



## REQUEST FOR PARTNERSHIP (RFP)

# OUR STORY OUR WAY

A staged process to secure Potential Partners for each of the four workstreams

### STAGE 1

Through this RFP, the Pilbara Aboriginal Health Alliance (PAHA) is seeking organizational and individual partnerships with appropriately skilled experts to support the development and implementation of **“Our Story Our Way”** including creation of the Pilbara Regional Aboriginal Health Data Registry.

In Stage 1, PAHA welcomes expressions of interest from diverse organisations and individuals who would consider joining us as a Potential Partner. This document supports Stage 1.

This document shares the origins, strategic directions and anticipated impact of OSOW. It describes the four workstreams and opportunities ahead. If you are interested in joining PAHA and Member services as a OSOW Partner for one, part or more than one workstream, we want to hear from you.

Please read the Application Guidelines and complete your Application online which is available at <https://paha.org.au/our-story-our-way> as soon as you can. On the basis of this information, PAHA will identify individuals and organisations to proceed to the detailed application requirements of Stage 2. Written Stage 2 applications will be subsequently evaluated by a joint committee appointed by PAHA and the Lowitja Institute, an Aboriginal and Torres Strait Islander community-controlled health research institute whose support we gratefully acknowledge.



## PROSPECTUS: OUR STORY, OUR WAY

My name is June Councillor. I am a proud Banjyma Traditional Owner who lives in the Pilbara. I am CEO of Wirraka Maya Health Service Aboriginal Corporation operating out of South Hedland and I am also the Chief Investigator on a body of work which we believe will be transformative for Pilbara Aboriginal Communities. I'd also like to introduce you to seven other Aboriginal and Torres Strait Islander leaders from the region: Jolleen Hicks, Michael Saylor, Richard Ansey, Billy Landy, Lawrence Whyoulter, Rowena Brown and Nora Cooke. Together we form the permanent Working Group for "Our Story Our Way". OSOW is how we envisage self-determination and community control improving Aboriginal health and wellbeing in the Pilbara.

We are excited to introduce you here to OSOW. This is a pathfinder initiative endorsed by the Boards of all three Aboriginal Community-Controlled Health Services who have authorised the Pilbara Aboriginal Health Alliance (PAHA) to manage day-to-day activities coordinating OSOW.

In this initiative, the health needs for more than 20 Aboriginal communities in the Pilbara will be thoroughly examined with communities given the unprecedented opportunity to use their own health data to identify their priorities and, importantly, their solutions. This requires new arrangements to return data collected about Aboriginal people and previously known only to governments to where decisions are best made: in local communities. PAHA is investigating return of data through the Office of Digital Government within the WA Department Premier and Cabinet. Data will be securely warehoused and curated by PAHA adhering to all legislative and statutory requirements.

Data will be used to create innovative multimedia health storyboards incorporating Aboriginal health concepts so that Aboriginal communities can discuss and make sense of these data to identify their priorities for service development, new investments and commissioned research. These storyboards will acknowledge history and our continuing struggle for our rights. To conduct this work, we will first pioneer 'yarning circles' in seven communities and set down their strategies for community-led solutions to improve regional planning and external health partnerships.

OSOW will also deliver capacity to pool de-identified data from all three Aboriginal community-controlled health services to monitor health demand and improve service delivery in primary health care. This information will also be used to shift investments towards prevention and evaluate the impact of these efforts in improving health and wellbeing.

As Aboriginal and Torres Strait Islander leaders, we have also realised for some time that we need to mobilise targeted research to more quickly answer research questions raised by communities in achieving their own health and wellbeing. OSOW will strengthen systems already highly regarded through PAHA to assert community priorities more effectively in research activities, moving towards co-design and Indigenist research methods while shifting the balance away from external research drivers. Over time, research will be led by local communities, ensuring their research priorities set the agenda for all research activity.

While we do not speak for any other Aboriginal communities, we believe our experiences as we progress with OSOW will be of interest to many who like us have been too far away from the central processes of health policy, resource allocation and research. Remote Aboriginal communities are strong, resilient and insightful. Our leadership is also committed to intergenerational change. Through OSOW, local Aboriginal people will be employed and given extraordinary opportunities to acquire high-level technical skills and ensure our efforts are truly transformative across time.

We invite philanthropic organisations to consider an investment through a partnership to accelerate OSOW to fully realize regional implementation of Priority Reform 4 of the National Agreement on Closing the Gap.

Sincerely



**JUNE COUNCILLOR**

Please contact me via Winnie Henry at the PAHA office [execops@paha.org.au](mailto:execops@paha.org.au)

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## Key Information for Potential Partners

Our Story Our Way (OSOW) will create an Aboriginal community-controlled data ecosystem across the Pilbara including an accessible data warehouse into which Pilbara health and social data can be captured, organized, analysed and curated in order to inform health services planning, service improvement, funding applications, research and knowledge translation led by Aboriginal people. Four workstreams have been agreed by the PAHA Board and three Aboriginal community-controlled health services in the Pilbara to realize the full suite of benefits of Priority Reform 4 of the National Agreement on Closing the Gap commencing 27 July 2020.

PAHA has secured the support of the Lowitja Institute to develop this RFP process using the pre-existing PAHRA research principles to ensure selected partners are able to work effectively with PAHA, three Aboriginal community-controlled primary health care services and Aboriginal communities in the Pilbara. We hope you will consider joining us for this exciting journey!

## OUR VISION

The **Pilbara Aboriginal Health Alliance (PAHA)** is a partnership between the three Aboriginal Community Controlled Health Services (ACCHSs) in the Pilbara - **Wirraka Maya Health Services Aboriginal Corporation**, **Mawarnkarra Health Service** and **Puntuturnu Aboriginal Medical Service** (known as PAHA Member Organisations). The PAHA Board is comprised of three Aboriginal Directors from each of these three ACCHSs. PAHA has an objective of increasing the level of Aboriginal health support services and improving health outcomes for Aboriginal people, families, and communities in the Pilbara Region (NOTE: the term 'Aboriginal' is used herein and refers to Aboriginal and Torres Strait Islander Peoples).

Our vision for OSOW and the initiatives it embraces through four workstreams is improved health and wellbeing for Aboriginal people in the Pilbara through best practice data sovereignty, intellectual property, contemporary health services planning and development, and evidence-based decision-making. To achieve this vision, PAHA will hold, use and expand collective health data of Aboriginal people in the Pilbara in a digitally secure and also culturally secure environment. PAHA will house a Pilbara Regional Aboriginal Health Data Registry which, when fully operational, will hold a number of de-identified real-time and interval data sets generated by the three PAHA Member Organisations as well as from government and non-government data custodians collecting data about Aboriginal people in the Pilbara. Our vision brings to fruition the promise of Priority Reform 4 in the current National Agreement on Closing the Gap commencing 27 July 2020.

At present however, data collected from and about Aboriginal people in the Pilbara are not sufficiently well shared with Aboriginal people in the Pilbara and their community-controlled organisations.

## OUR APPROACH

OSOW adapts and applies the Lowitja Institute's principles of Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG), namely:

**Indigenous Data Sovereignty (IDS)** – “The right of Aboriginal and Torres Strait Islander peoples to exercise ownership and control over Aboriginal and Torres Strait Islander data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination, and reuse of Aboriginal and Torres Strait Islander data”.

**Indigenous Data Governance (IDG)** – “The right of Indigenous people to autonomously decide what, how and why Indigenous Data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflect our priorities, values, cultures, worldviews and diversity.”

In addition to the PAHA Principles described below, Potential Partners should adhere to the five principles for IDS issued by the Lowitja Institute as below:

- Aboriginal control of the data system in the Pilbara
- Data that is contextual and disaggregated for the Pilbara region and its sub-regional catchment areas
- Data that is relevant and empowers sustainable self-determination and effective self-governance
- Data structures that are accountable to Aboriginal peoples in the Pilbara

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Data that are protective and respect Aboriginal individual and collective interests in the Pilbara. Potential partners must also bring capability and experience to implement each of the eight PAHA research principles:

### PAHA PRINCIPLES

1. That the research clearly addresses the Pilbara's Aboriginal health priorities.
2. That the appropriate regional organisations and prospective interviewees are involved in the co-design of the research methodology
3. That where assistance is sought in connecting researchers to community members that community connectors are paid for their involvement - thus allowance should be made for this in the research budget.
4. That depending on the duration of the research, staff of Aboriginal Health Services and/or community members be involved in the research project as research associates, provided training in research methodology, paid for their work, and given credit for their assistance in any publications.
5. That any costs incurred by Aboriginal Medical Services in support of the research (e.g. Transport, accommodation, human resources) are included in the research budget and reimbursed to the contributing agency.
6. That there is a clear commitment to feedback to the organisations, communities and individuals involved in the research the outcomes of that research and any plans to implement the research findings.
7. That where the research findings demonstrate the need for investment in a particular health initiative that the research organisation join with local health services as advocates for funding and support the development of funding proposals.
8. That Institutions wishing to conduct research in the Pilbara must commit to their researchers undertaking local place-based cultural awareness training also in the Pilbara

### PURPOSE AND SCOPE

The Pilbara Aboriginal Health Alliance (PAHA) is seeking organizational and individual partnerships with appropriately skilled experts (herein referred to as 'potential partners' for clarity in this RFP) to support the development and implementation of "Our Story Our Way". The purpose of each partnership is to collaborate with PAHA Member Organisations to support, as agreed, components of four OSOW workstreams. RFPs are encouraged for one, all or part of these workstreams. PAHA will consider best use of available resources, transactional costs and impact when selecting the final number of partners for Our Story, Our Way. Partners will work under the guidance and leadership of PAHA's governance structures for Our Story, Our Way. We expect all Potential Partners to show how they will respect and uphold the local Aboriginal community's rights to sovereignty and self-determination of the process. This RFP has been designed to encourage a broad range of people/organisations to consider offers of funding, in-kind support, expertise and partnership. OSOW must enable PAHA and Member Organisations to acquire data insights to drive investment in programs to improve health outcomes for the Aboriginal peoples of the Pilbara.

### DESCRIPTION OF WORKSTREAMS

Four workstreams have been agreed to realize the full suite of benefits of "Our Story, Our Way":

#### Stream 1 Internal Data Workstream

**Stream 1 Internal Data Workstream** is internally focused, empowering PAHA Member Organisations to come together to develop ethical data agreements and using Communicare data for needs assessment and service planning. This requires a common ethical and technical framework addressing data sovereignty, community reciprocity, patient consent and standardized coding. When PAHA's Data Registry is fully operational, it will include de-identified data generated by the three PAHA member organisations using Communicare. While each PAHA Member Organisation uses Communicare as its electronic clinical record system, each Communicare system is siloed by its respective Member Organisation in separate servers. Stream 1 will examine the advantages and disadvantages of unique patient identifier numbers in primary health care in the Pilbara to improve outcomes. Stream 1 will also develop the technical methods required to produce informative regional needs assessments using primary health care data from PAHA Member Organisations and other regional providers. In a proof-of-concept pilot to be

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supported by the Preferred Partner selected through this RFP, PAHA Member Organisations will identify a pathfinder health priority to test and improve procedures for accessing Communicare, producing regional health data insights and facilitating as a priority treatment and care co-ordination for Aboriginal people using more than one PAHA member service. Functionality must be over and above that currently possible using MyHealthRecord and/or time-limited access to be considered cost-effective. In addition to PAHA and Member services, key stakeholders for Stream 1 include the Pilbara Aboriginal Health Research Alliance (Panel), Aboriginal clients, patients, families and communities relying on ACCHOs for primary health care.

### Stream 2 Data Repatriation Workstream

Empowers PAHA to liaise with all relevant government and non-government data custodians to repatriate data about Aboriginal people in the Pilbara and negotiate transparent data provision agreements and reliable, ongoing data provision schedules. This includes the development of policies and procedures to comply with all data access requirements. PAHA has already commenced an application for HREC approval. In addition to PAHA and Member services, key stakeholders include external data custodians (government/non-government/private for profit), the Office of Digital Government (WA) and PeopleWA.

### Stream 3 Community Prioritisation Workstream

Produces data-informed health storyboards for specific Aboriginal communities in the Pilbara from an Aboriginal perspective. Each storyboard will emphasise historical, cultural and social determinants of health, and their manifestation in current health and wellbeing indicators. These will be used as the primary resource through iterative engagement and 'yarning circles' initially in each of seven communities to facilitate identification of priorities for new health investment, service enhancements and research commissioning. PAHA has already commenced an application for HREC approval. In addition to PAHA and Member services, key stakeholders include community members, subject Matter Experts (SMEs) and Indigenist scholars.

### Stream 4 Research Governance Workstream

Develops and consults external stakeholders about policies and procedures to develop respectful, reciprocal and rigorous mechanisms for research commissioning through PAHA including frameworks and policies to support successful research commissioning, a schedule of fees to remunerate Aboriginal participants in research, authorship policies, knowledge translation requirements and procedures to guarantee intellectual property. This stream may also include an exploration of options to commercialise Aboriginal data in the region. In addition to PAHA and Member services, key stakeholders include mainstream research entities, Aboriginal scholars employing Indigenist methodologies to answer health and medical research questions, future Aboriginal researchers in the Pilbara and research funders including NHMRC, WA Government, MRFF, Heart Foundation etc.

## DELIVERABLES BY STREAM

PAHA has developed an initial list of deliverables for each workstream to be achieved in partnership with the respective PAHA workstream governance structure:

### Stream 1 Internal Data Workstream

- A written exploratory report of the organisation of Communicare utility, functionality and data limitation with each ACCHO exploring expectations, barriers, ethical considerations (including consent) and conditions for widening Communicare access beyond the respective ACCHO
- An analysis of clinician record-keeping behavior and data management necessary to ensure meaningful automated de-identified data extraction from Communicare for regional needs assessments with recommendations to further develop this aspect of the PAHA Data Registry
- A written protocol and draft HREC application as required for a pathfinder health priority pilot project to test and improve procedures for accessing Communicare, producing regional health data insights and facilitating as a priority treatment and care co-ordination for Aboriginal people using more than one PAHA member service.



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- Implementation and evaluation in agreed timelines of the pathfinder health priority pilot project in partnership with the PAHA workstream governance structure
- Continuous risk assessment and management with regular reports to the respective PAHA workstream governance structure and prompt response to direction from the PAHA workstream governance structure
- Final drafts of protocols, templates and ongoing governance of the PAHA Data Registry to facilitate ongoing, confidential, patient-centered access to clinical information across Member Organisations and use of de-identified data to PAHA's Data Registry for regional service enhancements

### Stream 2 Data Repatriation Workstream

- Support for PAHA to comply with ethical and other data conditions put in place to secure data repatriation
- Design and installation of an electronic warehouse to be located with PAHA with functionality to organize, retrieve and manipulate de-identified data from diverse sources, particularly to monitor health trends over time
- Design of data protection and security systems and protocols for PAHA data warehouse
- Continuous risk assessment and management with regular reports to the respective PAHA workstream governance structure and prompt response to direction from the PAHA workstream governance structure
- Draft and final data provision agreements with external data custodians

### Stream 3 Community Prioritisation Workstream

- Drafting, refinement and production of high-quality health storyboards using multi-media as agreed with the PAHA workstream governance structure to facilitate community engagement through yarning circles to elicit community health priorities for service planning, development, research and advocacy
- Completion of an agreed number of facilitated yarning circles in partnership with participating communities, PAHA Board and the respective Member Organisation Board, with final report
- Continuous risk assessment and management with regular reports to the respective PAHA workstream governance structure and prompt response to direction from the PAHA workstream governance structure

### Stream 4 Research Governance Workstream

- Compendium of Aboriginal-led policy options, frameworks and procedures to support research commissioning through PAHA
- Facilitation of stakeholder engagement to identify and resolve issues affecting successful research commissioning
- Model agreement templates, guidelines and explanatory resources to enable PAHA to negotiate future co-design partnerships with research groups
- Drafts of additional resources to support successful research commissioning in action including but not restricted to Indigenous Data Sovereignty obligations addressing "Governance of Data" and "Data for Governance", schedule of fees to remunerate Aboriginal participants in research, authorship policies, knowledge translation requirements, publication policy and procedures to guarantee intellectual property

## PARTNER CAPABILITY

In Stage 1, PAHA seeks to connect with as many individuals and organisations as possible with capability, experience and intent as Potential Partners. Stage 1 EOIs to this RFP must convey:

- Understanding of Aboriginal concepts of health, reciprocity, consent and what matters to people, their health and their community.
- Sufficient pre-existing expertise in quantitative and/or qualitative data as pertaining to the respective workstream including identification of protective factors, a strengths-based approach to data use, cultural determinants, social determinants and positive indicators
- Prior examples of feedback to Aboriginal organisations, communities and individuals involved in any research, evaluation or service development activity and how you went about this

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- Experience in and/or willingness to operationalize Priority Reform 4 of the National Agreement on Closing the Gap
- Sufficient pre-existing expertise about robust and credible health data use needs
- Familiarity with the 17 socio-economic outcomes and targets of the National Agreement on Closing the Gap and progress reports issued by the Productivity Commission
- Understanding of the geography of the Pilbara, locations of each PAHA Member Organisation and organizational capacity to undertake a pilot with support on-site and virtually
- Governance of partnerships and instruments to negotiate and codify agreement, data sovereignty and control
- ACCHO sector including entities in the Pilbara
- Capacity to bring in-kind contribution to the partnership and workstream

### RESOURCES

To date, PAHA has funded conceptualization and initial planning for “OSOW” from within existing resources and continues to actively seek significant additional funding. Potential Partners enthused by this opportunity to support self-determination in the Pilbara and accelerate achievement of the 17 socio-economic targets and four Priority Reforms of the National Agreement on Closing the Gap in remote Australia are encouraged to complete the PAHA template. Potential Partners with capacity to invest in “OSOW” can nominate aspects of particular interest. Universities with capacity to negotiate funding mechanisms compatible with PAHA Principles and the requirements of this RFP are also encouraged to submit a Stage 1 EOI using the PAHA template.

### NEXT STEPS

If you are ready to submit a Stage 1 EOI, please use the PAHA Application available on the PAHA website under Our Story Our Way (OSOW) tab <https://paha.org.au/our-story-our-way/>