Terms of Reference: Pathfinder Studies for Health Research

This document outlines terms of reference for Pathfinder Studies on Health Research enabled by The Global Health Network and partners

Introduction to pathfinder studies

Generating new evidence and insights from health research studies can be very challenging, with specific challenges at different stages of the health research and data cycle. A pathfinder study is an 'add-on' study to a host research project that seeks to address a public health challenge. The pathfinder study uses a standardised approach to conduct process mapping for the health research cycle, enabling the identification of fundamental obstacles faced by the host project, such as those related to gaps in skills, technology infrastructure, data systems and tools. Critically, pathfinder studies seek to help identify solutions to overcome these barriers, building on knowledge and best practice across global health communities of practice.

Pathfinder studies can be associated with host projects that are addressing important research questions in any disease or area of global health challenge. Likewise, they can be associated with host projects that involve collection and use of quite different types of data, and large or small datasets. Importantly, pathfinders can be used as supplementary studies for host projects that: a) have already been completed and have key learnings and excellence to share; b) are currently underway and/or using secondary data; or c) are at early planning and design stage.

Key benefits and outcomes of pathfinder studies include the following:

- Acceleration of the health research and data cycle for the host project through finding solutions to overcome barriers, resulting in new research insights and evidence.
- From this embedded, action learning approach, the host project and its institution can learn from and strengthen methodologies and research processes.
- Identifying solutions, including approaches and tools, which can be openly shared with global health communities of practice, with appropriate attribution. This enables greater equity, reduces duplication, and strengthens standardised good practice.
- Foster external projection and recognition of the host project members, for their efforts in the daily practice by documenting creative solutions for known issues in research.
- Capacity building in research and data science, both for the host project and pathfinder study teams, their institutions, communities of practice, countries and regions where they are based.
- May include the mapping and strengthening of health data infrastructure - including data governance - for host project' institutions, therefore enabling and strengthening data access, re-use and sharing between institutions, countries and regions.

Objective

The 'add-on' pathfinder study aims to track the steps and processes taken by the host project and prepare a detailed process map. This helps identify the barriers and blocks, as well as learnings encountered in generating new insights and evidence from the host project's datasets. The pathfinder study also aims to identify solutions for the barriers experienced, therefore accelerating the health and research cycle and enabling the generation of new evidence and insights, including the opportunity to ask new questions from existing datasets.

Further objectives of the pathfinder studies are:

- Identification and open sharing of solutions to common barriers in health research and data cycle, including process and tools, enabling equity and sharing of best practice across global health communities of practice.
- Where appropriate, building and shaping a data sharing road map for the host project's institution(s) to increase trustworthy data access, re-use and sharing between institutions, countries and regions.
- Enable the scoping and development of a data sharing road map for the host project's institution. This will involve the mapping and strengthening of health data infrastructure, including data governance, and enable greater data access, re-use and sharing between institutions, countries and regions.

Eligibility

- Host projects may already be completed, be underway or currently being planned or designed, with the pathfinder study adding benefits for all three types.
- Host project's datasets could be large or small.
- Host project's datasets can contain both quantitative and qualitative data.
- Host projects should be addressing public health research questions and may come from a variety of health fields using different methodologies, e.g. clinical trials, epidemiological research, biomedical laboratory-based research or social sciences.
- Selected pathfinder studies may also be used to inform and shape the development of a data sharing road map at an institutional level. Where this is the case, key datasets from the host project should also be made available for access and re-use, even if only under certain conditions.
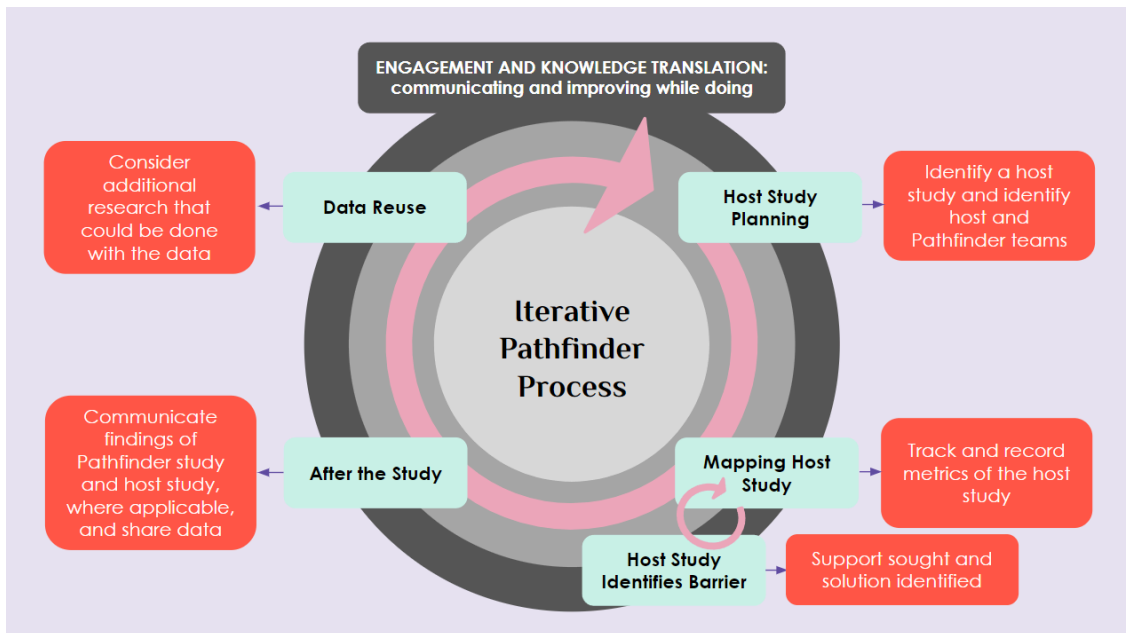
Figure 1. Iterative process of the Pathfinder method.

Deliverables

Eligible for any pathfinder study:

- The **pathfinder protocol** detailing the planning, process and steps undertaken with the host study to develop the pathfinder study. This document is intended to be used by teams wishing to run this add-on study alongside a host project where the text can be adapted and edited to the requirements of each specific study.
- A comprehensive **process map** for the collection, analysis, and utilisation of health data, setting out tools, methods, approaches and systems that were applied using the Tracking Tool stored in the database, when applied and DOI generated for it.
- A list of all **stakeholders** involved in the project, their roles and responsibilities, i.e. people, companies or institutions with some kind of participation in the management and results of the host project.
- A **synthetic document (e.g Pathfinder Brief Birth in Brazil II; Pathfinder Brief Vacina Maré)** with an analysis of challenges, obstacles and limitations for the host project and recommendations for addressing these challenges, obstacles and limitations, both for the host project itself and for future and related projects.

For data science projects:
- Development of a data management plan.
- Development of a data analysis plan.
- Development of a data sharing road map for the host project's institution(s) to increase trustworthy data access, re-use and sharing between institutions, countries and regions.

Other possible and desirable deliverables according to pathfinder's objective:

- An implementation plan for uptake of findings of the host project.
- Communication plan for effectively engaging with the participant community and other stakeholders.
- Community resources, such as toolkits or case study: a step-by-step guide about a topic of interest (successful project or procedure), informing practices and providing resources to be used by others as an implementation and/or inspirational roadmap.
- A workshop/webinar disclosing the main findings and promoting discussions and capacity building.
- Other training resources may be developed by the teams, when suitable, such as course modules, supported learning sessions and data clinics.
- A publishable paper summarising the findings and recommendations of the study.

Language

All resources must be available in at least one of the working languages within individual regions, e.g. Spanish or Portuguese in Latin America & Caribbean.

Methods for pathfinder studies

- Use of a tracker and process mapping template to capture important elements at each step of the health research and data cycle, including type of data, stakeholders, role of community, governance and ethical issues.
- Key stakeholder engagement steps captured to identify their needs and expectations.
- Review of process map produced by pathfinder study to identify blocks and lessons learned.
- Support for host project and pathfinder study team to identify solutions to blocks, including connections to other relevant research teams in global networks.
- Data science clinics with regional experts to also help develop tailored solutions for the challenges in health data collection, management and use.

Timeline

The project is expected to take **6 to 18 months** to complete, starting from the date of approval of the terms of reference by the host project/pathfinder team.

Communications

The add-on study must provide a **communications plan** with activities to disclose and disseminate the project´s findings and products.

Data management and re-use

The pathfinder studies can be carried out by a team of experts from different fields and collaborations. These can result in a) new data/ insights generated by the host project itself; b) data relating to the pathfinder study and process mapping. For both types of data, to ensure appropriate governance, including storage, management and analysis are key.

Host project teams are encouraged to make datasets **accessible and available** for re-use by other researchers, with appropriate data management and governance approaches and conditions in place. For the add-on pathfinder studies, the process mapping data should be shared more widely to enable effective knowledge sharing.