaries provides a unique insight into the lived experiences of those accessing digitally-enabled RMNCH services using digital personal data (DPD) with a particular focus on their right to privacy and gender equality which we identified were not the focus on prior research in this domain. The in-depth interviews with women yielded three main themes: women's perceived benefits of the initiative, the performance of the application, and issues of privacy and data protection. Most women appreciated that the e-MCH application was a constant source of educational and technical support in terms of reminders and tracking of their health data, as well as a way to expand the use of MCH services during emergencies such as the COVID-19 lockdown. The majority of respondents mentioned that the e-MCH application was easy to use, and most of them had no reservations about disclosing their personal information through this digital initiative.

As a result of this research we have been able to gather evidence of both positive and negative experiences which provide the foundation for developing evidence-based advocacy to ensure that the use of these new technologies ultimately benefit beneficiaries, and that where risks/harms are identified effective mitigation strategies are adopted in the design and implementation of digitally-enabled RMNCH services using digital personal data (DPD).

The findings from this research are already shaping the work of Privacy International in this domain to identify further areas of research and advocacy needed moving forward to effectively present the positive and negative implications of digital health interventions on people and their rights.

Project outputs and activities

Over the course of the project, the following activities were undertaken by project partners, collaboratively and independently:

JOINT ACTIVITIES

Planning

- Project kick-off meeting, May 1st, 2020.
- Project meetings: Regional meetings for the teams in Jordan and Palestine: A total of 11 meetings from March to October 2020.
- Meetings for all project partners: 4 meetings in April, May, June and September 2020.
- Formulation of two advisory committees in Palestine (Birzeit University) and Jordan (Jordan University of Science and Technology), and initial meetings. The first meeting for the advisory committee in Palestine was conducted on October 19th, 2020, where a total of 5 committee members attended and provided suggestions and insights on the

project's activities and preliminary mapping results. The advisory committee meeting in Jordan was not held in Jordan because of COVID-19 situation.

Trainings

- Two professor from JUST provided training sessions to four researchers on qualitative research methods including how to conduct observational study and conducting individual interviews with women. Later, those researchers were involved in data collection as research assistants, and they work in the field under our close supervision.
- Three researchers (2 from Palestine and 1 from Jordan) received in-depth training on how to assess the maturity level of digitalized RMNCH Services.
- For researcher (2 from Palestine and 2 from Jordan) were involved in self-training with significant help from Privacy International partners on levels of incorporation of human rights and gender equality and concerns in digital initiatives.

Research

- A micro analysis of policy initiatives in Palestine (Birzeit University) and Jordan (Jordan University of Science and Technology) through desk-based document analysis and interviews with key informants (9 interviews in Jordan, and 7 interviews in Palestine), which complemented by a wider macro analysis of how digital health is regulated and existing laws and regulations in place. (Privacy International). The macro and micro policy analysis is in its final stages of preparation of drafting and will be published in 2023.
- A journal paper presenting an assessment of maturity levels with regards to data governance/interoperability which was published in *Methods of Information in Medicine*: Alyahya, Mohammad S., Niveen ME Abu-Rmeileh, Yousef S. Khader, Maysaa Nemer, Nihaya A. Al-Sheyab, Alexandrine Pirlot de Corbion, Laura Lazaro Cabrera, and Sundeep Sahay. "Maturity Level of Digital Reproductive, Maternal, Newborn, and Child Health Initiatives in Jordan and Palestine." [*Methods of Information in Medicine*](#), 61, no. 05/06 (2022): 139-154
- Mapping digital personal data in Reproductive, Maternal, Newborn and Child Health (RMNCH) initiatives in Palestine (Birzeit University) and Jordan (Jordan University of Science and Technology). The findings were published in the *Frontiers in Digital Health*, section Digital Health Communication: Nemer M., Khader Y., Alyahya M., de Corbion A., Sahay S., Abu-Rmeileh N., "[**Personal Data Governance and Privacy in Digital Reproductive, Maternal, Newborn, and Child Health Initiatives in Palestine and Jordan: A mapping exercise**](#)", April 2023
- An assessment of maturity levels with regards to gender and human rights was undertaking is pending publication: A. Alyahya, Mohammad S., Niveen ME Abu-Rmeileh, Yousef S. Khader, Maysaa Nemer, Nihaya A. Al-Sheyab, Alexandrine Pirlot de Corbion, Laura Lazaro Cabrera, and Sundeep Sahay, "**Addressing human rights and gender equality in Reproductive, Maternal, Newborn, and Child Health (RMNCH)**

Digital Initiatives in Palestine and Jordan.” *(expected citation)*

- A study of beneficiaries’ perceptions of using digital RMNCH Initiatives in Jordan and Palestine. The manuscript is in its final stages of preparation: A. Alyahya, Mohammad S., Niveen ME Abu-Rmeileh, Yousef S. Khader, Maysaa Nemer, Nihaya A. Al-Sheyab, Alexandrine Pirlot de Corbion, Laura Lazaro Cabrera, and Sundeep Sahay, **“Women’s perceptions of using Digital RMNCH Initiatives – the UNRWA’s e-MCH application in Jordan and Palestine”**. *(expected citation)*

Dissemination and outreach

- Successful submission of a conference paper jointly by project partners to the “The Future of Digital Work: The Challenge of Inequality “IFIPJWC2020” international conference, Hyderabad, India, 2020, as part of the research in progress track.
- In November 2022, Privacy International hosted a session at Bread & Net, which is a conference organised by SMEX, one of Privacy International’s global partners in Lebanon. Bread & Net is an annual conference that promotes and defends digital rights across Arabic speaking countries. Hosted by SMEX, Bread & Net is a platform built for and sustained by hundreds of activists, technologists, journalists, researchers, lawyers, academics, entrepreneurs, and human rights defenders from around the world, with a particular focus on digital rights and digital freedoms in Arabic-speaking countries. The sessions was entitled: [Data and tech in maternal and reproductive healthcare](#) and it was an opportunity for project partners in Jordan and Palestine to present their findings as well as to share some insights into undertaking research in this domain. It was attended by 8 participants from the region including journalists, representative of aid and development agencies and CSOs. Dr Niveen Abu Rmeileh and Dr Yousef Khader participated actively and addressed different questions asked during the sessions. These included general questions about the current state of digital health in Jordan and Palestine, the nature of reproductive care and maternal digital health interventions, and the challenges faced in managing digital infrastructure. In this discussion, all speakers also answered questions about the current research project, methodology, research instrument, key findings from interviews with users, developers and implementers, and beneficiaries, and long-term implications for advocacy and anticipated policy changes.
- A session submitted by PI for RightsCon 2023 on “The use of data and technology in pregnancy and maternal healthcare: exploring the implications for privacy and human rights” was approved. Project partners in Jordan and Palestine represented by Dr Yousef Khader and Dr Maysaa Nemer alongside PI will be presenting the project research findings and demands moving forward for the various stakeholders targeted with this research including government authorities, implementers and designers of digital MNCHC initiatives.

Communications

- An episode entitled “Maternal Health and Family Planning in the Middle East: Gender and Power in an episode podcast via PI” was recorded for PI’s podcast “The Technology Pill” with Alexandrine Pirlot de Corbion, who is PI Director of Strategy, Nour El Arnaout, from the Global Health Institute, American University of Beirut, Lebanon and Professor Yousef Khader, from the Global Health Development, Eastern Mediterranean Public Health Network and the Faculty of Medicine, Jordan University of Science and Technology, Jordan. The podcasts discussed digital health in the Middle East and in particular digital maternal health and family planning initiatives they are working on, the impact of gender inequality, and the risks involved. The podcast is available here:

Cohort meetings

- The Project team participated two “IDRC –Digital Health & Data Governance Research Cohort meetings
 - A **Joint Learning Workshops activities**” which were held by Patricia Mechael on 21 November 2021 and on 8 February 2022
 - **“Collective Action Workshop: Scaling Up & Out”** on-line workshop which was managed by the IDRC team on 17 May 2022.

ACTIVITIES BY EACH PROJECT PARTNER

JUST

- Professor Yousef Khader, Professor Mohammad Alyahya, and Professor Nihaya Al-Sheyab participated in a scientific workshop titled **“Integrating Scientific Research in Big Data Tools”** that was held by Hashemite University on 25th of June 2022 in Jordan. In that scientific workshop Professor Yousef Khader and Jordan team members discussed their experiences about the “Challenges of Scientific Research in Light of the Tools of the Fourth Industrial Revolution”. Professor Khader also presented some findings and the methodology of the “Governing Digital Personal Data to Strengthen Reproductive, Maternal, Newborn and Child Health Services Delivery in Fragile Settings in Palestine and Jordan” projects
- Prof. Yousef Khader and Dr. Nihaya Al-Sheyab from JUST with collaboration with EMPHNET, International Academy of Public Health (IAPH), Himmetna initiative and other partners conducted three training workshops during in November 2022 for the medical staff of Princess Basma Health Center, where they have presented and trained the medical staff on topics related to family planning and health of women and children along with other community health topics as well.
- Dr. Yousef Khader participated actively in the workshop entitled” Strengthening Quality of Reproductive, Maternal, Newborn and Child Health Care in Countries with High Maternal & Child Mortality Burden in The Eastern Mediterranean Region" The workshop was held in Cairo, Egypt, 21-23 November 2022 and was organized by WHO,

UNFPA, and UNICEF.

- A blog titled “Context, gender, power, and choices” was authored by Nour El Arnaout from Global Health Institute, American University of Beirut, Lebanon and Yousef Khader from the Global Health Development, Eastern Mediterranean Public Health Network and the Faculty of Medicine, Jordan University of Science and Technology, Jordan on shaping digital health in the Middle East and North Africa. This blog was shared widely on the EMPHNET network and other extended networks. Available at: <https://ai-med.io/analysis/context-gender-power-and-choices/>

Birzeit University

- Dr. Nemer and Professor Abu-Rmeileh have participated in AI and D4D meetings, conducted by the [A2K4D center at the AUC](#), at the beginning to discuss governance findings in Palestine and later on to join a regional project focusing on AI in the region.
- Dr. Nemer participated in the civil society consultation workshop on Digital Innovation, Technologies, and the Right to Health, which was held on Tuesday 27th September, hosted by Privacy International and STOPAIDS.

Privacy International

- In 2021, PI published two analytical pieces drawing on the findings of this project:
 - A resource/background on digital health which provides an overview of what digital health initiatives have been rolled out, for what purpose, where and by who, as well as some of the concerns they raise for the enjoyment of fundamental rights and freedoms. See: <https://privacyinternational.org/long-read/4671/digital-health-what-does-it-mean-your-rights-and-freedoms>
 - In a long-read piece we present main discussions and measures we need to see being systematically adopted to inform decision-making about digital solutions in the health sector, and provide examples of where these were not integrated in decision-making processes and with what consequences. See: <https://privacyinternational.org/long-read/4674/why-we-need-talk-about-digital-health>
- Series of articles on the different digital tools used in the provision of maternal, sexual and reproductive healthcare and information:
 - [Telemedicine](#) (October 2021)
 - [SMS](#) (January 2022)
 - [Apps](#) (March 2022)
- Publication of [a tech explainer on SMS](#) to provide further insights into the varied uses of SMS, and the challenges arising from it: privacy, security and reliability-wise.

- In May 2023, following interest expressed by the WHO, PI met with various representatives from WHO's Sexual and Reproductive Health department, Prevention of Unsafe Abortion Unit and Digital Health team. PI had a chance to present its work on S&R and digital health, and present the findings emerging from this research project. The WHO representative showed interest and asked specific follow-up questions about our tactics and our work with partners. We have yet to identify an opportunity for collaboration but we will be exploring further opportunities for collaboration as they develop their own work in this domain.
- In October 2023, we hosted a session as part of Digital Health Week on "Data and tech in maternal and reproductive healthcare". They were 88 registered attendees. During the session we discussed the privacy implications and challenges arising from maternal healthcare systems with wonderful panel of experts from around the world including a representative from the Centre for Internet and Society (CIS), and Nour El Arnaout, from the Global Health Institute, American University of Beirut, Lebanon, who is also a recipient of a grant from IDRC.
- In November 2023, PI made two submissions to the UNSR on health following as part of her consultation for [her upcoming thematic report on digital innovation, technologies, and the right to health](#), which she will be presenting at 50th Human Rights Council session: a [free-standing submission](#) and a joint submission co-signed with STOPAIDS, the Global Fund Advocates Network, and others with contributions from Women's Link Worldwide, DRF and Action for Global Health.

University of Oslo

He participated in all the project team online meetings, providing comments and suggestions on the project activities and manuscripts in Progresses. He proposes to develop two manuscripts from the overall learnings of the project, one towards the ICT4D audience and the other towards global public health readership. In a Masters level course titled "ICT4D: Are we building a better world?", he has introduced a lecture on Digital Health and Human Rights, a lecture which was delivered by Alex from PI.

Project implementation and management

The project continued to be implemented by University of Oslo, Jordan University of Science and Technology, Birzeit University, Privacy International. Sundeep played a central role in the coordination of project activities, ensuring financial compliances in coordination with the UiO finance team.

Administrative and financial management

At the administrative side, there was some delay in getting the between partners contracts. This was not an issue as the different partners have started the preparation phase in January 2020 and kept working until the contracts were signed.

As a result of COVID-19, some project partners faced various challenges to cope with the emergency demands made on them which impacted their time and their availability in the first year of the project, and some of these developments impacted project budget expenditure.

Cumulating impact from COVID-19 which impacted this project from the start has meant that we faced delays which we were not able to overcome including:

- completing some of the research and subsequently to guarantee publication within the project timeframe with some outputs still awaiting publication, and
- undertaking an in-person launch of the research findings, and so we prioritised online forums to share the findings.
- strengthening dissemination of findings within university departmental research seminars.

Overall assessment and key takeaways

We are very pleased with the outcomes of this project in terms of the primary and secondary research we were able to undertake to i) understand the opportunities and challenges around the application of digital technologies for DPD in the provision of RMNCH services in Palestine and Jordan; ii) to map and understand the stakeholder ecosystem shaping this relationship (DPD-RMNCH services), as well as their respective obligations, responsibilities, and rights to effectively govern this relationship; and, iii) to critically understand how these responsibilities, obligations and rights enhance (or hinder) health equity, gender equality and data governance within ethically and legally defined frameworks. As noted above, because of the research was shared with a wider variety of stakeholders it has also helped to build the understanding of others exploring these issues and operation in the space of digital health and/or human rights.

Below we outline some of the main takeaways from this project:

- 1. Creating of new methodologies and tools:** One of the key results of this project has been the creation of tools for mapping and policy analysis required to undertake the data collection for this research project. These tools are not context-specific and can be used for other initiatives or in other setting. We believe that these would be an asset to other researchers, CSOs and other stakeholders exploring these issues.
- 2. Knowledge creation and capacity building:** An additional outcome of this research which must be highlighted and cannot be underestimated is the capacity and knowledge developed by all the project partners as a result of their engagement in this project. Project partners at the University of Oslo, Birzeit University and JUST to have developed their capacity to undertake research on issues of human rights and gender which they had not explored before. Equally for Privacy International this project helped them as a mission-driven human rights organisation to build their understanding of issues around public health as well as the particular dynamics of these issues in fragile settings thanks to the knowledge shared by other project partners throughout this project. This new knowledge and exposure to different perspective, in addition to the substance of the research findings, has shaped and informed PI's own work in this domain.

- 3. Enabling evidence-based advocacy and further research:** This project is the first in Palestine and Jordan that looks at digital health initiatives utilizing a comprehensive approach. We have been able to put in the public domain primary research on digital MNCHC initiatives in both countries. This is important because it means that there is information available to inform further research by other academics and researchers, but also it can be used by civil society organisations working on health as well as digital rights in Palestine, Jordan or on a global level to take these findings to inform their own research, advocacy, policy and campaigning work. Within the project timeframe, we have already seen the way some of our targets changed their behaviour from UNRWA or the Jordanian Ministry of Health considering further regulation in this domain, and we are confident that further similar developments are possible thanks to sustained dissemination of research findings by the project team and allies.
- 4. Urgent need for further outreach and advocacy:** Our research has shown that there are huge regulatory and legal gaps with many, if not most, digital MNCHC initiatives being deployed without ensure first that there is a robust mechanism in place to oversee their design and implementation. This has shed further light on a systemic problem that whilst their deployment are in full swing, and continue to increased, we're still at a stage where human rights approaches to digital health are lagging behind, and in practice human rights considerations inform very little the initial decision to adopt a digital solution, yet alone to inform its design and implementation. The findings of this research can be used by government official and regulators to push for safeguards through policy and legislative process as the nation level, as well as civil society organisations working on health as well as digital rights in Palestine and Jordan to call for the protection of beneficiaries.
- 5. Setting a foundation for future work:** The findings from this research as well as our lessons learned when it comes to researching these issues will provide a useful foundation to sustain our individual and collective efforts. Now that we have established a strong relationship and collaboration amongst our respective institutions, we are looking forward to continuing to work together – informally or through future projects - to keep exploring these issues and to support the efforts of others to ensure that data governance systems in national digital health strategies for reproductive, maternal, newborn and child health services are optimized to protect the human rights of beneficiaries – particularly focusing on vulnerable populations in fragile settings such as among refugees and marginalized communities in Jordan and Palestine, and beyond. As a project team, we have had a great collaborative relationship, and have developed deep understanding and trust with each other. We have promised to continue through our individual means, processes of dissemination of findings, relevant for policy and practice. We have promised to look for other opportunities for funding research projects that could build upon our learnings. Once the final accounts are developed (May, 30th), we will see unused funds if any, and possibly use for funding research publications in open access journals.

ANNEX – 1

Governing Digital Personal Data to Strengthen Reproductive, Maternal, Newborn and Child Health Services Delivery in Fragile Settings in Palestine and Jordan

Micro-level Analysis of two selected initiatives in each country

RMNCH Maturity Level

Note: The grading is from 0 representing No/None to 3 representing Yes/fully adequate

Please choose the most appropriate group(level)

Levels of digitization of RMNCH Services

Levels	Level 0	Level 1	Level 2	Level 3	Level (0,1,2,3)
Conditions	Only based on paper systems	Less than 10% of cases	In about 50% of the cases	Based 100% on computers	
Are RMNCH service delivery systems computerized					
Is routine point of care services based on digital data					
Are routine facility reports sent through computerized means					
Are budgets and resources earmarked for supporting digitalization initiatives					

Level 1: Digital infrastructure in place for RMNCH

Dimension	Components	Level 0	Level 1	Level 2	Level 3	Level (0,1,2,3)
ICT Infrastructure (Technological readiness)	Reliable power/electricity	<ul style="list-style-type: none"> Information on electricity/power access, sources and reliability at healthcare facilities, subnational and national level offices is limited and only collected when planning for specific Digital Initiative activities. Procedures for maintaining power infrastructure exist in limited settings. There is no power continuity 	<ul style="list-style-type: none"> An established governing body oversees standardized procedures for tracking and maintenance of electricity/power access, sources and reliability supporting Digital Initiative infrastructure at healthcare facilities, subnational and national level offices. Standardized metrics for measuring power outages and the duration of outage are defined. Localised systems can run on backup power, non-critical systems may experience data-loss in an outage 	<ul style="list-style-type: none"> Electricity/power access, sources and reliability profiles for healthcare facilities, subnational and national level are reviewed and updated on a regular schedule. The power infrastructure is monitored on a regular basis by the governing authority to ensure reliability at all levels. Backup power exists, small outages can be bridged by backup power. Backup power allows for the safe winding down of systems avoiding data loss or critical failure 	<ul style="list-style-type: none"> Information collected on electricity access, sources and reliability profile is used for planning and continuous improvement of Digital Initiative implementations and to meet emerging needs of the health sector. Power operates in a redundant mode, power failures can be bridged by redundancy or backup power, services remain continuous throughout power outages 	
	Hardware	<ul style="list-style-type: none"> The organization has few computers to support the Digital Initiative. No hardware dedicated to the Digital Initiative activities. 	<ul style="list-style-type: none"> Less than 50% of health facilities have adequate hardware (servers, computers, printers, connecting devices, etc.) to support the Digital Initiative. 	<ul style="list-style-type: none"> 50% or more of health facilities have the required hardware, including back-up hardware to support the Digital Initiative. A plan exists for backup and recovery as well as a plan for replacing old and broken computing devices. 	<ul style="list-style-type: none"> All or almost all of facilities have adequate computing hardware to support the Digital Initiative. Hardware is monitored and evaluated on a regular basis to ensure supported functions are operational. 	

		<ul style="list-style-type: none"> No guidance exists on the minimum specifications for the hardware. 		<ul style="list-style-type: none"> Critical systems operate with redundancy, however hardware failure may lead to outages 	<ul style="list-style-type: none"> Systems operate with redundancy, allowing for continuity during failures, parts can be hot-swapped if necessary 	
	Reliable networks and Internet connectivity	<ul style="list-style-type: none"> Unreliable Network and Internet Unreliable 2G, 3G, 4G Very low percentage of the health facilities have access to the Internet Negligible broadband service subscriptions Unreliable supply chain 	<ul style="list-style-type: none"> Somewhat reliable Network and Internet Somewhat reliable 2G, 3G, 4G Less than half of the health facilities have access to the Internet <p>Low broadband service subscriptions (Domestic grade broadband service, No Service Level Agreement, Greater than 20:1 contention ratio)</p> <ul style="list-style-type: none"> Parts/services available in weeks 	<ul style="list-style-type: none"> Reliable Network and Internet Reliable 2G, 3G, 4G Approximately half of the health facilities have access to the Internet Moderate broadband service subscriptions (Business grade broadband service, Some Service Level Agreement (but not exceeding to 99.999% or greater availability), Less than or equal to 20:1 contention ratio) Parts/services available inhouse 	<ul style="list-style-type: none"> Approximately all of the health facilities have access to the Internet High broadband service subscriptions (Fixed Line Service (such as a leased line), Service Level Agreement with 99.999% or more availability. Tending toward 1:1 contention ratio) Reliable for critical apps for patient care Parts/services available with Quality Improvement in place 	
	Operations and maintenance (for computer technology)	<ul style="list-style-type: none"> Operations and maintenance services for electronic systems are ad hoc or non-existent. Unclear what backup processes are in place 	<ul style="list-style-type: none"> Maintenance for network and hardware is a mix of reactive and evolving preventive procedures. A backup strategy exists, and some critical data is backed up 	<ul style="list-style-type: none"> Computer operations and maintenance services are part of the Digital Initiative. 	<ul style="list-style-type: none"> The operations and maintenance services plan is continuously reviewed and adapted to evolving the Digital Initiative interoperability requirements, and follows industry-based standards. 	

				<ul style="list-style-type: none"> ▪ A disaster recovery plan for the Digital Initiative is in place, and it meets best practices. ▪ Onsite backups exist 	<ul style="list-style-type: none"> ▪ Regular simulations are undertaken to increase the ability of technology staff to respond to a disaster. ▪ Onsite and Offsite backups exist 	
	Training and education (includes continuous professional development)	<ul style="list-style-type: none"> ▪ Training and education programs for the Digital Initiative competencies are at the initial stages of development. ▪ The digital initiative training curriculum is not standardized. 	<ul style="list-style-type: none"> ▪ Training is regarded as critical and exist in limited settings. ▪ Training courses are available for specific domains or activities. 	<ul style="list-style-type: none"> ▪ Training, academic curricula, and processes for developing training and education programs to build skills and competencies nationally are standardized (and include a gender-related component). ▪ Clear and measurable learning outcomes are defined for training courses. 	<ul style="list-style-type: none"> ▪ Training and education plans are integrated in the Digital Initiative implementation plans and the results are measurable. ▪ Training and education programs are conducted periodically to refresh existing skills and impart new skills, are reviewed on a regular basis by the designated authority to ensure alignment with the Digital Initiative needs and technology. ▪ There is sufficient infrastructure to support different modes of trainings, including distance learning. 	

Level 2: Data governance and interoperability

Dimension	Components	Level 0	Level 1	Level 2	Level 3	Level (0,1,2,3)
	Drivers for Data Governance Planning	<ul style="list-style-type: none"> No risk assessment was done 	<ul style="list-style-type: none"> Riske assessment was done, but not formally (not a comprehensive assessment). 	<ul style="list-style-type: none"> Forma risk assessment was done, but did not inform the design, implementation, and maintenance of the system. 	<ul style="list-style-type: none"> Formal assessment was done and it informed the design, implementation, and maintenance of the system 	
Governance	Data Governance Planning	<ul style="list-style-type: none"> There is awareness of the need to develop a plan or update the existing one, but the process for planning is at an early stage. <p>Planning is mostly focused on small or short-term projects.</p>	<ul style="list-style-type: none"> There is an established planning process which involves key eHealth stakeholders and is formally approved by the Ministry of Health. There is a current plan that includes standards, legislation, appropriate technical and service delivery aspects, as well as ensuring there are financial and human resources to deliver them. 	<ul style="list-style-type: none"> A budgeted plan is aligned with and integrated in the national health plan/strategy. Implementation is monitored and there is a set schedule for periodic review and update for corrective action. 	<ul style="list-style-type: none"> A continuous improvement planning process is maintained. 	
	Governance structure	<ul style="list-style-type: none"> Evolving governing body for the Digital Initiative is constituted on a case-by-case basis OR no governing body exists. 	<ul style="list-style-type: none"> Governing body is formally constituted and has a scope of work that includes the people responsible for data governance oversight. The governing body oversees interoperability directly or through a separate technical working group (TWG). 	<ul style="list-style-type: none"> The governing body conducts regular meetings with stakeholder participation. 	<ul style="list-style-type: none"> The governing body is government-led, consults with other ministries, and monitors implementation of the Digital Initiative interoperability using a work plan. It mobilizes resources—financial, human resources (HR), and political—to accomplish its goals. 	
Legislation,	Data ethics and human rights	<ul style="list-style-type: none"> The Digital Initiative has no healthcare-specific data laws, regulatory frameworks, or ethics 	<ul style="list-style-type: none"> The Digital Initiative has an approved health data regulatory framework. 	<ul style="list-style-type: none"> The health data security and privacy laws have been implemented, and there are 	<ul style="list-style-type: none"> The Digital Initiative has a recognized mechanism (e.g., committee or working group) 	

		provisions to guide data security, privacy, and confidentiality.		<p>guidelines on how to operationalize the laws in the Digital Initiative.</p> <ul style="list-style-type: none"> Digital Initiative users have been sensitized and trained on the data security and privacy laws. 	for reviewing data ethics issues at the national level, and for updating policies, procedures, and laws, as needed.	
Standards and Interoperability	Data and exchange standards	<ul style="list-style-type: none"> No defined technical standards exist for use in data management and exchange, or may exist for specific activities. No health data sharing policy 	<ul style="list-style-type: none"> The Digital Initiative has adopted and/or developed standards (data sharing policy) for health data management and exchange, but standards/policy may be localized to specific projects/organizations. There is an effort nationally to standardize the process. 	<ul style="list-style-type: none"> The national data management and exchange standards/policy are integrated in the national HIS and/or health plan. Exchange standards/policy are tracked, monitored, and reviewed through a standardized process. A documented schema exists to transfer or export data in a structured way 	<ul style="list-style-type: none"> Electronic data transmission is the default method for moving data among systems, facilities, and information systems. A documented national policy and schema exist to transfer or export data in a structured way 	
	Personal data exchange	<ul style="list-style-type: none"> There is limited capability to support standardized patient data exchange between systems within local or specific implementations. Data exchange is based on peer-to-peer interfaces, which require major 	<ul style="list-style-type: none"> Capabilities to support automated patient data exchange using internationally recognized standards between systems exists in limited settings. 	<ul style="list-style-type: none"> There are nationally defined data standards based on international standards to support patient-level data exchange in use. Most applications have integrated data standards with 	<ul style="list-style-type: none"> Minimal effort is required to realize data exchange. Applications are implemented mostly on plan 	

		efforts to implement and manual intervention during data exchange.		well-developed interoperability verification regimes.	with requisite interoperability quality.	
	Aggregate data exchange	<ul style="list-style-type: none"> ▪ Limited capability exists for exchanging aggregate data using standards between systems. ▪ Aggregate data reporting is achieved via manual import/export process. 	<ul style="list-style-type: none"> ▪ Capabilities to support automated aggregate data reporting exists in limited settings. ▪ Data formats used for data exchange are application/software-specific and require major efforts to implement. 	<ul style="list-style-type: none"> ▪ A documented schema exists to transfer or export data in a structured way ▪ Applications have the ability to automatically exchange aggregate data, using defined standards at all levels. 	<ul style="list-style-type: none"> ▪ A documented schema exists to transfer or export data in a structured way ▪ All data exchanges are based on certified interoperability standards. With appropriate documentation ▪ Robust maintenance and update processes are planned including feedback to SDOs to improve the standards. 	
Data Quality and Use	Data management	<ul style="list-style-type: none"> ▪ Data management processes are not documented, or documented processes lack clarity. 	<ul style="list-style-type: none"> ▪ Data management processes are clearly documented in a nationally recognized and established mechanism to ensure quality of data being transmitted across health system levels. 	<ul style="list-style-type: none"> ▪ Standard operating procedures for national health data management are integrated in the national HIS and/or health plans and data quality is actively monitored and shared with stakeholders. 	<ul style="list-style-type: none"> ▪ Standard operating procedures for health data management are periodically reviewed and/or revised to ensure alignment with evolving HIS and/or health data needs. 	
	Data use availability strategy	<ul style="list-style-type: none"> ▪ A data use strategy document (which includes information needs, data collection and reporting, data dissemination, and production of 	<ul style="list-style-type: none"> ▪ The data use strategy (including use of sex-disaggregated data) is documented and available, but may not be up to date or harmonized across health facilities. 	<ul style="list-style-type: none"> ▪ Implementation of the data use strategy (including use of sex-disaggregated data, where applicable) is monitored, reviewed, and overseen by an 	<ul style="list-style-type: none"> ▪ The data use strategy is adapted to meet emerging decision-making needs of program managers, policymakers, and providers interacting with other HIS 	

		targeted information products) is absent or briefly outlined.		established governing body for data review.	and it is integrated in the long-term health plan to promote a culture of data use.	
	Data synthesis and communication	<ul style="list-style-type: none"> ▪ The purpose, type (e.g., technical report, policy brief, table, chart, etc.), target audience (level of health system), and intended result of an information product and a dissemination and/or feedback plan are not explicitly documented. 	<ul style="list-style-type: none"> ▪ Guidance on the design and use of information products highlights gender issues and is documented and available. 	<ul style="list-style-type: none"> ▪ Data are shared with stakeholders (<i>in accordance with standards and within regulatory frameworks</i>). ▪ Guidance on the design and use of information products is integrated in the HIS plan and/or health plan. 	<ul style="list-style-type: none"> ▪ Guidance on the design and use of information products is periodically reviewed and revised, to ensure its applicability and relevance to emerging and future decision-making needs. 	
	Reporting and analytics features	<ul style="list-style-type: none"> ▪ Reporting and analytics features are limited. Routine reporting of critical health indicators is not standardized, and it occurs on an irregular basis. ▪ The reporting process is predominantly manual. 	<ul style="list-style-type: none"> ▪ Some efficiency measures have been implemented in the reporting process by consolidating reporting tools. ▪ Electronic submission of routine reports from subnational levels exists in limited settings. ▪ Analytical features are in separate statistical software applications. 	<ul style="list-style-type: none"> ▪ Automated data reporting (including sex-disaggregated data, where applicable) is implemented nationally from point of service on a routine basis. ▪ Features to support data discovery, integration, analysis, and visualization exist at all levels. 	<ul style="list-style-type: none"> ▪ Metrics on reporting and analysis capabilities with feedback from users are used for continuous improvement. 	

Levels of incorporation of human rights and gender concerns in digital infrastructure

Levels	Level 0	Level 1	Level 2	Level 3	Level (0,1,2,3)
Conditions	None	In limited cases	Around 50% of cases	Completely	
Does system design reflect human rights and gender considerations					
Are there governance mechanisms to oversee and/or address human rights and gender concerns					
Is data routinely collected on a routine basis in a human rights / gender equality compliant with data protection					
Are there any policy and/or guidance that address human rights and gender concerns					

Levels of incorporation of human rights and gender considerations in digital initiatives

Levels	Level 0	Level 1	Level 2	Level 3	Level (0,1,2,3)
Conditions	None	In limited cases	Around 50% of cases	Completely	
Is patient consent taken prior to collection of patient data					
Is there a clear avenue for patients to report human rights and gender concerns					
Is citizens civil society/patients represented in health facility /initiative management processes					
Are there any patient satisfaction surveys conducted pre- and post-access to care					

Level 3: Human rights/gender equality considerations in RMNCH digital health the digital initiatives

Dimension	Components	0	1	2	3	Level (0,1,2,3)
Planning	Vision, objectives, and guidelines	The digital initiative does not consider any human rights or gender equality principles in its Vision, objectives, or guidelines	The digital initiative does not consider any human rights or gender equality principles but meaningfully differentiates users based on gender or other characteristics (e.g. age, race, religion/belief, disability, income).	<ul style="list-style-type: none"> The digital initiative is built on and considers many human rights/gender equality instruments, commitments, policies, and assessments (e.g. National Gender Action Plans, Universal Human Rights & Global Gender Gap Index) The guidelines developed to guide the digital initiative protect the rights of women and men and marginalized/ vulnerable population and ensure access to improved care. 	<ul style="list-style-type: none"> The guidelines developed to guide the digital initiative protect the rights of people and in particular marginalized/ vulnerable population with aim of improving access to effective care. The objectives of the digital initiative are clearly related to practical and strategic pre-identified needs including gender, human rights and access to effective care (availability, accessibility, acceptability, and quality). The digital initiative is built on a gender-inclusive design that reflects gender issues throughout the different digital initiative stages. Women/gender focused groups, associations are consulted/included during the planning of the digital initiative. 	

	Participation and evidence-base development	Patients/beneficiaries were not consulted during the planning phase.	Prior evaluations of patient satisfaction and needs considered during planning.	<ul style="list-style-type: none"> Some consultations with patients/beneficiaries were undertaken during the planning phase but findings/outcomes had limited/no influence on decision-making processes. 	<ul style="list-style-type: none"> Consultations with patients/beneficiaries were undertaken during the planning phase and served to inform the need for and design of the initiative. Wider engagement with experts and stakeholders representing patients/beneficiaries were undertaken during the planning phase and served to inform the design of the initiative. 	
	Data protection risk assessment	No risk assessment was undertaken prior to design and implementation.	<p>A risk assessment was undertaken but outcomes did not inform the design of the systems, i.e. use of encryption,</p> <p>Protection data at rest and in transit, regular audits, etc.</p>	A risk assessment was undertaken and the outcomes informed the design of the systems, i.e. use of encryption, protection data at rest and in transit, regular audits, etc.	<ul style="list-style-type: none"> The risk assessment was the foundation of all decision-making and specific consideration were given to risks to be mitigated. Regular evaluations and audits are planned during which risk assessment will be revisited. 	
	Assessment of implications for marginalized individuals and groups	No assessment of barriers that may be faced by or needs of marginalized individuals and groups (i.e. persons with disabilities, person who are illiterate, rural vs urban access to services, ethnic/religious minorities, legal status – migrant populations, etc.)	Prior evaluations of needs and of barriers faced by some marginalized individuals in accessing effective care (availability, accessibility, acceptability, and quality) considered during planning.	Some vulnerable or marginalised individuals and groups in the given context have been identified and considered but this had limited/no impact on decision-making process.	<ul style="list-style-type: none"> The needs and particular situations of vulnerable or marginalised individuals and groups in the given context were identified and considered and this served to identify steps to be taken to ensure this informed decision-making process. 	
	Enabling control of the individual	No consideration was given to enable Patients/beneficiaries to control their data.	Consideration was given to importance of enabling patients/beneficiaries to control their data but no steps were taken to facilitate it.	<ul style="list-style-type: none"> Consideration was given to importance of enabling patients/beneficiaries to control their data and some steps were taken to 	<ul style="list-style-type: none"> Patients/beneficiaries, especially those considered vulnerable or marginalised individuals and groups, given the user control of their data by being provided clear 	

Design				facilitate it but patients/beneficiaries not informed about them at the moment of collection or subsequent transaction/interactions of care/treatment.	information about data processing of their data, and their rights over that data, i.e. to know who has access to it, to correct, etc. <ul style="list-style-type: none"> Patients/beneficiaries have access to mechanisms to seek redress should their data be misused. 	
	Gender needs and access	Gender needs and norms are not considered in the design of the digital initiative	Gender needs and norms are not considered in the design of the digital initiative but there are no negative effects on women or men	<ul style="list-style-type: none"> Gender needs and norms are considered in the design of the digital initiative and women and men have equal access to resources The digital initiative is accessible to all equally 	<ul style="list-style-type: none"> Gender needs and norms are considered in the design; men and women have been consulted in identifying needs and opportunities related to the general purpose of the digital initiative The outcomes, outputs and activities of digital initiatives are designed to meet the different needs and priorities of women and men Women and men are equally involved in the digital initiative design, there are representatives for marginalized/ vulnerable population New technologies and designed systems are accessible to women and men 	

Data and Statistics	Needs of patients/beneficiaries	Needs of patients/beneficiaries are not considered in the design of the digital initiative.	Needs are not considered in the design of the digital initiative, but no negative effects foreseen in terms of access, ensuring access to effective care (availability, accessibility, acceptability, and quality).	Needs of patients/beneficiaries are considered in the design of the digital initiative, and steps taken to ensure that no group is excluded (digital divide, rural urban) or negatively impacted (denial of services, i.e. legal status) or targeted (i.e. profiling, surveillance, mission creep)	<ul style="list-style-type: none"> Needs of patients/beneficiaries are considered in the design; they, in particular vulnerable or marginalised individuals and groups, have been consulted in identifying needs and opportunities related to the general purpose of the digital initiative. The outcomes, outputs and activities of digital initiatives are designed to meet the different needs and priorities of patients/beneficiaries. 	
	Data review and analysis by sex	The digital initiative does not collect or use sex-disaggregated data in the planning or evaluation stage	The digital initiative collects and uses sex-disaggregated data in the evaluation stage but not for monitoring gender issues	The digital initiative collects and uses sex-disaggregated data and qualitative information to analyse and track the gender issues it addresses and for planning and evaluation stages of digital initiative	<ul style="list-style-type: none"> The digital initiative collects, uses sex-disaggregated data by sex use it in the planning stage The digital initiative collects and uses sex disaggregated data and qualitative information to analyse and track the gender issues it addresses and for the evaluation stage of digital initiative Indicators, targets and a baseline exist to measure progress in achieving benefits for women and men 	

Specialised knowledge and Capacities	Data review and analysis by marginalized/v vulnerable population	The digital initiative has not identified criteria/indicators of marginalization or vulnerability.	The digital initiative has identified criteria/indicators of marginalization or vulnerability and collects relevant data in the planning or evaluation stage	The digital initiative collects and uses data on marginalized/vulnerable populations to analyse and track access issues and for the planning and evaluation stages of the digital initiative	<ul style="list-style-type: none"> • The digital initiative collects and uses data relevant to criteria/indicators of marginalization and vulnerability in the planning stage • The digital initiative collects and uses relevant data to analyse and track access issues it addresses and for the evaluation stage of the digital initiative • Indicators, targets and a baseline exist to measure progress in achieving benefits for marginalized/vulnerable population 	
	Evaluations and audits	No evaluation or audits of the digital initiative undertaken.	Evaluation or audits of the digital initiative undertaken but only at the level of the users, i.e. medical facility/professionals, not patients/beneficiaries.	Comprehensive evaluation or audits of the digital initiative are undertaken at different levels including the users, i.e. medical facility/professionals, and patients/beneficiaries.	<ul style="list-style-type: none"> • Evaluation or audits of the digital initiative are based on risk and needs assessment undertaken in the design stage. • Evaluation or audits of the digital initiative are analyzed to assess any positive and negative impacts on patients/beneficiaries, i.e. better or worse access to care, more or less control over data, concerns of misused/surveillance, etc. 	
	Gender expertise/ knowledge	The digital initiative manager and/or other key personnel do not have gender expertise/ knowledge	The digital initiative manager and/or other key personnel do not have gender expertise/ knowledge but there are detailed/finalised plans for the digital initiative staff to complete related training, e.g. gender awareness course	The digital initiative manager and/or other key personnel do not have gender expertise/ knowledge but recruitment for a gender advisor or expert to help in the digital initiative implementation is underway	The digital initiative manager and/or other key personnel have gender expertise/ knowledge	

Management & Implementation	Human rights expertise/ knowledge	The digital initiative manager and/or other key personnel do not have human rights expertise/ knowledge	The digital initiative manager and/or other key personnel do not have human rights expertise/ knowledge but there are detailed/finalised plans for the digital initiative staff to complete related training, e.g. human rights course	The digital initiative manager and/or other key personnel do not have human rights expertise/ knowledge but recruitment for human right/legal advisor or expert to help in the digital initiative implementation is underway	The digital initiative manager and/or other key personnel have human right expertise/ knowledge.	
	Gender participation	Women and men unequally participate in the design of digital initiative and in the implementation and the evaluation stage	Equal opportunities are provided for both women and men to participate in the design of digital initiative and in the implementation and the evaluation stage	The digital initiative ensures that both women and men can provide inputs, access and participate in the digital initiative activities but less than 40% of whichever gender is represented	<ul style="list-style-type: none"> • Women and men can provide inputs, access and participate in initiative activities (more than 40 % of whichever gender) • The digital initiative implementation arrangements follow gender equality and equal opportunities principles (i.e. gender balanced recruitment of the digital initiative personnel, and gender balanced representation in the digital initiative committees) • There are equal opportunities for both women and men to be appointed to project management positions • The digital initiative implementation arrangements follow human rights principles (i.e. as 	

					provided for in national or international law)	
	Transparency and accountability.	It is unclear who the actors are who are involved in the digital initiative.	The actors are who are involved in the digital initiative are clearly defined but it is unclear what their roles and responsibilities are but some limited information on roles and responsibilities of private actors.	<ul style="list-style-type: none"> • The actors are who are involved in the digital initiative are clearly defined and what their roles and responsibilities are Including of private actors. • Limited or no mechanisms in place to oversee and ensure effective accountability of actors involved. 	<ul style="list-style-type: none"> • An effective and transparent accountability mechanism is in place including for private actors. • Individuals (patients/beneficiaries) are informed and empowered to make use of complaint and other mechanisms to exercise control over their data, i.e. to access their data, to rectify, stop processing, redress in case of a breach, etc. 	

Interview Guide

Interview setting:

- Date
- Time
- Place of interview
- Name of targeted digital initiative
- Interviewee:

Contacts:

☐ Developer ☐ Policy maker & key stakeholder ☐ Implementer

Infrastructure and capacities:

- Do you believe that we can rely on the electricity power to implement the Digital Initiative? Why?
- Do you believe that the networks and internet connectivity are reliable enough to implement the Digital Initiative?
- Do you believe that the healthcare facilities involved in implementing the Digital Initiative have adequate hardware (i.e. computers, servers, printers...)?
- Does the initiative have enough/adequate operations and maintenance services for electronic systems (network & hardware)? Why?
- Does the initiative have established training and education programs such as curriculum, learning outcomes, infrastructure, etc...?
- Do you have a clear plan for this initiative? Can you tell us more on the process by which the plan was developed? And why such plan was developed?

Data governance and interoperability:

- Does the initiative have a governing body? If yes, who are its members? what are the main roles of the governing body?
- Does the initiative have health data regulatory framework? Please explain?
- Does the initiative have clear defined data exchange standards? Please clarify?
- Does the initiative support personal data exchange? Please explain how?
- Does the initiative support exchanging aggregate data and reporting process? Clarify how?
- Does the initiative have clear documented data management processes/plans? Can you tell us more on the process by which the plan was developed? And why such plan was developed?
- Does the initiative have a clear documented data use strategy?

Data sharing and data flow process:

- Could you please describe “in details” data sharing process of this initiative?
- Could you please describe “in details” data flow process of this initiative?

References:

- Digital Strategy Toolkit. Digital Maturity Assessment Tool. Available: https://www.dpc.sa.gov.au/_data/assets/pdf_file/0010/46567/Digital_Maturity_Assessment.pdf
- The Digital Maturity Model 4.0 Benchmarks: Digital Business Transformation Playbook by Martin Gill and Shar VanBoskirk January 22, 2016. Available: <https://forrester.nitro-digital.com/pdf/Forrester-s%20Digital%20Maturity%20Model%204.0.pdf>
- Health information systems Interoperability Maturity Toolkit: Users' Guide. Available: <https://www.measureevaluation.org/resources/tools/health-information-systems-interoperability-toolkit>
- Liaw ST, Zhou R, Ansari S, Gao J. A digital health profile & maturity assessment toolkit: cocreation and testing in the Pacific Islands. J Am Med Inform Assoc. 2020 Nov 29;ocaa255. doi: 10.1093/jamia/ocaa255. Epub ahead of print. PMID: 33249472.
- Scale for Measuring the Health Information System Stages of Continuous Improvement. Available: <https://www.measureevaluation.org/resources/publications/tl-17-04a>
- Gender Mainstreaming Checklist for initiatives: https://www.thegef.org/sites/default/files/documents/UNIDO-Gender_Mainstreaming_Checklist_for_The_digital_initiatives_0.pdf
- Guidelines for gender mainstreaming in initiative stages: https://www.civicus.org/documents/toolkits/guidelines%20for%20gender%20mainstreaming%20in%20the_digital_initiative%20stages.pdf
- Gender Mainstreaming Checklist for Legislation, Public Policies and Programmes: https://www.women.gov.hk/download/enabling_env/GM-checklist-form.pdf
- WHO checklist tool for gender: https://www.who.int/gender/mainstreaming/GMH_Participant_GenderHealthChecklist.pdf?ua=

ANNEX – 2

Micro-level Analysis of two selected initiatives in each country

Outcome 3 - Beneficiaries

Checklist for participant observations

No.																													
1	<p><u>Setting of the observation:</u></p> <ul style="list-style-type: none"> • Date • Time • Place • Name of targeted digital initiative 																												
2	<p><u>Interaction between the beneficiary and the provider:</u></p> <ul style="list-style-type: none"> • Time spent in waiting: [] Minutes • Time spent in the consultation: [] Minutes • Persons attended consultation with the women (number of them, their gender, and their relation to the woman) <table border="1" data-bbox="355 1136 1286 1289"> <thead> <tr> <th>ID</th><th>Gender</th><th>Relation to the woman</th></tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <ul style="list-style-type: none"> • Type of data collected - Which of the following personally identifiable health data elements are collected as part of providing individual health care? <table border="1" data-bbox="383 1659 1416 1843"> <thead> <tr> <th>1. Name</th><th>1. No</th><th>2. Yes, Orally</th><th>2. Yes, in writing</th></tr> </thead> <tbody> <tr> <td>2. Date of birth</td><td> </td><td> </td><td> </td></tr> <tr> <td>3. National identification number</td><td> </td><td> </td><td> </td></tr> <tr> <td>4. Medical record numbers</td><td> </td><td> </td><td> </td></tr> </tbody> </table>	ID	Gender	Relation to the woman										1. Name	1. No	2. Yes, Orally	2. Yes, in writing	2. Date of birth				3. National identification number				4. Medical record numbers			
ID	Gender	Relation to the woman																											
1. Name	1. No	2. Yes, Orally	2. Yes, in writing																										
2. Date of birth																													
3. National identification number																													
4. Medical record numbers																													

5. Photographic identifiers (such as photos on a driver's license or passport)			
6. Mailing address			
7. Phone numbers			
8. Medical notes			
9. E-mail address			
10. Employment information			
11. Income			
12. Marital status			
13. Number of children			

- Which of the following physical measures are used for protecting patient privacy while collecting information?

1. Minimize exchange of information verbally	1. No	2. Yes
2. Use a partition or curtain in open rooms		
3. Use of a separate room with a soundproof barrier		

- What other physical precautions are taken to secure personally identifiable health data?

	3. No	4. Yes
1. Workspaces, cabinets, paper copies and computers with personally identifiable information are located within a secure area with no public access.		
2. Sensitive documents are stored in cabinets and locked.		
3. Only authorized personnel can access these cabinets and computers.		

- Are confidential matters discussed where others might over hear?

1. Yes 2. No

	<ul style="list-style-type: none">• Are data collected offline (paper form) and then recorded electronically? <p>1. Yes 2. No</p>
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Interview guide

Interview setting:

- Date
- Time
- Place of interview
- Name of targeted digital initiative

Women characteristics

- Age [] year
- The highest education level obtained
 1. No formal education
 2. Completed primary school
 3. Completed middle school
 4. Completed high school
 5. Completed 1-2-year post-secondary/vocational
 6. Completed university/college
 7. Completed postgraduate degree
- Nationality
 1. Palestinian
 2. Jordanian
 3. Syrian
 4. Others, specify
- Employment status
 1. Full-time employed in the workforce (including self-employed)
 2. Part-time employed in the workforce (including self-employed)
 3. Unemployed
 4. Retired or on a pension
 5. Full-time student
 6. Part-time student
 7. Housewife/ Home duties

Experience in access and use of the digital initiative

- Name of the initiative (service)
- What do you know about (name the initiative)?
- When did you start using it?
- How did you know about it?
- How do you describe your experience in using and accessing it? (better access, easier to use, faster to use ...)?

Level of trust of the beneficiary

- Do think that people might disclose your personal information? How much you are concerned about this?
- Do you think that your personal data are shared with others? How much you are concerned about this? Do you trust those whom your data shared with?

Perceived gaps in design and implementation

- What are the problems you encounter when using this initiative?
- What should be done to make this initiative better in your opinion? Or to give you a better experience?

Awareness of the issues around personal data

- What do you know about your data that you provide through the digital initiative?
- Do you feel that some of the information that was asked was unnecessary?
- Have you ever felt that you were asked too much information?
- Were you told if you could decide NOT to provide this information? If yes, did you feel like you still had to provide it even if it optional?
- Have you ever refused to provide information required by the application/system? If yes, why?
- Do you feel worried about providing your personal data through the application/system? If yes, what concerns you? (Notes: *others can see it, lack of control, etc.*)
- Were you told about a privacy policy and where to find it? If yes, when were you first told about a privacy policy? (for example, upon first interaction with the application/system)
- Do you read the privacy policy/terms and conditions of use/ or any related documents if available? If yes, was the privacy policy easily accessible and/or understandable? Please elaborate.
- Do you ask the health provider about issues related to your personal data? Please elaborate.
- Were people other than you know your detailed information because of this initiative?

Assessment of their experience/perceptions

- Do you think that the information that is asked from you helps you access better healthcare?
- Have you seen a change in the quality of the care you have received over time,.i.e. get more information, regular updates, access to treatment? Or no change?
- Did you encounter any problems in: i) seeing a medical professional, and ii) receiving care, iii) access medication, iv) updating information recorded about you, iv) other?
- Have you tried to request what information is held in your record? Were you given this information? If yes, in what format, what did it include? If not, were you given a reason? Did you appeal?
- Do you use any features of the system? is there an option for people to access their records online or receive notifications/reminders, etc?
- Do you wish it worked differently, and why?
- What additional features/services would you want it to provide?