Terms of Reference

Developmental Evaluation of Project REG-19-009 *Using technology to facilitate international research on diagnosis and treatment of borderline personality disorder in adolescents including low- and middle-income countries – a strategy based on direct clinical benefit*

1. Introduction

Background on Funding Partner

Fondation Botnar is a Swiss-based foundation established in 2003 whose core purpose is to improve the health and wellbeing of children and young people in growing secondary cities around the world. We do this by investing in sustainable solutions, learning with, connecting and catalysing diverse partners.

At Fondation Botnar, we recognize the value of learning in effectively driving towards systemic change, and are committed to cultivating and nurturing learning both within and outside of the organization.

Background on Implementing Partner ("Grantee")

The grantee is part of a research group focusing on the early diagnosis and treatment of personality disorders in adolescents affiliated at the Child and Adolescent Psychiatric Hospital of the University Psychiatric Hospitals of the University of Basel (UPK). The mission of this research group is aligned with the Global "Alliance for Prevention and Early Intervention for Borderline Personality Disorders" (GAP). GAP calls for action through a set of scientifically based clinical, research and social policy strategies and recommendations (Chanen et al., 2017).

In this project, UPK collaborates closely with (mental) health institutions, including the *Instituto Milenio para la Investigación en Depresión y Personalidad* (Millenium Institute for Depression and Personality Research MIDAP, Santiago, Chile), the Department of Psychology and University Clinical Centre of Kosovo at the University of Pristina (Kosovo) and the Muhimbili National Hospital in Dar Es Salaam (Tanzania). Furthermore, TwigAplha in Dar Es Salaam are partnering for joint software development.

Project description

The prevalence of Borderline Personality Disorder (BPD) in adolescents is estimated between 1-3%. Even at subthreshold levels, BPD in adolescence is associated with severe impairments in social, occupational, and other areas of functioning, posing a severe subjective and societal burden that is substantially higher than that found in other psychiatric diseases. Characterized by an early onset (as early as 12 years old), without adequate care, BPD may run a chronic course, resulting in substantial burden of the illness for patients, families, and societies. Experts broadly agree on the necessity of early detection and concurrent specialised evidence-based interventions, to limit deficits in psychosocial functioning and a heavy impact on the development of the patients. Early detection and treatment have been related to substantial savings for health care systems in studies in Germany and Australia, as well as a significant gain in quality of life and functioning for affected patients.

However, despite significant scientific achievements in detection procedures and treatment development, most adolescents with BPD will not receive a timely diagnosis and this will not receive appropriate care, particularly in low and middle-income countries. A significant gap can be identified between best available clinical science and current routine clinical procedures affecting a great number of patients and their families. To address these issues and in order to benefit patients, the project is developing a pilot and proof of concept in collaboration with three centres from different low- and middle-income settings (Tanzania, Chile, Kosovo). The core activity of the project is the development and implementation of a clinical and research software, namely the Mental Health Information Reporting Assistant (MHIRA). In settings where current clinical science for detection, treatment, and research in adolescent BPD is not typically available, MHIRA will facilitate reliable detection of BPD and other common mental health disorders through evidence-based assessment using standardized clinical instrumentation. Based on these assessments, MHIRA will produce customised reports of clinical findings, and data analysis for clinical and research purposes at the same time. MHIRA will also be able to supply clinical recommendations to treaters based on assessment profiles, thus aiding in bridging the gap between best available treatment evidence and routine care in settings where such a gap is most pronounced and detrimental to the care of patients. In a multi-centric process, the participating centres contribute to software design and content for their specific context, while re-thinking their clinical routine. Counselling by international experts will enrich the process.

The project is intended to:

● Contribute to further developing research priorities defined by the Global Alliance for Prevention and Early Intervention for BPD (GAP) with a major focus on early detection and intervention.
● Improve early detection and treatment of BPD and other common adolescent mental health problems using technology in settings where the clinical science based-routine care gap is most pronounced.
● Support research groups from lower-resource settings to participate in international research and provide their specific point of view to the international research community. MHIRA will include standard clinical instrumentation that will help local centres produce high quality data to develop research projects and help advance clinical science.

- Provide a generic software application to facilitate research and data exchange which is at the same time useful for clinical purposes by facilitating data collection and providing direct feedback to the health care professionals.
- Support for local researchers and clinicians for further low-threshold settings and context adapted dissemination of knowledge and skills concerning early diagnosis and treatment of BPD and build awareness in the local communities.
- Capacity building by clinical exchange, PhD programs, involving local programmers, working with clinicians on how technology can support them.
- Finally, link complex diagnostic data and successful low-cost intervention strategies using machine learning, and research ways of improving clinical work with technology.

More efficient clinical processes are expected to strengthen BPD diagnosis and treatment, leading to immediate effects on some 150 participating adolescents and their families.

An explicit theory of change that would define how the project can contribute to improvements in the lives of BPD-affected youth and their social environments has been elaborated. Current impact, outcome and output indicators focus on the software development and implementation process.

Current state of project implementation

The three-year project formally started on 15 July 2019; however, its activities begun with a kick-off meeting in late November 2019. Accordingly, the project implementation plan has been shifted by three months. As of October 2020, key preparatory steps have been completed: Partnerships have been established and formalised, a software developer recruited, and baseline reports and implementation plans for the three centres established. A formal concept of MHIRA has been prepared, along with a brief research plan for the overall project. Restrictions linked to the COVID-19 pandemic have prevented face-to-face meetings and real-life workshops, making coordination between the centres difficult.

As of late 2020, the software is being developed, a process that includes, *inter alia,* the translation and cultural adaptation of questionnaires. That process has been somewhat hampered by contact restrictions linked to the COVID-19 pandemic and the ensuing limitations on field research. The software is expected to be introduced in April 2021.

In parallel with developing its software, the research team should start developing a funding strategy for work beyond the Fondation Botnar grant period, for instance under European Union programmes, the Swiss National Science Foundation and new such platforms as Crowdhelix (www.crowdhelix.com), and develop plans for the financial sustainability of using MHIRA in low-income settings. Fundraising activities could then start immediately upon completion of the first version of the software.

2. Evaluation objectives and questions

The evaluation begins at an early moment of project implementation and is expected to serve developmental purposes, supporting the grantee iteratively by pursuing the following objectives.

1. To create spaces for externally supported reflection and advice on specific aspects of the programme identified by the grantee, who has identified the following key areas of interest:

    a. Marketing and financial sustainability of the MHIRA

    b. Data security and security certification for MHIRA

2. To support the grantee's reflection on the ways in which the project can contribute to change in the lives of children and young people in low-income countries. This may include further definition of the specific aim and benefit of MHIRA, including its added value compared to currently available software.

Fondation Botnar works with a systemic approach, which assumes that change does not take place along a linear path, but rather requires several different factors to align and contribute to making the change. The evaluation should support the grantee's reflection on the project by creating an understanding of the project's long-term critical path and context that influences it.

3. To learn about the status of the research, and assess its fairness and equity.

Fondation Botnar supports the concept of fair partnerships in research based on the principles developed by the Swiss Commission for Research Partnerships with Developing Countries (KFPE) and the Research Fairness Initiative. It is important for the Foundation that the research that is supported is fair and equitable, building lasting partnerships and capacity sustainably. The evaluation should appraise the current status of research fairness in the project for both the foundation as a grant maker and the grantee as a researcher to reflect on and initiate improvements.

4. To feed into the development of the overall monitoring and evaluation (M&E) and knowledge management system of Fondation Botnar

Fondation Botnar has been developing its strategic learning and evaluation system. The evaluation can contribute to this process by contributing to the development of indicators and/or guiding questions that could be used across research projects funded by the Foundation.

Evaluation Questions

1. What is the place and **relevance** of the project in the wider context of diagnosis and treatment of BPD among children and adolescents in low resource contexts? What conclusions can be drawn for similar projects on other common mental disorders among adolescents?

2. Which **challenges** have been met during the project, including *inter alia* challenges linked to

managing remote teams and challenges in software development? How has the grantee managed these challenges, to what effects?

- How has the COVID-19 pandemic influenced the project in its process and outcomes, and how does the grantee manage issues linked to the pandemic?

3. What is the **project status** with respect to answering the research questions?

- Which successes or promising results have been attained so far? What are the most important insights the project has generated to date?

- What difference has the grant by Fondation Botnar made and is it likely to make – and what data need to be gathered, how, to determine this difference?

4. How has the project been aligned with the **Research Fairness** Initiative, in particular:

- Decision-making and responsibilities in the project, i.e. how research partners share their responsibilities in the project to ensure decisions are fair and effective?

- Capacity building

- Project ownership, in particular how research partners share costs and benefits of the research?

- How can research fairness be optimized in further steps of the project?

5. What can be done to ensure the **use of digital media** and artificial intelligence responds to criteria and standards for data security and privacy, equity, and inclusion, including relevant European regulations?

- How can health care data be put to fair use while respecting privacy and regulations?

- What are pragmatic ways of obtaining appropriate security certification for MHIRA?

- Is there any evidence of unintended consequences or harm caused by the deployment of such technology?

6. How can the longer-term financial **sustainability** of research, dissemination, and continuous updating of the MHIRA software be secured?

- How can the software be marketed without compromising its deployment and accessibility in low-resource settings?

- How can an open source community be developed to support the development of MHIRA and training of MHIRA users?

- How can project finances beyond grant money be managed in an effective and efficient manner?

7. How can the research project **inform policies and practice** to improve young people's well-being in low income countries? What steps have been undertaken, what else can be done (including questions on other actors to be involved)?

During the inception phase, the evaluator(s) can review and develop additional evaluation questions as necessary, in consultation with Fondation Botnar and the implementing partner.

Alignment with Fondation Botnar Strategic Learning and Evaluation

The project is part of the research portfolio of Fondation Botnar, which aims to support the foundation's objectives by providing scientific evidence in the various areas of activity. Fondation Botnar emphasises learning to understand the systems affecting young people's wellbeing and to advance on the path towards the Foundation's vision. Strategic learning agendas guide this approach through learning questions for focused enquiry. For Fondation Botnar, the **primary** learning question for this evaluation is:

How can scalable and sustainable digital approaches and artificial intelligence (AI) in urban and peri-urban ecosystems enhance children's and young people's wellbeing?

3. Methodology

Approach

A developmental evaluation is expected to accompany the project iteratively, at several moments throughout its remaining implementation process, to support decision-making and learning. The evaluator is expected to foster participation throughout the evaluation, working in close cooperation with the grantee's team.

The use of a mixed-methods approach that triangulates methods and perspectives should be considered.

The evaluator or evaluation team is expected to document the evaluation process, as well as lessons learnt and recommendations for future Fondation Botnar evaluations of science grants.

Role of the External Evaluator(s)

Fondation Botnar is committed to partnering closely with grantees to enhance learning directly related to implementation and the follow-on phases of the program, be it with or without Fondation Botnar support.

The External Evaluator or evaluation team implementing the contract must be able to situate themselves as a partner with the recipient organization for maximum transparency and utility of the evaluation findings for program improvement.

In midterm and developmental evaluations, the primary focus should be on program improvement to leverage results. The consulting evaluator or evaluation team is expected to work in tandem with the project lead based in Switzerland to understand the research process and its prospective use. The contracting evaluator or evaluation team is expected to collaborate closely with the implementer to:

A) Reach a shared understanding of the evaluation objectives and questions, and develop the evaluation approach and process accordingly.

B) Unpack or develop the broader theory of change for the project and potential future steps towards introducing the treatment, so as to identify fields of observation/indicators and simple monitoring tools that can be used to track project process.

C) Consult regularly with the project team to develop and continually adjust a developmental evaluation process that responds to the team's needs, and boosts both the validity of findings and the relevance of recommendations.

D) Recommend adjustments to project's measurement framework as needed so as to effectively inform future steps – this may also include supporting training of those gathering data in the project sites.

E) Facilitate validation workshops or consultations (online) with the grantee and partners at key moments of the evaluation process. Representatives of Fondation Botnar should be part of the validation workshops to discuss findings and recommendations.

4. Evaluation logistics

Scope and Field Visits

The evaluation is expected to take place between January 2021 and October 2022, as an exercise that is staggered over a period of more than year, with an overall budget of CHF 20-40,000.

Ideally, it should include visits to project sites (hospitals and schools in Chile, Kosovo and Tanzania). However, in view of current travel restrictions (including restrictions to domestic travel for evaluation team members in the project countries) and risks linked to the COVID-19 pandemic, it is expected that online collaboration via videoconference and visual collaboration tools will be the primary communication tool at least in the early phases of the evaluation.

Ethical Considerations

The evaluator or evaluation team is expected to comply with evaluation ethics throughout the evaluation process, as set out in the OECD/DAC Quality Standards for Development Evaluation (http://www.oecd.org/dac/evaluation/qualitystandards.pdf).

Collaboration throughout the evaluation

The evaluation consultant(s) will design and facilitate workshops at several moments of the evaluation process, starting with an inception meeting (on-line or in a hybrid format) with representatives of Fondation Botnar and of the implementing organisation and concluding with a final debriefing workshop with the same participants.

The inception report will outline at which moments of project implementation the evaluation team will gather and analyse data, and discuss intermediary findings with the grantee.

Proposed Timeline

Evaluation activities will start in early 2021 and conclude no later than October 2022. The Final Report including the respective slide deck should be submitted no later than October 2022.

Work Packages/Action	Responsible	Time/deadline
Selection of evaluator/ team	Fondation Botnar/Grantee	December 2020
Kick-off/inception meeting	Evaluator/evaluation team	January 2021
Submission of inception report	Evaluator/evaluation team	January 2021
Evaluation research and analysis, including validation workshops	Evaluator/evaluation team, grantee	February – October 2022 as defined in inception report
Intermediary briefings	Evaluator/evaluation team	As defined in inception report
Submission of draft final report	Evaluator/evaluation team	September 2022
Feedback on draft evaluation report	Fondation Botnar/Grantee	September 2022
Closing workshop	Evaluator/evaluation team	October 2022
Submission of Final Report	Evaluator/evaluation team	October 2022

Deliverables

The deliverables expected from the evaluation are as follows:

- Inception report of 5-15 pages (plus annexes) including:
  - Understanding of the evaluation purpose and scope (– i.e. what is in and out of scope)
  - Proposed adjustments to evaluation objectives and questions as appropriate
  - Data collection and analysis plan(s)
  - Tentative work-plan and schedule for the overall evaluation process, specifying involved stakeholders' roles and moments for communication between the specific stakeholders
  - Preliminary proposal for the dissemination of findings
  - Draft instruments for data collection and analysis
- Methods documentation package including data collection instruments and analysis plan (data collection protocols, including training plans for any field workers, if appropriate, are expected to be developed and iterated with implementing partner
- Presentations of intermediary findings and recommendations
- Draft outline of the evaluation report (anticipating up to two rounds of feedback)
- Full draft evaluation report of up to 30 pages including a three-page executive summary
- Closing Workshop
  - Discussion of Learnings
  - Reflection on the evaluation process

Final evaluation report (after one round of feedback) accompanied by a short briefing slide deck

5. Evaluator Requirements

Evaluation experience

- Theory-based evaluation
- Participatory evaluation
- Touch points with or knowledge of research fairness approaches (RFI or KPFE Principles)

Contextual experience or linguistic capability

- Excellent written and spoken English
- Knowledge in the field of the diagnosis and treatment of psychological disorders
- Experience with software applications in the field of mental and other health care
- Experience in conducting interviews, group discussions and workshops via online platforms
- Working knowledge of a second project language (Spanish, Kiswahili or Albanian) is an asset

References

Applicants are requested to include at least three hyperlinks to examples of evaluations that are broadly representative of the evaluator's or the evaluation team's capability vis-à-vis this call.

6. Expression of Interest and Deadline

Expression of Interest

The expression of interest should be no longer than **2 pages** consisting of:

● Introduction of the evaluator or evaluation team including relevant experience and skills
● Short proposal of the methodological approach
● Rough day-rate

An annex can include further documentation such as CVs, reports and publications or other relevant documentation. The 2-pager, however, will be the main basis for decision-making.

Deadline

Interested experts are requested to send their expression of interest by 30 November 2020 at 11 am Central European Standard Time. Applications in pdf format can be electronically submitted to m.raab@posteo.de cc. dsuhr@fondationbotnar.org and grants@fondationbotnar.org