

Jembatan: Developing a replicable model and practical tool for integrating  
infertility in Sexual and Reproductive Health and Rights (SRHR) plans and  
programmes

Report of workshop 1



The report is prepared by **ResultsinHealth**  
September 24, 2018

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## List of Abbreviations

|           |  |
|-----------|--|
| ART       | Assisted Reproductive technologies   |
| GP        | General Practitioner   |
| ICPD      | International Conference on Population and Development                                 |
| IPPA/PKBI | the Indonesian Planned Parenthood Association/Perkumpulan Keluarga Berencana Indonesia |
| IVF       | In vitro fertilisation   |
| MNCH      | Maternal Neonatal and Child Health   |
| NGO       | Non Governmental Organization  |
| PKBI DIY  | Perkumpulan Keluarga Berencana Indonesia Daerah Istimewa Jogjakarta                    |
| PoA       | The Program of Action  |
| PTPH      | Pejuang Tangguh Permata Hati   |
| RiH       | ResultsinHealth  |
| SRHR      | Sexual Reproductive Health and Rights  |
| Uva       | University van Amsterdam   |
| WHO       | World Health Organization  |

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## Acknowledgment and disclaimer

This workshop would not have been possible without the active and engaged contribution of the participants in the first Infertility Workshop Jembatan project in Yogyakarta.

We would like to thank all participants from Pejuang Tangguh Permata Hati , Perkumpulan Keluarga Berencana Indonesia (PKBI) Chapter DI Yogyakarta, and Permata Hati infertility Clinic RSUP Dr. Sardjito, Yogyakarta Indonesia.

The following individuals deserve a very special thank you for their invaluable expertise and experiences and provided us with insight into the problems faced by involuntary infertile couples in Indonesia:

Trudie Gerrits from University of Amsterdam  
Aryanti Radyowijati from ResultsinHealth  
Endang Purwasari from ResultsinHealth  
Titing Martini from ResultsinHealth  
Linda Rae Bennet from University of Melbourne  
Dr. Ita Fauzia from Permata Hati infertility Clinic RSUP Dr. Sardjito, Yogyakarta  
Safa from Permata Hati Infertility Clinic RSUP Dr. Sardjito, Yogyakarta  
Gama Triono from PKBI DIY  
Fitri Kawuri from PKBI DIY  
Workgroup Infertility ShareNet International

In the end, we claim sole responsibility for the content and analysis in this report.

Leiden, 16 September 2018

## 1. The Jembatan Project

Infertility is highly prevalent in the Global South, including in Indonesia, and has a devastating impact on those affected. The Programme of Action (PoA) of the International Conference on Population and Development (ICPD) (United Nations, 1994) —and since then various other international organizations, like WHO (2017) and Guttmacher (2018) —have called for including prevention and treatment for infertility in SRHR plans and programs. Nevertheless, typically, donors, policy-makers and NGOs focusing on SRHR neglect the issue.

Research shows that non-governmental organizations (NGOs) focusing on SRHR engage pay hardly any attention to the problem of sub- or infertility, neither do they collaborate with support groups of clients at infertility clinics. From University van Amsterdam (UvA) previous project with Share-Net Small Grant in Ghana and Kenya, we have learned that these support groups are keys in providing information on infertility and counselling and to address the stigma associated with infertility. Research also shows that health related support groups have an excellent track record of positively influencing NGOs.

To address this gap, ResultsInHealth together with UvA; PKBI Yogyakarta; Permata Hati Clinic infertility support group; and the Share-Net Infertility Working Group will work together in a project called Jembatan. Jembatan is a project to develop a (replicable) model and practical tool for integrating infertility in Sexual and Reproductive Health and Rights (SRHR) plans and programmes. Jembatan is intended to stimulate exchange and collaboration between infertility support groups and NGOs focusing on SRHR with the goal of up scaling and improving interventions addressing infertility. Specifically, Jembatan will promote collaboration between PKBI Yogyakarta and the Permata Hati infertility clinic support group. In detailed, there are 4 objectives of this project as stated below:

- Develop learning and knowledge exchange and collaboration between PKBI Yogyakarta and the Permata Hati infertility clinic support group.
- Document the experiences, practices and knowledge shared as well as the processes of cross-learning and collaboration between PKBI Yogyakarta and the infertility support group and translate the findings into a practical model.
- Develop a tool in Indonesian and in English for integrating infertility in SRHR plans and programmes, based on the practical model developed.
- Widely disseminate the findings of the project and the tool.

To achieve the above objectives, several activities will be carried out as described below:

- Desk study of experiences and lessons learnt on the operations of support groups.
- Participatory workshops between senior staff of PKBI Yogyakarta and members of the infertility group to: exchange information on and experiences of infertility (including in the context of broader SRHR issues) and access to services; assess needs and opportunities for joint work; delineate ways of working; and define concrete actions.
- Monitor and document processes and results from the workshops as well as joint activities between meetings.
- Develop plan of action for continuing collaboration
- Produce and disseminate a tool in Indonesian and in English outlining in practical terms how to integrate infertility in SRHR plans and programmes.

The timeframe for this project is 5 months (from 1 July until November 23, 2018). At the end of the project, we hope that: PKBI Yogyakarta will include services for people affected by infertility in their future plans and programmes and the Permata Hati infertility clinic support group can strengthen and expand their interventions. These exchange and collaboration will be based on the

approach/method developed by the UvA and Workgroup Infertility team and will be documented to produce the tools for integrating infertility in SRHR plans and programmes.

## 2. Introduction

The first workshop was organized from Saturday – Sunday, 11-12 August 2018 at PKBI DIY Office in Yogyakarta, Indonesia. The workshop was led by Aryanti Radyowijati from ResultsinHealth and Trudie Gerrits from UvA (University of Amsterdam) and assisted by PKBI DIY for the organization of the workshop.

This first workshop served as kick-off for the project, Trudie and Aryanti arrived few days before the workshop to meet with all the stakeholders involved in this project. Their schedule included:

- Holding interviews with 2 candidates for the position of project assistant to assist with documenting the workshop process,
- Meeting with Gama Triono (director of PKBI DIY), Dr. Ita Fauzia from Permata Hati Clinic and Linda Bennet (Melbourne university)

### 2.1. Workshop Program

Table 1. workshop program

| Day 1 – 09.00 – 16.00  | Day 2 – 09.00 – 13.00  |
|--|--|
| <ul style="list-style-type: none"><li>• Opening and introduction of participants</li><li>• Infertility as a global issue and Introduction to the Jembatan project</li><li>• Infertility as a public health issue – clinical explanation on fertility</li><li>• Infertility in the Indonesian context 1: Challenges faced by women with fertility problems in health care systems in Indonesia</li><li>• PKBI DIY- who they are and their activities related to SRHR and infertility</li><li>• The Support Group for couple with fertility issues – PejuangTangguh Permata Hati (PTPH)</li><li>• Small group work: Idea generation - issues for couples with Fertility problems in Indonesia and how best to help couples with fertility problems</li></ul> | <ul style="list-style-type: none"><li>• Infertility in the Indonesian context 2: Intervention to address infertility in Lombok</li><li>• Stories about women's different strategies for trying to overcome infertility and live with childlessness</li><li>• Small group work: How to support couples with fertility issues – Using the list of selected activities (from idea generation in Day 1) – small group discussions. The groups are PKBI, PTPH and the core group (PermataHati and Jembatan Project)</li></ul> |

### 2.2. Workshop Participants

The workshop was attended by 27 participants: 22 were women and 5 were men. Four of the men are husbands of the female participants:

- University of Amsterdam : 1 participant
- ResultsinHealth : 2 participants
- PKBI DIY : 12 participants
- Permata Hati Infertility Clinic : 2 participants
- Pejuang Tangguh Permata Hati : 9 participants
- Linda Bennet

### 2.3. Workshop Results

The workshop was opened by Wuri (PKBI DIY), by welcoming the participants, introducing herself and her role in the workshop, and then asking a representative of RiH to lead and continue the agenda of the workshop.



### 2.3.1. Workshop objective 1: The Jembatan project and its Stakeholders

Information on the the Jembatan project can be read in page 4. Stakeholders of the Jembatan project and their role in Workshop 1:

#### 1. ResultsinHealth (RiH)

RiH has been active in the field of International Public Health since 1993, addressing issues related to HIV/Sexual Reproductive Health and Rights (SRHR), Gender, Maternal Neonatal and Child Health (MNCH) and Pharmaceutical Policy at community, regional, national and international levels. Its mission is to improve the health and development of poor and vulnerable populations, and to strengthen their access to essential health care through its innovative advisory and research activities.

In this project the RiH consists of 3 people; Aryanti, Titing and Endang and their roles in this project are:

- Coordinator of project activities;
- Documentation of processes and results of the workshop as well the activities within the Jembatan project.
- Prepare financial and administration report of Jembatan project.

In this first workshop, RiH acted as facilitator and presenter (Aryanti) to introduce the project and project assistant (Endang) to document the process and to develop profile of PTPH. RiH will also preparing the workshop report to be share with all the stakeholders involved.



#### 2. University van Amsterdam (UvA)

The UvA team consists of 3 people (Trudie, Henny and Floor). The role of UvA in this project is as subject matter expert and advisor. Their activities are:

- Developing learning and knowledge exchange and collaboration between PKBI DIY and PTPH.
- Preparing concept and content for each workshop including:
  - ⇒ Identify the approach/method for each workshop
  - ⇒ developing guidance for observation for the project assistant
  - ⇒ support the analysis of the process within the Jembatan project



In this first workshop, the UvA was represented by Trudie Gerrits. She presented the background of this project and the global perspective of infertility.

### 3. PKBI DIY

Established in 1957, the Indonesian Planned Parenthood Association (IPPA or PKBI in Indonesian) is the oldest NGO which leads the family planning movement in Indonesia. The PKBI founders were of prominent community figures and health experts and the organisation originally aimed to address population issues and high maternal mortality in Indonesia.

PKBI has a national office in Jakarta and regional branches in almost every province in Indonesia, including in Jogjakarta. PKBI was established because of strong concerns about the safety of mother and child. The sensitivity and genuine concern of PKBI for women's health issues ultimately inspired people to put family planning in broader perspective into reproductive health. PKBI states that the development of its various programs are based on gender sensitive rights-based approaches and improving the quality of services as well as favouring the poor and marginalized through the slogan "fight for the fulfilment of sexual and reproductive health rights".

PKBI DIY was established in 1967. Initially PKBI DIY was a training centre, but overtime its activities expanded to include: research, community engagement, counselling, and outreach advocacy.

In this project PKBI DIY activities are the following:

- Provide information related to the SRHR
- organize the workshops:
  - preparing the venue
  - invite PKBI DIY staff and member of PTPH support group for the workshops
  - assign note taker for the workshops



In this first workshop, PKBI DIY were represented by Wuri and Gama Triono. Gama presented PKBI DIY's current activity and their view on working with couples with fertility issues.

### 4. *Permata Hati Infertility Clinic* (Permata hati means Jewel of the heart)

Permata Hati infertility clinic (PH) is a health facility which helps married couples with fertility problems. PH is located at and part of the Dr.Sardjito Hospital in Yogyakarta. PH provides a broad spectrum of Assisted Reproductive technologies (ART) for their patients, such as intracytoplasmic sperm injection. The PH is the only government clinic that runs IVF programs. PH Clinic was founded in 1997 and currently has done more than 200 successful IVFs. The success rate of their IVF programs is around 30%. The average age of couples receiving their care is between 30 and 44 years.

The PH clinic is represented by Dr. Ita Fauzia and Nurse Safa; and their role is to act as subject matter experts (SME) in treatment/programme for couples with infertility in Indonesia and supporter of PTPH. Nurse Safa is the contact person for the PTPH support group and the link between PTPH and the PH clinic.

For workshop 1, Dr Ita gave a presentation on the issue of infertility from the clinical and public health perspectives.



##### 5. *Pejuang Tangguh Permata Hati* (Strong warriors of Permata Hati)

The *Pejuang Tangguh Permata Hati* (PTPH) is the name of the support group of patients from the PH Clinic. Members of PTPH are current and those who have ever been patients of PH Clinic. The group has more than 500 members; and they reside in Yogyakarta and elsewhere in Indonesia (East Java, Sumatra, Kalimantan, Sulawesi and Papua). The PTPH group was established as an initiative of several female patients who felt the need for a forum in which they can share their experiences with other (female) patients. The type of information shared is medical related issues, provide emotional support to each other and also practical information (place to stay during treatment etc).

PTPH is a women (wives) only group; if men (husbands) have concerns or questions related to the ART program, they will ask the group through their wives or ask their doctor directly. Most members of this group do not share their problems with their family/extended family; as they think that extended family can be a source of stress. They prefer to share their problems with their husband, close friend or the staffs at the clinic to avoid being scolded or blamed because their inability to have children.



There are currently 2 groups within PTPH, Facebook-based group (semi open, about 545 members) and WhatsApp-based group (closed, need to have a medical record to be a member). For the Facebook group, both men and women can join, while for the WhatsApps group, only women can join.

In this project the PTPH Support Group is the key stakeholders (target group) and their input and needs will largely determine the outcome of the project. In the first workshop the representative of PTPH presented the history of their group and what they have done so far.

6. Linda Bennett (University of Melbourne)

Linda Bennett is a medical anthropologist who has worked on gender, sexuality, and reproductive and sexual health and rights in Indonesia. She is based at the University of Melbourne and had done extensive work in infertility in Indonesia.

In this project Linda shared her knowledge and experience working in Indonesia in the field of SRHR including infertility. Linda have two presentations on the issue of fertility in Indonesia.



2.3.2. Workshop Objective 2: Infertility in the world and in Indonesia

See slides of Trudie Gerrits, Ita Fauzia and Linda Bennet in Annex 1

2.3.3. Workshop Objective 3: Dialogue and Discussion on how to support couples with Infertility

Results of small group discussion (mixed groups) on issues faced by couples with fertility problems in Indonesia and how best to help couples with fertility problems (Day 1):

Table 2. Result of discussion-day 1

|    | Problems/Issues   | Ideas for solutions   |
|----|---|---|
| 1a | Psychological problems – being themselves strong  | Join and get support from the support group and praying (resort to religion)  |
| 1b | Psychological problems – pressure from families and communities – attending neighbourhood meeting                                 | Sensitizing public – radio programme on infertility, “coming out – addressing the issue in the public” – just smile<br><br>Join and get support from the support group and praying<br><br>Collaboration between fertility clinic, Ngo and support group |
| 2a | Limited access to information and services – no standardized information on treatment   |   |
| 2b | Limited access to information and services – not enough information on sperm analysis   | Appropriate and clear information for every step of treatment   |
| 2c | Limited access to updated information and services – very limited information on internet or other channels (GP, obgyn, Midwives) | Dedicated nurse within the infertility programme  |
| 3a | High financial cost for treatment – high taxes on   | Lobby, influencing politician, demonstration  |

|    | Problems/Issues  | Ideas for solutions   |
|----|--|---|
|    | medicine-  |   |
| 3b | High financial cost for treatment – not covered in any insurance or any subsidy                    | Infertility treatment should be covered in insurance – lobby, influencing politician, demonstration                                     |
| 3c | High financial cost for treatment – costs of diagnostic test and expenses                          | There should be more fertility clinic to cut expenses   |
| 3d | High financial cost for treatment – discontinued programme – age and fertility                     | introduction of low cost IVF technology; cutting salaries of providers; individualized treatment (only by experienced health providers) |
| 4  | Unwillingness of husband to engage in programme/treatment – wives have to do everything themselves | Appropriate and clear information form husbands   |
| 5  | Intensity of infertility treatment – length of treatment vs employment                             |   |
| 6  | No appropriate referral system – esp. rural area – delay in starting infertility treatment         | There should be a referral system within the health systems   |
| 7  | Health providers - No standard treatment for infertility   |   |
| 8  | Quality of care – waiting time of patients   | Appointment should be timely attended and Use the waiting time at clinic for patients education   |

Results of small group discussion (in stakeholder groups) on how fertility problems should be addressed (prevention and support) and and in collaboration with whom (Day 2)):

Table 3. Result of discussion-day 2

| Pejuang Tangguh Permata Hati  | PKBI DIY   |
|---|--|
| <b>What would you like to do to prevent infertility?</b>  |  |
| Provision of health education on reproductive health from an early age  | Add issues on protecting fertility for all people (age and status) into the current reproductive health modules of PKBI.   |
| Provision of information on genetic hygiene from early age. Ideally this should start from the family to the community  | Conduct campaign through PKBI's media channels and networks such as radio, newspapers, leaflets, web, social media on protection of fertility.                   |
| Provision of Information on reproductive health within the school curriculum and from early age   | Conduct strategic advocacy on the issue of infertility   |
| Encourage and raise awareness among parents to provide information about reproductive health  | Development of IEC materials related to the infertility issues.  |
| <b>What would you like to do to better support couples living with infertility?</b>   |  |
| Establish an organization to accommodate aspirations of couples living with infertility. If possible to also to provide support in term of cost for treatment | Establish information on Referral system   |
| Advocate to include cost of infertility treatment to be part of health insurance in Indonesia.  | Provision of information (IEC) regarding the issue of fertility for example; when is the woman has their fertile days, how to calculate it, coitus position etc. |
| Facilitate support needed by couples during their infertility treatment such as provision of support from a psychologist and or religious leader              |  |
| Support for male patients   |  |
| <b>How and with whom would you want to collaborate?</b>   |  |
| Conduct hearings with member of legislative body(ies) to advocate easy access, facilities and costs for infertility treatment.                                | Collaborate with PH clinic to do referral for PKBI DIY clients   |
| Conduct dialogues with hospitals that have infertility  | Collaborate with PTPH to introduce PKBI clients for  |

| Pejuang Tangguh Permata Hati   | PKBI DIY  |
|--|---|
| facilities to provide support to patients who seek infertility treatment | support both psychologist and other support needed  |
|  | Collaborate with other stakeholders to educate government to provide support for the IA program or "desire to have children" program. |

#### 2.3.4. The Jembatan Project Core Group

After the 1 workshop, the Jembatan project formed a core group for Jembatan project, consisting of: ResultsinHealth, UvA, representatives PTPH, representatives of PKBI DIY, representatives Permata Hati clinic, Linda Bennet, and WG Infertility. The main task for the core group is to assist and advise in the implementation of the Jembatan project.



The core group met after the workshop and for the next steps, the core group agreed that the following activities should take place between now and the end of September 2018 (before workshop 2):

Table 4; Activities and timeline

|   | Activity   | Who  | In collaboration with | Time period         |
|---|--|------|-----------------------|---------------------|
| 1 | Sensitize PTPH members about the Jembatan Project and results of the first Workshop      | PTPH |                       | August              |
| 2 | Organize meeting between PT PH and PH to establish contact and communication             | PH   | PTPH                  | August              |
| 3 | Sensitize PH staff about PT PH's needs and about Jembatan Project                        | PH   |                       | August              |
| 4 | Integrate a module on infertility in the PKBI's manual on Comprehensive Sexual Education | PKBI | PTPH and PH           | August-September    |
| 5 | Conduct a Radio Programme on infertility (as part of PKBI weekly program)                | PKBI | PTPH and PH           | August-September    |
| 6 | Exploring the possibility for Capacity Building Workshop for PTPH members                | PTPH | PKBI and JP           | September – October |
| 7 | Organise An patients – led Open Forum  | PTPH | PKBI, PH, JP          |                     |

PTPH = PejuangTangguh Permata Hati , PH=PermataHati Infertility Clinic, JP=Jembatan Project

During the Core Group meeting it was suggested that the next meeting can be in the form of Capacity Building Workshop aiming to support PTPH in defining their goals, and strengthening the structure, activities, etc. as an organisation. The suggested timing was early October 2018 and after the previous activities (1-5) have been undertaken (see above).

### 3. Workshop Evaluation

At the end of the workshop, participants were asked to complete an evaluation form. The result of the evaluation is presented below:

Table 5. Evaluation result

| No   | Question   | Score* |    |          |   |         |
|--|--|--------|----|----------|---|---------|
|  |  | 4      | 3  | 2        | 1 | Average |
| 1  | Information on this workshop is adequate and properly clear                                | 9      | 5  |          | 1 | 3.47    |
| 2  | The purpose of the 1st Workshop is clear   | 9      | 5  | 1        | 0 | 3.53    |
| 3  | The presentations of this workshop were useful for me                                      | 8      | 7  | 0        | 0 | 3.53    |
| 4  | The group discussion of this workshop were useful for me                                   | 10     | 4  | 1        | 0 | 3.60    |
| 5  | During the workshop, I feel comfortable and free to ask questions and expressed an opinion | 11     | 4  | 0        | 0 | 3.73    |
|  |  | Yes    | No | Not Sure |   |         |
| 6  | I plan to come to the next workshop  | 14     | 0  | 1        |   |         |
| *Legend:<br>4 = strongly agree; 3 = agree ; 2: neutral; 1 = disagree |  |        |    |          |   |         |

From the workshop evaluation, it can be concluded that most participants are satisfied with the programme, organization and results of workshop 1 and planning to attend workshop 2. Participants were also asked to provide suggestions for the Jembatan project and for the next workshop:

- Provision of material about fertility
- Invite more participants
- Invite government and/or related parties
- Invite more participants from PTPH and give every one of them the opportunity? to share their stories
- More focussed and detailed so that there is a solution that can be realized
- Give up-to-date information on infertility treatment
- Provide materials on fertility protection
- Conduct an early counselling to handle a client with infertility problem
- Ensure a follow-up internally from each stakeholder that will be shared in the next workshop
- Establish target and achievement from each stakeholder on their individual activity and in collaboration with other stakeholders.
- Less food for the workshop