fondation BOTNAR

Terms of reference

Mid-term evaluation of project 6061: Developing strategies to identify, prevent and treat the complications of severe childhood obesity, 4/2017-4/2022

1.Introduction

Background on funding partner

Fondation Botnar is a Swiss-based foundation established in 2003 whose 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, and by connecting and catalysing the work of diverse partners. At Fondation Botnar, we are committed to cultivating and nurturing learning both within and outside of the organization so as to effectively contribute to the change we want to see.

Background on implementing partner ("grantee")

The Wellcome Trust-MRC Institute of Metabolic Science (IMS), University of Cambridge is one of the world's leading centres for research into obesity, diabetes, and endocrine problems. The Institute houses over 20 group leaders with expertise in basic and clinical research, extending from genetics, molecular and cell based research to translational research. The Institute has a strong track record of developing new treatments and of implementing those treatments to change the clinical care for patients. IMS has connections with the MRC-Epidemiology Unit where the primary focus is population-based science looking at the problems of obesity and Type 2 diabetes in the community. A number of the group leaders focus on disorders that present in children. Collectively, these researchers (including the PI of this grant, Professor Farooqi) have an extensive network of colleagues and collaborators across the UK who refer children with unusual conditions to Cambridge. The Institute is considered world-leading in several areas, including severe obesity in childhood (Professor Farooqi), severe insulin resistance (Professor O'Rahilly), thyroid hormone resistance (Professor Chatterjee), lipodystrophy syndromes (Professor Savage), and congenital hypothyroidism (Dr Nadia Schoenmakers).

Project description

The aim of the project supported by Fondation Botnar is to identify the key factors that drive obesity associated complications in some children and not in others. The original aim of the study was to conduct a large study in children with severe obesity recruited to the Genetics of Obesity Study (GOOS). The aim was to identify groups of children with obesity and either high or low levels of fasting plasma insulin who would either be at risk of metabolic complications, or potentially protected from complications. The IMS's early genetic studies identified a new gene, Steroid Receptor Coactivator-1 (SRC-1) in which multiple rare variants were identified. Subsequent molecular work on this gene and clinical studies led to the description of a new genetic obesity syndrome published in Nature Communications 2019 (PMID: 30979869). This discovery and the delineation of the mechanism by which SRC-1 is involved in the regulation of weight led very rapidly to the ability to offer a treatment to these patients. The IMS team was able to enrol those patients in a clinical trial of Setmelanotide (a melanocortin-4 receptor agonist) that IMS was already using. As a result, in a very short time the patients with this new identified genetic disorder have benefited from treatment with a substantial improvement in their health and quality of life.

The project funded by Fondation Botnar formally began on 1 April 2017; the planned end date is 1 April 2022. The Fondation Botnar grant amounts to 1,830,000 pounds (UK).

Current state of project implementation

Other aspects of the work have been severely impacted by the COVID-19 pandemic. IMS was planning to bring in a number of patients for extensive physiological and genetic studies to identify distinct subtypes of severe obesity. However, in view of the pandemic, they have been unable to bring patients from across the UK to Cambridge for research studies. As a result, IMS has diverted their focus to new genetic conditions they have identified, particularly those where a treatment for patients is likely to be forthcoming in the very near future. With these genetic discoveries (three papers in review), IMS will be more rapidly able to treat children and adults with severe obesity.

Alongside a continuing programme of clinical research in patients with genetic disorders who can be treated, IMS plans to undertake a large project to look at the impact of obesity on mental health. The scientific rationale for this project is that IMS is aware from clinical experience that there is a significant burden of mental health problems (depression, anxiety, self-harm) in children and adolescents with severe obesity.

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2. Evaluation objectives and questions

The evaluation pursues the following objectives:

1. To support the grantee's reflection on the ways in which the research can, in the medium to long term, contribute to change in the lives of children and young people.

For midterm evaluations, the focus should be on program improvement to leverage results – i.e., a reflection on (i) the potential downstream impact of the research and associated activities on people's lives, (ii) the conditions that need to come together for this impact to materialise, and (iii) how the project can contribute to such impact in its future steps.

2. To learn about the status of the research carried out in the project..

The scientific quality of the research undertaken by grantees is regularly reviewed by external experts in the specific field of each project. Therefore, the mid-term evaluation is <u>not</u> supposed to replicate the research undertaken in the project (e.g., by measuring effects that the product under development may cause among its target groups) or to verify the project's overall scientific quality.

Evaluation questions

- 1. What is the place and relevance of the project in the wider research landscape on the prevention and treatment of severe childhood obesity and related metabiolic and neuro-behavioural complications?
 - What difference has the grant by Fondation Botnar made or is it likely to make?
- 2. 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?
 - To what extent can these research results be generalised?
- 3. Which **challenges and new oppportunities** have been met in the course of the project and 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? What adjustments are needed to make the best of the current conditions?
- 4. How can the research and communication carried out under the project contribute to the prevention and treatment of childhood obesity and associated complications in middle- and low-income settings? How can the project monitoring system be enhanced to support planning for such downstream impact?

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

3. Methodology

Approach

Fondation Botnar is open to a wide range of evaluation approaches and methods. Regardless of the approach chosen by the evaluation team, the evaluators are expected to foster participation at key moments of the evaluation, seeking the grantee's advice and support (i) during the inception phase, when crafting the evaluation instruments, (ii) during the data analysis phase, and (iii) in developing recommendations. As a rule, methods and perspectives should be triangulated in all evaluations.

The evaluator or evaluation team is required to document the evaluation process and – if applicable – include lessons learnt and recommendations for future mid-term evaluations of Fondation Botnar projects in the evaluation report.

Role of the external evaluator

The external evaluator or evaluation team is expected to work in partnership with the grantee and the project lead at Fondation Botnar so as to maximise the transparency and utility of the evaluation process and products. The contracting evaluator is expected to collaborate closely with the grantee to:

- Reach a shared understanding of the evaluation objectives and questions, and develop the evaluation approach and process accordingly
- * unpack or develop the broader theory of change for the project and potential future steps for downstream impact
- consult regularly with the project team to boost both the validity of findings and the relevance of results and recommendations, also taking into account the grantee's internal communication needs
- recommend adjustments to project's monitoring framework as needed so as to effectively inform future steps to enhance downstream impact
- * facilitate a validation workshop or consultation (online) so as to discuss initial findings and recommendations with the implementor and Fondation Botnar.

As a rule, Fondation Botnar representatives will be involved in the inception and debriefing phases.

4. Evaluation logistics

Scope and field visits

The evaluation is expected to take place between September 2021 and February 2022. Its overall budget must not exceed CHF 40,000 (Swiss francs).

Ideally, face-to-face contact with the project team and visits to project sites should be included. It is acknowledged that current travel restrictions and risks linked to the COVID-19 pandemic may preclude travelling. Therefore, data collection and other evaluation activities can be carried out via phone and online platforms, such as videoconference and visual collaboration tools.

Ethical considerations

The evaluator is expected to comply with evaluation standards throughout the evaluation process, as set out in the OECD/DAC Quality Standards for Development Evaluation (<u>http://www.oecd.org/dac/</u><u>evaluation/qualitystandards.pdf</u>), as well as with the research ethics applied in the project.

Proposed timeline

Evaluation activities will start upon execution of the consultancy contract and conclude no later than 28 February 2022. The Final Report including the respective slide deck should be submitted no later than 31 March 2022.

Work packages/action	Responsible	Time/deadline
Selection of evaluator	Fondation Botnar/Grantee	September 2021
Kick-off/inception meeting	Evaluator	November 2021
Submission of inception report	Evaluator	November 2021
Evaluation research and analysis, including validation workshop	Evaluator/Grantee	Nov. 2021 – February 2021
Submission of draft evaluation report	Evaluator	February 2022
Feedback on draft evaluation report	Fondation Botnar/Grantee	February 2022
Submission of Final Report	Evaluator	February/March 2022

Inception and dissemination consultations

At a minimum, the consultant will facilitate two workshops with the grantee and possibly representatives of Fondation Botnar. The minimum set of activities are specified as follows:

- Inception meeting or workshop (on-line or in a hybrid format) with representatives of Fondation Botnar and of the implementing organisation
- * Validation workshop (on-line or in a hybrid format) with the implementing organisation, to verify and deepen findings, reflect on future steps and gather inputs for recommendations.

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
 - Proposed adjustments to evaluation objectives and questions as appropriate
 - Data collection and analysis plan(s) including draft instruments and training plans for any field workers, if appropriate, to be developed in consultation with the grantee
 - 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
- Methods documentation package including data collection and analysis instruments as used in the evaluation, and discussion of the evaluation process
- * Draft outline of the evaluation report (anticipating one round of feedback from Fondation Botnar and the grantee)
- Full draft evaluation report of up to 30 pages including a three-page executive summary (anticipating one round of feedback)
- * Presentation and discussion of findings and recommendations in a debriefing workshop
- Final evaluation report accompanied by a three-page slide deck summarising the conclusions and recommendations

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5. Evaluator requirements

Evaluation expertise

- * Theory-based evaluation and/or theory of change development
- Participatory evaluation

Contextual experience

- ✗ Excellent written and spoken English
- * Experience in conducting interviews, group discussions and workshops via online platforms
- ✗ Knowledge in the field of health research

References

Applicants are requested to include 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 (EOI) should consist of **2-5 pages** presenting:

- 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 EOI, however, will be the main basis for decision-making.

Deadline

Interested experts are requested to send their expression of interest by 13 September 2021 at 11 am Central European Standard Time. Applications in pdf format can be electronically submitted to <u>m.raab@posteo.de</u> cc. <u>dsuhr@fondationbotnar.org</u> and <u>grants@fondationbotnar.org</u>