

WORKSHOP Report

PARTICIPANTS

Tara Batista (Columbia University), Sungano Bondayi (Africaid), Charles Copley (Praekelt.Org Patient Engagement Lab), Brian DeRenzi (Dimagi), Eli Grant (Praekelt.Org Patient Engagement Lab), Eric Green (Duke University), Brandon Guthrie (University of Washington), Damian Hacking (Médecins Sans Frontières), Elizabeth Haight (Planned Parenthood), Jakub Hein (Médecins Sans Frontières), Christine Lenihan (VillageReach), Nick Pearson (Jacaranda Health), Ilon Rincon (Empilo), Keshet Ronen (University of Washington), Jennifer Velloza (University of Washington). Remote contribution from Brian Ahimbisibwe (Ariel Superstars Group).

INTRODUCTION

On May 23, 2019, a workshop titled “Leveraging Smartphone-enabled Group Messaging for Global Health” was held at Columbia University School of Social Work in New York City. The purpose was to present and discuss findings and learnings from smartphone-enabled internet protocol (IP) mobile messaging projects that had been implemented in various locations around the world. Growth of these types of interventions has been exponential, but the lessons learned from these interventions have not been effectively shared. The workshop brought together the above mentioned organizations (see Participants) that have been delivering these types of IP messaging programs and provided a chance for them to present their work, share lessons, and set a research agenda for this emerging field. On May 24th, 2019, the workshop organizers met at Columbia School of Social Work again to reflect on the work presented and the discussion the day before. They used this second day to plan the next steps. This report is the result of the workshop findings and follow-up activities. It highlights a summary of current practices, planned outputs, and progress made on next steps.

WORKSHOP SUMMARY - MAP OF CURRENT PRACTICES

The workshop described current interventions, discussed the state of the evidence of IP Messaging projects, and the community of practice's needs, according to the workshop participants. Workshop participants represent a sample of the broader community of practice.

1. INTERVENTIONS

The workshop participants conducted a wide range of digital intervention purposes, structures, and design approaches. The purposes of the digital interventions were largely from three main areas. The first area was about support and information services, both for patients and for professional staff. The second area pertained to the field of data collection and research, which included messaging reminders to complete data collection and reminders to attend group discussions. The final major focus area was that of behaviour change, both social behaviour change as well as behavioral change communication systems.

Various IP messaging intervention structures and features were discussed. Messaging structures generally were comprised of groups, one-way push messaging, two-way interactive messaging, or combinations of these. If interventions offered counseling, the counseling was provided by a live person, bot, combination of both, and/or help desks. Interventions differed in their features as well, specifically, in their levels of anonymity, consent procedures, and whether participants could opt-in or out.

The workshop participants also discussed their interventions' design approach. Some interventions used evidence-based practice (e.g., theories of change, evidence reviews), with participatory and other qualitative formative research strategies. Several projects mentioned community-based or consultative processes; some mentioned user-centred design (or human-centred design). There was consensus on the importance of user involvement and consultation, but doubts about where human-centered design specifically fit and what it added to evidence-based and participatory approaches.

The various technology channels and platforms that implementers were using was discussed. It was discovered that most organizations used WhatsApp but that other platforms are being explored (Telegram, Facebook messenger, and Signal). There was a tension between capitalizing on an existing user-base for platforms and pushing users to a platform that is best suited for the intervention implementation. WhatsApp API considerations were also discussed. Most implementers used manual messaging. The community of practice recognized that advances in automated messaging provided advantages, but API access and cost were important limitations. Few projects linked IP groups with other data sources (Redcap, DHIS2).

Workshop Participants were delivering interventions in three main areas:

1. support and information services
2. data collection and research
3. behaviour change

Messaging structure and intervention components varied

Interventions used a combination of evidence-based practice and participatory approaches

2. EVIDENCE

The type of evidence collected from interventions or used to inform the development of interventions was discussed.

Qualitative acceptability data was available from all projects, but carried with it variable privacy concerns. The community of practice showed a general interest in digital groups, but there was a tendency for people to share very personal information in these groups. User engagement data was available for several projects. Few projects had collected data on health outcomes, although some projects had health impact data collection planned.

Workshop participants discussed leveraging technology to improve evaluation. The potential that has not been fully explored for optimisation of intervention content via rapid impact measures and integrating impact and experimental process evaluations to improve interventions over time. Digital platforms could be used for nimble, creative, evaluation designs.

Types of analyses were discussed. Multi-lingual data makes text more difficult to summarise with natural language processing (NLP). Implementers expressed challenges with extracting and summarizing images and audio recordings. Some advances in social network analysis made group monitoring more feasible. The necessity of data engineering capacity from setup to support analysis was recognized by the community of practice.

All projects collected qualitative acceptability data. Several projects collected user engagement data. Few projects collected health outcome data. Technology could be leveraged to improve evaluation.

3. COMMUNITY

Needs identified across the broader community of practice were identified by workshop participants. These needs included clarity regarding data regulation and ethics, sustainable funding, and tool sharing. Workshop participants also discussed promising areas and their concerns.

Data regulation was discussed. Privacy laws and their implications are complex. It was unclear where the balance lies between privacy requirements and needs for safe service delivery and evidence. It was noted that data privacy regulations keep changing. The community identified the ability to ensure appropriate levels of privacy when delivering across jurisdictions as particularly challenging. The need for standardised data pipelines which protect data and can be used by smaller organisations that don't have internal data engineering capacity (eg. integrated with Rapid Pro or Redcap) was identified as well.

Ethics were also discussed. Participants found it unclear when experiments for optimising or updating digital interventions require ethics committee review and when these are classed as monitoring and evaluation. Nevertheless, it was agreed that safety should be considered when designing digital interventions, as the digital space provides ample opportunity for unintended consequences to emerge.

Workshop participants identified funding sustainability as a key concern. The workshop organizers agreed to follow up to get more information so that the diverse business models being used are reflected in future workshop outputs. Therefore, a question was included in a landscape survey asking about funding models.

Participants discussed a need to share existing tools. There was also a need to develop interoperable software. A tools clearinghouse might be a good investment. Needs for sharing guidance for group facilitators and interpretations of data policies were also identified.

Workshop participants also expressed concerns that might affect the entire community of practice. For example, equity and access for special populations was discussed. Concerns about scalability, sustainability, ethics, safety, and data governance were also identified. Challenges associated with conforming to WhatsApp's business API restrictions were also identified as were risks of developing tools based on one business' model.

Workshop participants identified that clarity was needed regarding data regulation and ethics. There was also a need to share existing tools. Equity, scalability, sustainability, safety, and WhatsApp API restrictions were all cited as key concerns.

OUTPUTS

Planned outputs from the workshop included a case report, an academic paper, and a position paper. The intended outputs are described below. Progress on these outputs are detailed in the next section.

- Case report: intended to be a compilation of the 13 case studies. The aim was to submit the report for publication to Bill and Melinda Gates Foundation Open Research.
- Academic paper: comprised of a landscape analysis using the in-depth information provided from these case reports, a literature review, and results from a wider survey of implementing groups.
- Position paper: outlined an agenda for IP intervention, research, and funding priorities to be disseminated to key funders, technology agencies, and WHO Expert Advisory Panel for Digital Health.

NEXT STEPS

On May 24th, the workshop organizers formulated next steps after reflecting on implementing organizations presentations of the key themes discussed the day before. The organizers decided to collect more feedback, create an official community of practice, and plan knowledge products.

Feedback

On June 12, 2019 workshop participants were emailed a link to a summary of the workshop themes in the form of consolidated notes and invited to share feedback on the workshop, their interests, and the summary notes. They were also given a list of next steps and invited to participate in those next steps.

Community of Practice

One of those steps was to create an official community of practice. On August 1, 2019 an invitation to a [google group](#) called IP4GH (IP messaging for Global Health) was sent to workshop participants. The group provides a forum for workshop participants to continue to be part of and participate in the community of practice by joining ongoing conversations. It also serves as a knowledge product and workshop output repository. The group's aim is to:

- share experiences, get input, and facilitate collaborations using IP for global health
- disseminate evidence, tools, and best practices in using IP for global health
- set an agenda for the use of IP for global health

All workshop participants joined the google group. Currently, the group has 23 members.

Case Report

As previously mentioned, one of the planned workshop outputs was a case report that compiles 2-3 page case studies that showcase the various workshop attendees IP messaging projects, research studies, and the participating organizations' views on the future of the field. On August 12, 2019, workshop participants were invited to support the IP4GH organizers in creating the individual case studies about their projects by scheduling a 1 hour interview with a Praekelt researcher. Eleven of the thirteen workshop participants scheduled the interview. Therefore, eleven individual case studies were drafted, revised by participating organizations, and included in the final case report. The report becomes available on October 31, 2019.

Landscape Survey

The IP4GH leadership team created and administered an IP survey of the wider community. On August 12, 2019, as part of the case study interview invitation, workshop attendees were asked to complete a linked landscape survey. Attendees were encouraged to disseminate the post-workshop survey to their contacts in the digital health space. Currently, 46 respondents have taken the survey and preliminary analyses have begun. In fact, some survey results are reported below (Tables 1 and 2). Additionally, an outline for an academic paper has been drafted and a literature review has been conducted. The paper will incorporate the landscape survey results into the state of the field discovered through the literature review. The paper will be submitted to a peer reviewed scholarly journal by the end of November 2019.

Table 1. Characteristics of survey respondents' organizations

Characteristics	Total N=43 n= 42 (%)
Sector	
NGO (non-profit)	16(61.5)
NGO (for-profit)	4 (15.4)
University	5(19.2)
Government	0(0.0)
Other	1(3.8)
Study Population	26(100)
Organization Headquarters	
Sub-Saharan Africa	8(30.8)
North Africa & Western Asia	1(3.8)
South Eastern Asia	1(3.8)
The Caribbean	2(7.7)
North America	12(46.2)
Europe	2(7.7)

Table 2. Characteristics of IP messaging projects

Characteristics	Total N= 43
	n (%)
Duration of participant engagement ^a	
< 2 months	19(45.2)
> 2 months< 1year	25(59.5)
> 1 year < 2 years	10(23.8)
open	17(42.5)
Number of participants	
<100	11(26.2)
101-500	14(33.3)
501-1,000	3(7.1)
1001-5,000	4(9.5)
5001-10,000	1(2.4)
10,001-100,000	4(9.5)
100,001-1 million	1(2.4)
> 1 million	0(0.0)
Not Applicable	4(9.5)
Geographic region ^b	
Sub-Saharan Africa	31(75.6)
North Africa & Western Asia	1(2.4)
Central & Southern Asia	6(14.6)
South-Eastern Asia	4(9.8)
Central & South America	2(4.9)
The Caribbean	3(7.3)
North America	2(4.9)
Projects' purpose ^b	
Information/support for patients	31(75.6)
Professional support	21(51.2)
Data collection	21(51.2)
Behavior change	25(61.0)
Other	3(7.3)
Health focus of projects ^b	
Maternal child health	15(36.6)
Sexual/reproductive health	20(48.8)
Mental health	7(17.1)
HIV	23(56.1)
Vaccination	12(29.3)
Hygiene	6(14.6)
Nutrition	13(31.7)
Domestic/Gender/Partner violence	5(12.2)
Other	17(41.5)

a: represents multiple projects. Categories are mutually exclusive. Totals may be greater than 100%.

b: represents multiple projects. Categories are not mutually exclusive. Totals may be greater than 100%.

Table 3: Technical Features of the Projects

Characteristics	Total N= 43
	n (%)
Project features ^b	
Digital discussion groups	22(71.0)
1-way push messages	15(48.4)
2-way interactive messages w agent	18(58.1)
Chatbot	6(19.4)
Helpdesks	9(29.0)
Live chat	11(35.5)
Rich media	14(45.2)
Design Approaches ^b	
Participatory-based Research	20(47.6)
User or Human Centered Design	33(78.6)
Evidence-based Practices	23(54.8)
Expert-led design	19(45.2)
IP Platform Used ^b	
WhatsApp	36(83.7)
Facebook Messenger	10(23.3)
Telegram	5(11.6)
Snapchat	0(0.0)
Instagram	1(2.3)
Signal	0(0.0)
WeChat	1(2.3)
iMessage	2(4.7)
Custom software	10(23.3)
Other	11(25.6)
Not sure	2(2.7)
Message handling ^b	
Manual	28(65.1)
Programmed API access	20(46.5)
Unsure	4(9.3)

b: represents multiple projects. Categories are not mutually exclusive.

Totals may be greater than 100%.