

## **Transdisciplinary Insights 2017**

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### Abstract

Challenge: Blueprint for sustainable electricity supply in Belgium after 2025.

This paper investigates how electricity could best be produced in a sustainable manner in Belgium post-2025, taking into account the planned nuclear power phase-out and the Paris 2015 Climate Agreement. For this purpose, a survey was made of the possible application of different types of renewable energy in Belgium, including hydropower, bioenergy, solar energy, wind energy and geothermal energy.

The resulting plan for the production of electricity in Belgium post-2025 includes a (considered to be realistic) maximum number of renewable energy resources to be used, with natural gas being suggested both to replace nuclear power and to ensure that the demand for electricity can be guaranteed. This scenario, with about 66% of the electricity being generated by CO<sub>2</sub>-emitting fuels, would lead to a significant increase in CO<sub>2</sub> emissions in comparison to the reference situation of 2014. An alternative scenario, in which two of the newest nuclear reactors remain in operation beyond 2025, would suggest about 41% of the electricity being produced using CO<sub>2</sub>-emitting fuels, leading to no net increase in CO<sub>2</sub> emissions with respect to 2014.

Further, it is suggested that the government would invest heavily in the research and development (R&D) of renewable energy sources. A special focus should be on R&D related to renewable energy sources that seem to be promising for Belgium but have not yet been fully explored, such as biofuel cells, third generation biofuels, improved geothermal system energy and tidal energy.

Finally, the electricity plan is complemented with suggestions for the optimization and rationalization of electricity consumption, including the insulation of houses, exchanging light bulbs for LED lamps, smart grid use and the spread of electricity consumption. Accompanying policy measures to achieve this are suggested as well.

### Key words

Electricity, renewable energy, nuclear power plants, Belgium



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## Electricity Production Plan for Belgium post-2025

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### Challenge

**Blueprint for sustainable electricity supply in Belgium after 2025**

### Introduction

In January 2003 the Belgian Senate in a Federal Act approved the ban on new nuclear power plants and decided that the already existing ones should be shut down after 40 years of activity (1). Belgium has two sites with commercial nuclear power plants; the Doel nuclear power station, with four reactors which have been running since 1975 (two reactors), 1982 and 1985, producing a total of 2912 MW (2). The other power station is at Tihange, with three reactors running since 1975, 1982 and 1985 respectively, and together producing 3024 MW (3). Following the Federal Act of January 2003, all seven reactors should be shut down between 2015 and 2025. This Federal Act can be overridden if the *Commission de Régulation de l'Électricité et du Gaz* recommends it in order to avoid a systemic shortage of electricity. This has happened already once (for the two oldest reactors), but all reactors are now planned to be shut down between 2022 and 2025.

We investigate the possibilities for electricity production in Belgium post-2025, when all nuclear reactors will in principle have been shut down. Ideally this new plan will include a maximum of energy sources allowing emissions of CO<sub>2</sub> and greenhouse gases to be kept below the limits agreed in the Kyoto and Paris agreements. Consequently, we focus on the use of renewable, CO<sub>2</sub>-neutral and CO<sub>2</sub>-free energies. We investigate

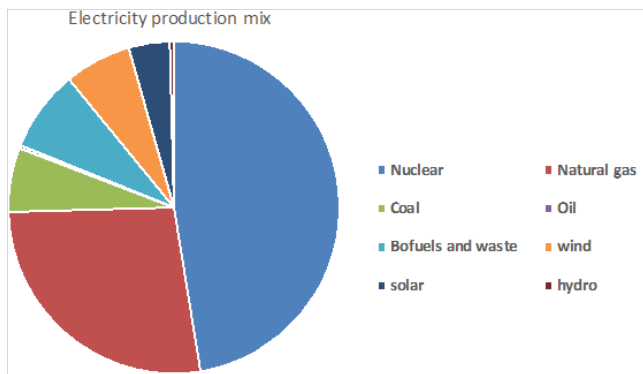


Fig. 1 Belgian electricity production in 2014, according to the latest report of the International Energy Agency (IEA) (4). In May 2016 all coal power plants were closed.

the different types of renewable energies available, and estimate their possible role in electricity production in Belgium. In addition, we also consider possible measures to reduce electricity consumption.

In 2014, nuclear energy accounted for 47.2% of total electricity production (4), 8.16GW. We do not consider an increase in the imports of electricity as this is already close to the limits of the existing connections between the electrical grid and neighboring countries. Our focus is thus on investigating whether the share of renewable energies in the current electricity production mix can be further increased.

### Renewable energies overview – Water-related electricity generation

Water-based renewable electricity sources have been around for centuries. Usually three main sources are considered: hydropower, wave power and tidal power.

Hydropower is one of the oldest forms of renewable energy derived from the potential energy of water. Testimony to this is the large number of water mills decorating the Belgian landscape. It is also the only form of water-based energy currently used in Belgium, and not very large. According to most recent statistics, only 3% of the renewable electricity production in Belgium (and a meagre 0.4% of the total electricity production) is from hydropower (4). The main disadvantage of this method is the requirement of large water bodies and large height differences. However, unlike solar and wind energy, it is a very constant source of energy.

So-called “pumped hydro” is also considered an important means of energy storage and a way to even out the peaks in electricity demand. Here low-cost

energy is used to pump water into a basin, which is subsequently released when demand/costs are high. Such facilities exist already (i.e. at Coo-Trois Ponts, 1164 MW, and at Plate-Taille, 143 MW) and have proven their worth. However, like other hydropower plants, installing such pumped storages requires a large area and specific geography. Nevertheless, pumped hydropower is not intermittent like wind and solar energy, making it a necessary part of a renewable future. Engie-Electrabel has plans for installing a third pumped hydropower unit at Coo-Trois Points, worth another 600 MW.

Wave power is energy derived from the kinetic and potential energy in waves. Harvested by so-called “near-shore” and “off-shore” wave farms, it is not currently used in Belgium. While waves carry great power (on average about 40 kW/m) and have the potential to yield significant amounts of electricity, the Belgian coastline is not very long while several other factors (e.g. shipping routes and eco-systems) also strongly limit wave power’s possible application in Belgium.

Tidal power is energy derived from tidal motions in the sea. While very predictable and strong, several factors limit its possible application in Belgium. A major one is the huge investment cost, which the consumer ultimately pays for. However new technologies and R&D are expected to significantly reduce the price, even down to competitive levels. While not something for the near future (i.e. 2025 to 2030) we consider it worthwhile to invest in this technology, for potential use from e.g. 2050 on.

### Renewable energies overview – Bioenergy

Bioenergy refers to the energy derived from the conversion of any form of biomass. In Belgium in 2014, biomass represented about 80% of the energy production from renewable energies (4) (roughly 5% of the total energy production). Bioenergy is traditionally obtained by burning biomass. Its main advantages are the ease of use and the fact that it can be used in combination with other ‘fuels’ in heat power plants leading to low investment costs. In terms of carbon footprint, bioenergy is often considered to be CO<sub>2</sub> neutral as the CO<sub>2</sub> released during the combustion of the different energy sources was previously stored in the object. However, it is sustainable only when the biomass or organic waste (9) is produced ‘locally’ and does not have to be transported over long distances,

while in its simplest mode of consumption, i.e. as source of energy, it is also quite inefficient (5).

Bioenergy can also be obtained from biofuel (i.e. biodiesel or bioethanol), making it a good possibility as a substitute for normal fuels. Biofuels can easily be stored and transported and can also be used in normal heat power plants. Nevertheless, first generation biofuels bring with them the problem of food versus fuel (6,7). Second and third generation biofuels avoid this problem but are not yet fully developed, while, in addition, their cost-efficiency is still low (8).

The main factors to be considered in estimating the potential of biomass are land availability and population distribution (10). Belgium is a small and densely populated country, and hence the biomass demand exceeds the production potential (11). Additionally, only first-generation biofuels and traditional biomass uses are cost-effective and competitive with fossil fuels (7). Consequently, we believe that biomass and bio-energies cannot yet be included in the electricity production plan post-2025. However, it will be an important player in the plan for the farther future if further technological developments are achieved. Hence we greatly recommend government support and investment for R&D in bio-electricity and bio-energies. More efficient second and third generation biofuels could certainly advance the advent of these new technologies.

### **Renewable energies overview – Solar energy**

The Sun is a very large source of renewable and sustainable energy. Using photovoltaic (PV) cells this energy can be captured and converted into an electric current (12). The efficiency (yield) of PV cells has been improved over the years, currently reaching about 20% (13). As Belgium does not have the space available to build large-area solar power plants, the inhabitants can play a crucial role. In 2008 Belgium had 4,822,301 households, which in theory could provide 30% of Belgium's electricity needs using solar panels (14,15). We are convinced that persuading the population to purchase solar panels is essential in view of even only a partial phase-out of nuclear energy by 2025.

The use of PV cells on a large scale would save society money, and even allows some profit to be earned over time. We believe the population is held back because of several thresholds, such as the still substantial costs, but also because the appearance of the classic 'board-type' solar panels is not very appealing. However, for

the latter, alternatives are now available. An important downside of solar panels is the production process, which is not sustainable at all, underlining the need for a good and efficient recycling system.

By 2025, solar electricity production could be increased to up to 10% above the national requirement. However, in order to stimulate the population to act, dedicated policies and subsidies have to be put in place. Thus, e.g. the threshold of the initial costs has to be lowered, and extra benefits should be offered for sustainability-minded people.

### **Renewable energies overview – Geothermal energy**

Geothermal energy is the energy that is stored below ground in the form of heat generated by the earth (16). It can be used both for heating purposes and electricity generation. The latter application requires temperatures above 100°C (16–19). In areas with lower temperatures at shallow depth, geothermal electricity can still be generated (next to heat) in so-called binary power plants by drilling into a reservoir at larger depths (i.e. 3 to 5 km) (18, 19). In such binary plants the geothermal heat from the reservoir is used to vaporize organic fluids with a boiling point lower than water. This vapor then passes over a turbine to generate electricity (19–22). In regions where no hydrothermal reservoirs can be found in the underground, an improved geothermal system (EGS) can be installed, whereby reservoirs are artificially created through fracking (19, 23). This technique is still in a development phase but has already proven to be a successful alternative for classical hydrothermal systems.

Geothermal energy has major advantages compared to other renewable types of energy. It is one of the most environmentally friendly energy types (20) and, in contrast to solar or wind energy, it is a non-intermittent form of energy, independent of the weather conditions (16, 20, 23). This makes it very appropriate to deliver base load electricity/heat (20, 23). The major disadvantage of geothermal energy is the need for high investment costs causing financial risks related to the explorational drillings (19, 23).

In Belgium, geothermal energy currently has a negligibly small part of the total share of renewables (4). However, very recently experts from the Flemish Institute for Technological Research (VITO) have found that geothermal energy may become an important



future source for sustainable heat and electricity production in the region of north-eastern Flanders (18, 23). In the Campines ("Kempen") region (in the provinces of Antwerp and Limburg), a large hydrothermal underground reservoir was found with temperatures suitable for generating electricity. Initially, one pilot geothermal binary plant will be set up in Mol. Plans exist in a later phase to build many (up to 80) geothermal plants within the region so as to provide an entire region with heat and electricity. Experts estimate that in the long run (years 2030 to 2040) up to 0.5 GW of electricity (and 1 GW thermal power) could possibly be produced. In the very long run (2050) a further development of EGS is expected, whereby geothermal energy could also be produced elsewhere in Belgium, with thus a further increase in capacity for electricity production. These developments would help Belgium to reach its sustainability goals (23).

## **Renewable energies overview – Wind energy**

Wind is an important and booming renewable source of CO<sub>2</sub> emission-free energy. Wind turbines use the kinetic energy of wind to generate electricity. Wind power is proportional to the third power of the wind speed, so higher wind speeds result in significantly more electricity being produced. However, wind turbines only produce useful power in wind velocities ranging from 2-5 m/s up to 25-30 m/s (24,25). Further, in Belgium on-shore wind turbines have a total efficiency of only about 15%, while off-shore turbines are somewhat better with an efficiency of about 30%. Nevertheless, wind turbines can provide a significant proportion of Belgium's electricity needs.

Currently the government is making significant efforts to generate more energy using wind turbines. Over the last 5 years large investments/subventions have gone into the construction of wind turbines, both onshore and offshore. At the end of 2016 a total of 408 active wind turbines were providing 870 MWe. The government is trying to realize the "Windkracht 2020" wind pact (cabinet of Minister B. Tommelein, private communication, 2017), a plan to get an additional 1.563 GWh out of wind (by installing 280 onshore wind turbines) by 2020.

Wind energy is a clean source of energy, consumes no water, and requires only relatively small areas of land. We believe that its advantages with respect to different aspects of sustainability (i.e. ecological, economic and social) are much more important than the disadvantages.

One of the main issues in order to realize "Windkracht 2020" is radar interference. Discussions with airline companies and investing in new technology to minimize radar interference will be crucial in this. It is our conviction that wind energy still has great potential in this country and Belgian governments should make significant efforts to produce a maximal amount of electricity using wind turbines.

## **Optimization and rationalization of electricity consumption**

Another central part of this project is the optimization and rationalization of the consumption of electricity. The more electricity can be saved the less electricity has to be produced, resulting in positive effects at both economic and environmental levels. We propose here several practices that will help to reduce electricity consumption, and we will formulate suggestions for the regulatory framework to ensure this can be achieved. Our final electricity production plan will take into account the reduction that would occur if these proposed strategies were implemented.

### ***Optimization of the insulation of houses and EPC indices***

Energy Performance Certificates, or EPCs, are granted to given houses or apartments based on their energy consumption in terms of efficiency and insulation.

To reduce energy and electricity consumption we suggest establishing a limit of E index for all rental houses from the year 2025 on. Approximately 25% of all houses and apartments in Belgium are under a rental regime (based on the numbers and figures of Eurostat (26)). If the E EPC index goal is attained by 2025 the amount of electricity we estimate would be saved by this is about 5 % of the current consumption.

### ***Other possible measures***

In addition, we propose a series of good practices for reducing the consumption of electricity. As the precise effect of these is difficult to estimate we will not include them in our final electricity plan, but still advocate that they be followed/implemented. These are:

- Light bulb change: LED and CFL light bulbs have an electricity consumption respectively 6 and 4

times lower than the traditional incandescent light bulbs.

- Smart grid and consumption spreading: one of the main problems of electricity consumption is that it is not homogenous, but rather concentrated around certain hours of the day. The timeframe in which people arrive at home after work and start consuming electricity represents a peak of electricity consumption that the grid needs to deal with. To avoid shortcomings, it is thus necessary during the day to produce more electricity than is needed and to store the extra amount in order to be able to cope with the increased demand in the evening. We suggest the use of local batteries for electricity storage, either at home or on a larger scale for neighborhoods or small communities.

## Policy plan

In order to achieve the above insulation plan for houses and the already mentioned possible increase in solar power up to about 10 % of total electricity production, we have thought of a set of policies and suggestions:

- *Solar energy favoring policies:* we believe the cost of solar panel installation is one of the main causes stopping people from installing them. To circumvent this problem, we suggest a subsidy plan with an energy payback fee. Specifically, 50% of the cost of solar panels would be paid by the government and afterwards energy generated from those solar panels would be drawn back into the grid and sold (at a fixed price to avoid under-pricing) by the government to the electric companies until 40% of the investment was repaid. This payback period should be limited in time to half the lifetime of the solar panels to make installation profitable for owners.
- *Insulation plan:* In a similar way, to help rental house owners to undertake the required renovations we suggest a segmented subsidy plan by which renovation investments would be partially funded by the government (2500-7500 € → 25% funded, 7500-15000 € → 50% funded, 15000-30000 € → 70% funded). A 70% insulation improvement can be achieved with an investment of around 30,000 euros (36), so all the insulation requirements would be fulfilled with investments included in this subsidy plan.
- *Disfavouring fossil fuels:* We suggest that a CO<sub>2</sub>-emission tax be installed on energy produced from

fossil fuels and that the money from these taxes be used to reduce the price of the electricity from renewable sources.

## Final electricity production plan

Based on the data gathered and investigations and calculations we have developed two different electricity production plans for Belgium post-2025. The first, implying a full nuclear phase-out, is based on the redirection of the energy resources saved from house insulation into electricity production, the increased use of renewable energies and the increased use of natural gas to fulfil the total demand. The second avoids the additional use of natural gas, causing increased CO<sub>2</sub> emissions, by a continued use of part of the available nuclear power despite the possible social outcry this may cause.

### Plan 1 – Nuclear phase-out

In this case all nuclear power has to be replaced by power from other sources, preferably renewable ones. Anticipating that the supporting measures we suggested would have the desired effect we anticipate that by 2015 about 1 GW of solar energy could be available. Solar energy would then meet about 13% of the total demand for electricity. Further, it seems reasonable to suppose that an additional 1 GW of wind energy could also be made available, covering in total 20% of the needs. About 8.5% would come from biofuels and waste. The rest of the electricity required to replace all nuclear power would then be generated using gas. Also the available capacity for producing (with gas) the 5% of electricity that will be saved for heating of buildings due to improved insulation can be part of this. Being an ambitious plan, in this scenario about 33% of the electricity would then be from renewables (wind, solar, hydro; Figure 2). However, due to the increased amount of natural gas to be used, the CO<sub>2</sub> emissions for electricity production would in this plan increase by as much as about 70% (i.e. about 12.5 Mtoe) compared to the reference year 2014 (Fig. 1). This plan is therefore not in line with the Paris 2015 Climate Agreement.

### Plan 2 – Partial nuclear phase-out

In this scenario (Figure 3) we assume the same amounts of wind-, solar-, hydro- and bio-energy as in plan 1. The rest would this time not all come from gas, but from the two newest nuclear reactors at the Tihange nuclear



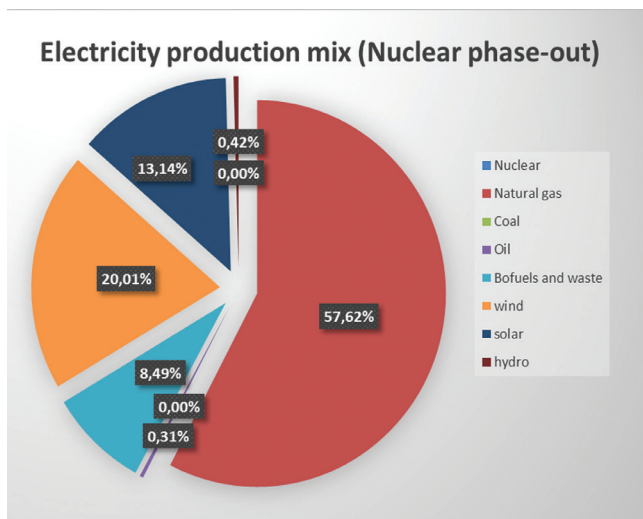


Figure 2: Electricity production mix for a full nuclear phase-out, the 0% corresponds to coal and nuclear energy.

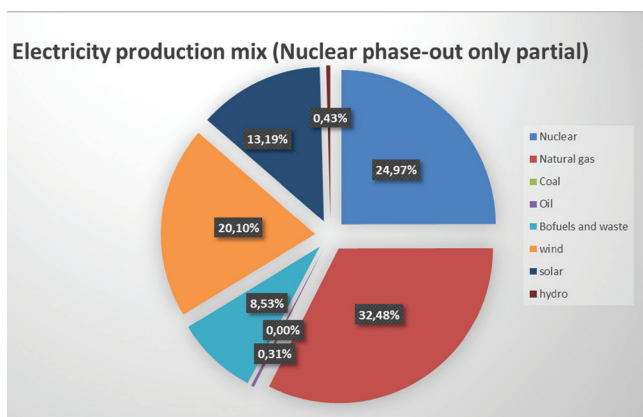


Figure 3: Electricity production mix for a partial nuclear phase-out, the 0% corresponds to coal.

power plant. Tihange 2 and 3, with a total power of slightly over 2 GW, corresponding to about 25% of the electricity mix, would now be kept in operation. This of course requires the necessary maintenance and/or improvement works as well as safety checks. In this way the CO<sub>2</sub> emissions for electricity production would remain about the same as in the reference year 2014 (Fig. 1). We believe that pointing out the benefits of the prolonged use of nuclear power in terms of electricity generation and CO<sub>2</sub> emissions suffices to persuade the majority of the population to accept this.

## Outlook

### Research and development (R&D)

We believe the above two plans are to be seen as intermediate solutions only and that more R&D should

be performed so as to further increase the amount of renewable energy in the electricity production mix. Sources such as geothermal energy, tidal energy, 3<sup>rd</sup> generation (algae-based) biofuels and biofuel cells could all contribute significantly to the Belgian electricity mix by e.g. 2050, provided the government supports the required R&D as well as the initial implementation. This support could e.g. consist in a tax reduction for the company based on the electricity commercialized from a new technology developed by that company and which could be proven to be efficient, renewable and sustainable.

### Possible baseload problem

With the largest part of the renewable energy in both plans coming from wind and solar energy, two intermittent energy sources, one could be facing a problem of baseload availability. We see two options to cope with this:

1. Continue maintaining several natural gas plants and keep these on 'standby' to be used as back-up when needed (depending on the weather conditions).
2. Overcome the problem by incorporating different types of renewables energies and combining them with the use of batteries and/or additional pumped hydropower plants for electricity storage. Thus, none of the available energies would account for a larger part of the share and decreases in its production could then rather easily be compensated for with other sources or by drawing energy from batteries or hydropower stations. We suggest the local and regional (Brussels, Flanders and Wallonia) governments invest in these smart-grid and large electricity storing facilities.

### Personal view

We believe that option 2 (partial nuclear-phase out) is the better and also the more sustainable of the two plans suggested. We believe that, instead of building new natural gas plants, as required for option 1, it would be better to continue using part of the available nuclear power which, contrary to natural gas, represents a CO<sub>2</sub>-neutral source of electricity, and use the resources that would be required to build the gas

power plants for option 1 rather for funding further research and development on renewables energies. We believe that too strong a focus on trying to achieve the nuclear phase-out may turn out to be the least sustainable option. If the government were nevertheless to decide to stick to the nuclear phase-out, additional natural gas power plants would be built to ensure electricity supply. These could at a later time be used as a back-up source as soon as a much higher share of the electricity can be provided by intermittent renewable energies. Still later, when they were no longer required, these natural gas plants could gradually be phased out so as to reduce CO<sub>2</sub> emissions.

As regards the current government policy towards more sustainable energy, which is mostly concerned with investing in small projects here and there (mainly wind and biomass, with almost no support to solar energy anymore), we believe the current policies are not ambitious enough, i.e. more could be done and at a faster pace, with clear supporting measures (see our non-exhaustive suggestions above).

Finally, as we feel the responsibility for energy production in Belgium is much too fragmented we plead for a strong collaborative effort of all parties involved. The same holds for the European level, where a strong common policy on energy at present does not exist. Belgium cannot be self-sufficient when it comes to renewable energy. But the geographical differences between the countries in Europe could be put to good use. For example, windmills could produce electricity for export in e.g. Great Britain, Denmark, and Germany, and solar energy farms in the southern EU countries. Combined with a significant extension of the power lines connecting the different EU countries, this could significantly increase the share of renewable electricity throughout the European Union. To combat climate change and promote sustainable development, one needs to look at the bigger picture, and we suggest the governments do the same.

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## **Exploring the value and acceptability of peer support in the process of improving adherence to HIV antiretroviral drugs in Tanzania, Dar-es-Salaam**

**Joram Dehens, Maud de Hemptinne, Michaël Galouchka, Abdus Sajud, Reinier Petrus van Otzel, Cedric Vanhoorebeeck, Małgorzata Wyszowska, Fausta Mosha, Raphael Zozimus Sangeda, Edwin J Bernard, Marc Thompson, Anneleen Kiekens, Saar Baert, Jorge Ricardo Nova Blanco, Michael R Jordan, Anne-Mieke Vandamme**

### **Abstract**

Challenge: A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa.

This transdisciplinary team focused on the problem of continuously rising levels of HIV drug resistance in Africa that as a result can lead to increased rates of mortality and morbidity. The main source of the HIV drug resistance problem is believed to be insufficient adherence to therapy. The challenge submitter suggested to explore whether improving the relationship between patient and health-care provider would be the next best step to improve adherence. However, after gathering knowledge from different sources, it was found that the burden on local doctors was already very high and would only increase in the coming years. A better relationship with the patient would be an extra burden on the time of health personnel. Instead, the team researched the feasibility of implementing peer support groups in Dar Es Salaam, Tanzania, as a possible way to increase patient adherence. With the creation of a questionnaire, a first step was taken in researching the value and acceptability of peer support groups in combating problems with adherence in regions where time constraints on skilled health workers limit possible interventions.

### **Key words**

HIV, peer support, adherence, drug resistance, transdisciplinary tools



## **Exploring the value and acceptability of peer support in the process of improving adherence to HIV antiretroviral drugs in Tanzania, Dar-es-Salaam**

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### **Key words**

HIV, peer support, adherence, drug resistance, transdisciplinary tools





## Exploring the value and acceptability of peer support in the process of improving adherence to HIV antiretroviral drugs in Tanzania, Dar-es-Salaam

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### Challenge

**A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa**

**Background:** This transdisciplinary team focused on a challenge provided by Dr. MPH. Michael R. Jordan: "A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa" (Suppl. 1). The problem concerns continuously rising levels of HIV drug resistance (HIVDR) in Africa that as a result can lead to increased rates of mortality and morbidity. The main source of the HIV drug resistance problem is believed to be insufficient adherence to

therapy. Some studies indicate that suboptimal adherence to antiretroviral therapy (ART) might be caused, in part, by a poor relationship between patient and health-care provider, and it was suggested to explore ways to improve this relationship.

The group initially consisted of seven Master's degree students at KU Leuven – University of Leuven (shared first author of this abstract), led by Prof. Anne-Mieke Vandamme.

**Methods:** The development of the methodology is described in a separate abstract (this issue). Transdisciplinary research tools, such as an Actor Constellation and a Three Types of Knowledge exercise ([www.transdisciplinarity.ch/toolbox](http://www.transdisciplinarity.ch/toolbox)), were leveraged to encourage transdisciplinary thinking within the initial group, and to identify missing experts and stakeholders. As a result, the initial group sought support among non-governmental organizations (NGOs) and reached out to experts on the subject, in order to form a transdisciplinary team. The final transdisciplinary team consisted of the following experts and stakeholders, in addition to the initial group. Biomedical support came from Dr. Jordan, Dr. Mosha, Dr Sangeda and Dr De Oliveira. NGO support came from Mrs Baert, Mr. Bernard and Mr. Thompson, who each work for a different NGO familiar with the topic. Support in the organization came from Mrs. Kiekens and Mr. Nova Blanco.

**Results:** The initial group began with fact-checking the assumptions stated in the challenge description and reformulated the challenge to include their insights into the assumptions based on literature searches (Suppl. 2). The purpose of the re-formulation was to clarify the goal of the challenge. The assumptions were found to be valid, and it was decided to follow the suggestion of the challenge submitter and focus on the patient-provider relationship. Following the transdisciplinary exercises, additional actors were added to the team, and knowledge was gathered. Most knowledge on the current situation was obtained through video conference calls with local experts and information sourced from the World Health Organization (WHO) and government agencies, in addition to reviewing the literature. However, after gathering knowledge from the supporting team and different sources, it was decided that intervention in the patient-provider relationship was not the best next step to increase adherence to antiretroviral drugs (ARVs) because the burden on local doctors was already very high and would only

increase in the coming years. A better relationship with the patient would be an extra burden on the time of health personnel.

Instead, the team researched the feasibility of implementing peer support groups in Dar Es Salaam, Tanzania, as a possible way to increase patient adherence. This would circumvent the time constraints on doctors and take cues from other regions where these groups showed promising results. A questionnaire targeting HIV patients in Dar Es Salaam was created with the experts with the purpose of gaining practical knowledge on the perceived value and acceptability of peer support groups in Dar Es Salaam (Suppl. 3 and 4). The supporting team suggested a similar questionnaire also for the doctors treating these HIV patients (Suppl. 5). Answers to these questionnaires are currently being collected under ethical clearance number NIMR/HQ/R.8a/Vol.IX/2228.

To visualize the steps taken to achieve the goal and to publish the output of this project, the team created infographics and started a blog, serving as a guide for future transdisciplinary teams. The transdisciplinary procedure, illustrated with these infographics, was written down as a separate abstract (Dehens et al, this issue). The “*Ten Reflective Steps*” approach was applied to the project retrospectively (suppl 6). This can be used as a guidance tool for further transdisciplinary research around this challenge.

**Conclusion:** With the creation of the questionnaire, a first step was taken in researching the value and acceptability of peer support groups in combating problems with adherence in regions where time constraints on skilled health workers limit possible interventions. The results of the questionnaire will suggest the desirability and feasibility of setting up peer support groups. As this team was a pilot group, a new team will continue this challenge in the next academic year to build on the insights described here. We suggest that they use the blog to update the progress of the project.

#### Supplementary materials:

1. The original challenge document
2. The amended challenge document
3. Questionnaire for patients (Swahili)
4. Questionnaire for patients (English)
5. Questionnaire for doctors (English)
6. Ten reflective steps applied to the challenge

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Honors Program at the KU Leuven – University of Leuven: building a team, developing and improving a transdisciplinary project through addressing a challenge on HIV drug resistance in Africa. *Transdisciplinary Insights* 1, 33-39. <https://doi.org/10.11116/TDI2017.1.3>.

## BANK OF TRANSDISCIPLINARY CHALLENGES

### PROGRAMME: HONOURS PROGRAMME TRANSDISCIPLINARY INSIGHTS (LEUVEN)

#### SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Welcome to the Bank of Transdisciplinary Challenges! ([Web form](#))

#### SECTION 2 OF 5 – CHALLENGE SUBMITTER (GENERAL INFORMATION)

##### **Michael R. Jordan MD MPH.**

Assistant Professor of Medicine, Assistant Professor of Public Health and Community Medicine, Geographic Medicine and Infectious Disease, Tufts Medical Center, 800 Washington Street Box 41 Boston, MA 02111

Affiliation: Academia as a Researcher

#### SECTION 3 OF 5 – ABOUT THE CHALLENGE-

##### **NAME OF THE CHALLENGE**

##### **A WAY TO UNDERSTAND AND INSTRUCT ON BEST PRACTICES FOR DELIVERING AND ACCEPTING HIV DRUG TREATMENTS IN AFRICA**

**Could you please state a specific challenge, problem or question?** If you have more than one challenge, please submit each challenge separately. Please be aware that if the same or a very similar challenge is submitted by multiple actors, we will pool this into a single challenge, and as a result, the challenge might diverge slightly from what you submitted.

As of 2016, 18 million people are receiving antiretroviral therapy (ART) for the treatment of HIV infection. Some level of HIV drug resistance (HIVDR) is inevitable and expected to emerge and be transmitted in populations infected with HIV and receiving ART. However, recent data suggest an increase in levels of HIVDR to a point that there may be increased mortality and or morbidity. Levels of HIVDR in Africa, the continent most heavily affected by HIV, may be elevated due to drug stock outs, difficulty in patient adherence to ART and difficulty in programs in retaining them.

In WHO's 2016 global based on data from 59 countries from more than 12 000 clinics from cohorts of patients receiving ART between 2004 and 2014, high levels of appropriate antiretroviral (ARV) drug prescribing were observed, with over 99% of people prescribed regimens according to national or international HIV treatment guidelines. Global levels of loss to follow-up (LTFU) (unknown outcome) at 12 months during the same period averaged 20%, exceeding the WHO-recommended target of 15%.

Moreover, global levels of LTFU among clinics reporting data increased significantly over time, from 11.9% in 2004 to 24.5% in 2012 (11.9% in 2004 to 24.5% in 2012 ( $p < 0.001$ )). Globally, retention on ART at 12 months averaged only 73.5% amongst clinics reporting data, falling short of the WHO-recommended target of 85% or above. Estimates of retention varied considerably across regions. Adherence, as estimated by on-time pill pick-up and on-time appointment keeping, fell below global targets. On-time pill pick-up was a strong predictor of clinic-level viral load suppression ( $p < 0.001$ ) suggesting that identifying clinics with less-than-desirable pill pick-up, then targeting their patient

populations for adherence interventions, may lead to improvements in overall population-level outcomes. Amongst 1150 clinics monitoring drug stock outs, 35.7% had at least one drug stock out of routinely dispensed ARV drugs during their respective reporting year, thus failing to attain the WHO-recommended target of no ARV drug stock outs.

WHO worries that no matter how good the drugs may be, the infrastructure built over the last decade will be pushed even further when more people are initiated on ART in the face of dwindling resources. Moreover, increasing HIVDR in Africa may jeopardize HIV treatment in other parts of the world.

Strong doctor-patient or health care provider-patient relationships are vital to sustaining millions of patients on ART in resource limited countries (RLS). However, some recent evidence suggests that interactions between health care providers and patients may be strengthened by making it more of a partnership and less paternalistic. For example, in Malawi, 14% of traced patients who had disengaged from care and stopped ART reported that they feared being scolded for having interrupted care if they returned to clinic. 5% felt they were better and did not need care, 9% had work obligations, 2% felt the medicine was not helpful, 9% had side effects (Ministry of Health Malawi/WHO unpublished data). Strengthening of the provider-patient relationship elimination of paternalistic behaviors on the part of health care providers may help to minimize these and other causes of disengagement from care.

**Would you like to add some objectives to that challenge?** For example, can you imagine how you want the future to be with regard to this specific challenge. Is there any specific result that you want the research group to reach?

The research group is asked to identify the best next steps to strengthen provider-patient relationships in ART clinics in Africa. The group will conduct case studies in Windhoek, Namibia and in Durban South Africa, with local people to characterize provider-patient relationships and identify ways to improve them. Through a series of case studies and conversations with patients, doctors, nurses, health care providers, general public and community members, the group should suggest steps that can be taken to improve the provider-patient relationship.

**Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?**

WHO has drafted a 2017-2021 action plan to reduce HIV drug resistance in developing countries, outlining a collective strategy, including surveillance activities, service delivery interventions, diagnostic strengthening, and enabling mechanisms. These cover several disciplines in various domains of science.

This action plan outlines the problems, the goals and the possible steps to take. However, this action plan is not detailed with regard to specific local situations that can vary wildly. It stresses global efforts and working along with local authorities and communities. The action plan describes local enabling mechanisms, but it would be interesting to see these mapped for a particular case study, and whether what WHO described is possible and sufficient for that particular case study.

**Transdisciplinary context: Could you indicate from which disciplines you want a researcher to address this challenge, you need to pick at least one of each domain.**

**Domain of Humanities and Social Sciences:**

- Arts
- Canon Law
- Economics and Business
- Law



- Philosophy
- Psychology and Educational Sciences
- Social Sciences
- Theology and Religious Studies
- Other: \_\_\_\_\_

**Domain of Science, Engineering and Technology:**

- Architecture
- Bioscience Engineering
- Engineering Science
- Engineering Technology
- Sciences
- Other: \_\_\_\_\_

**Domain of Biomedicine:**

- Kinesiology and Rehabilitation Sciences
- Medicine
- Pharmaceutical Sciences
- Other: \_\_\_\_\_

**SECTION 4 OF 5 – SUPPORT, PARTNERS & SHARING-**

**How would you like to support that challenge?**

- As a mentor, guiding one student in your specific discipline
- As an external expert in one of the fields
- Financially
- As a research coach, guiding a team around a specific challenge
- Providing research facilities, equipment, samples, supplies, material...
- Through taking part in the research discussion
- Other:

**Possible partners, experts and/or other stakeholders to involve in this challenge discussion.** If you want your challenge to be dealt with not only by a transdisciplinary research group but also by stakeholders, could you please suggest stakeholders' name(s) to get involved in this research and if you have them, some contact details of each one?

The Africa Centre for Population Health Studies and the Centre for the AIDS Programme of Research in South Africa (CAPRISA), with Tulio de Oliveira and Salim Karim, Durban, Kwazulu Natal, South Africa. Steven Hong, Tufts University School of Medicine, Boston USA and Windhoek Namibia.

**How can we introduce your challenge to other stakeholders?**

- By using your name
- By using your name and your affiliation
- By using only your affiliation
- Anonymously
- Other:

**SECTION 5 OF 5 – THANK YOU FOR YOUR SUBMISSION AND SUPPORT.**

## BANK OF TRANSDISCIPLINARY CHALLENGES

### INCLUDING AMMENDMENTS ON THE ASSUMPTIONS

#### SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

20<sup>th</sup> March 2017

##### NAME OF THE CHALLENGE

**A WAY TO UNDERSTAND AND INSTRUCT ON BEST PRACTICES FOR DELIVERING AND ACCEPTING HIV DRUG TREATMENTS IN AFRICA**

#### Could you please state a specific challenge, problem or question?

This challenge focuses on HIV drug treatment in Africa. As of 2016, 18 million people were receiving antiretroviral therapy (ART) for the treatment of HIV infection. Some level of HIV drug resistance (HIVDR) is inevitable and expected to emerge and be transmitted in populations infected with HIV and receiving ART. However, recent data suggest an increase in levels of HIVDR to a point that there may be increased mortality and or morbidity. In Africa, the continent most heavily affected by HIV, levels of HIVDR are elevated due to insufficient levels of adherence to therapy. This may be in part due to drug stock outs; difficulty in programs in retaining the patients; problems in communication due to low quality of patient-provider relationship, low number of providers, amongst other reasons. In recent documentation, WHO states that increasing HIVDR in Africa may jeopardize HIV treatment in other parts of the world.

Data show that though African HIV patients are medicated according to accepted guidelines, many still do not follow their therapy plan correctly. In WHO's 2016 draft global action plan available at the time of writing (final document: <http://www.who.int/hiv/drugresistance/hivdr-action-plan-2017-2021/en/>), based on data from cohorts receiving ART between 2004 and 2014 in 59 countries and 12 000 clinics, high levels of appropriate antiretroviral (ARV) drug prescriptions were given (<http://www.who.int/hiv/pub/drugresistance/ewi-hivdr-2016/en/>). Over 99% of prescriptions were according to national or international HIV treatment guidelines. Global levels of loss to follow-up (LTFU) at 12 months during the same period averaged 20%, exceeding the WHO-recommended target of 15%. Moreover, global levels of LTFU increased significantly over time, from 11.9% in 2004 to 24.5% in 2012 ( $p < 0.001$ ). Globally, retention on ART at 12 months averaged only 73.5% amongst clinics, falling short of the WHO-recommended target of 85% or above. Estimates of retention varied considerably across regions. This suggests that the number of people not taking their prescribed drugs on a regular basis is on the rise.

Such evidence of poor adherence to therapy as described above is indeed a notable factor associated with the emergence of drug-resistant HIV. Notably, resistant strains of HIV are selected for when the viral load stays above  $>50$  copies/ml when at the same time there is sufficient ARV drug present in the blood [1]. This means that no resistance develops in individuals whom either have very poor adherence or have excellent adherence ( $\geq 95\%$ ) [2]. Also of note is the finding that the adherence-resistance-development curve is bell-shaped [2], with peak selection for resistance between 70%-89% adherence rates for NNRTI-based ART [3]. In spite of that, average adherence rates of only 70% are reported [1]. The rate of development of drug resistant virus through suboptimal adherence has been shown to be different for each class of drugs [4]. These findings suggest the need to aim for nothing less than excellent adherence.

Strong health care provider-patient relationships are vital to sustaining millions of patients on ART in resource limited countries (RLS). Trust and a therapeutic relationship between patient and physician remain central in the ART initiation process [5]. A study conducted in China reveals that a good patient-provider relationship positively impacted

patients and their ability to maintain their health, especially when they were isolated from other sources of support due to intense AIDS stigma [6]. The AIDS Treatment for Life International Survey suggests that there is a critical need to improve patient-provider communication about the importance of ART adherence and its benefits for patient's health [7]. Additional research shows that a poor relationship between patient and health care provider is associated with low adherence [8-10]. Furthermore, it has been shown that the patient-provider relationship can lose a level of trust and transparency if the provider exhibits overly paternalistic behaviours toward the patient [11]. For example, in Malawi 14% of traced patients who had disengaged from care and stopped ART reported that they feared being scolded for having interrupted their care (Ministry of Health Malawi/WHO unpublished data).

Recent evidence suggests that interactions between health care providers and patients may benefit more from using patient-centered healthcare rather than more paternalistic approaches to healthcare [12-15]. It has been found that paternalistic behaviours obstruct clear communication between the patient and health care provider. This leads to disengagement from care and may influence patients' decisions because of stigma related to HIV testing. Patient-centred efforts may help to minimize some of the causes of disengagement from care. However, it is worth noting that sometimes paternalistic behaviours can be productive. For instance, paternalism could cause health care providers to omit offering patients the opportunity to decline the opt-out HIV test.

There is a wide range of documentation on how a functional and strong patient-provider relationship can improve patient outcomes [16-21]. However, there is far less information on practical ways to actually improve the relationship. There are no usable case-studies on how such methods have been put into practice and the results found from such initiatives. One trend that does seem apparent among policy researchers is to give practitioners more time with patients by cutting time spent on other duties. The South African organisation Right to Care is a good example of this policy. Their mobile app, the Medication Adherence App, is one way that reminders can be set for patients without secretarial staff having to spend time on this themselves. So these schemes create time for improving the patient-provider relationship, but are not directly related to the improvement of such relationships. The challenge is to find ways to directly improve the patient-provider relationship.

### **Would you like to add some objectives to that challenge?**

The research group is asked to identify the best next steps to strengthen provider-patient relationships in ART clinics in Africa. The group will conduct case studies in Windhoek Namibia, Durban South Africa, Dar es Salaam Tanzania, with local people to characterize provider-patient relationships and identify ways to improve them. Through a series of case studies and conversations with patients, doctors, nurses, health care providers, general public and community members, the group should suggest steps that can be taken to improve the provider-patient relationship.

The way to progress from here would be to find think-tanks that research in the medical field and see if these organisations have created such case-studies, or even have reports on ways to improve the patient-provider relationship, especially in the context of HIV in Africa. One suggestion for the group project would be the organisation of such a case-study. This would entail finding methods to implement, linking with a partner clinic, and then having an experimental phase to test the methods in question. Another option would be to compile ways in which the patient-provider relationship could be improved. It may be that there is more on this in western countries, so the challenge would be to see how it may fit into the African context.

Ultimately, case-studies will no doubt be helpful in seeking to find new and innovative ways to improve the patient-provider relationship. Either there are some available, which would require more search time and questioning policy researchers and such, or the project could create one and thus provide a useful resource for health practitioners.

### **Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?**

WHO has drafted a 2017-2021 action plan to reduce HIV drug resistance in developing countries, outlining a collective strategy, including surveillance activities, service delivery interventions, diagnostic strengthening, and enabling

mechanisms. These cover several disciplines in various domains of science. This action plan outlines the problems, the goals and the possible steps to take. However, this action plan is not detailed with regard to specific local situations that can vary widely. Though the WHO action plan describes local enabling mechanisms, it would be interesting to see these mapped for a particular case study, and whether what WHO described is possible and sufficient for that particular case study. For this purpose, the transdisciplinary research team could make a significant contribution.

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## Dodosa juu ya 'wagonjwa wanaosaidiana' (Kiswahili)

Msaili: \_\_\_\_\_

Namba ya mgonjwa: \_\_\_\_\_

Tarehe: \_\_\_\_\_

Namba ya utafiti: \_\_\_\_\_

### Maelekezo:

Umekuwa sehemu ya tafiti ya awali ya kuchunguza iwapo "msaada rafiki" unapokelewa na kujua kama una maoni gani. Majibu yako yatasaidia wahudumu wa afya kuboresha huduma kwa watu wanaotumia dawa za kupunguza nguvu ya virusi vya ukimwi (VVU). Tafadhali jibu kwa umakini kadili uwezavyo.- tueleze nini wewe binafsi unataka kusikia na sio unachofikiri sisi tunapenda kusikia. Maelezo yako hayataandikwa jina na hivyo kuweza kuhusishwa na wewe moja kwa mola.

## MASW ALI YA MSINGI

a. Umri wako ni upi?

chini ya 20;       20-40;       40-65;       >65

b. Jinsia yako ni ipi?

Mme;       Mke;       Nyingine

c. Kiwango cha kipato chako ni kipi?

Chini ya 100,000 Tsh       500,000 Tsh – 1,500,000 Tsh  
 100,000 Tsh to 500,000 Tsh       Zaidi 1,500,000 Tsh

d. Je ni lini ulipima kwa mara ya kwanza kama na kugunduliwa kuwa na virusi vya ukimwi (VVU)? \_\_\_\_\_ (mwaka)

## KIKUNDI CHA WAGONJWA WANAOSAIDIANA

a. Wagonjwa wengi wanapata ugumu kumeza dawa zao, kwa sababu mbalimbali. Kama ulikosa kumeza dawa zako, sababu kubwa ilikuwa ipi? Unaweza kujaza kisanduku zaidi ya kimoja.

<input type="checkbox"/> Sijawahi kukosa dawa zangu	<input type="checkbox"/> Dawa zinanifanya niumwe
<input type="checkbox"/> Dawa kuisha kwenye famasi/kliniki	<input type="checkbox"/> Sijui dawa zinavyofanya kazi
<input type="checkbox"/> Kupoteza muda wakati ninapoendea kliniki	<input type="checkbox"/> Sijui muda na jinsi ya kunywa dawa kuchukua dawa
<input type="checkbox"/> Nakosa msaada familia na ndugu	<input type="checkbox"/> Dawa zina radha mbya
<input type="checkbox"/> Nakosa msaada wa wahudumu wa hospitali	<input type="checkbox"/> Ugumu wa kumeza vidonge
<input type="checkbox"/> Nakosa msaada wa jamii	<input type="checkbox"/> Huwa najisahau tu
<input type="checkbox"/> Sipati faragha ya kunywa dawa zangu	<input type="checkbox"/> Sina muda
<input type="checkbox"/> Sipati faragha nikiwa kliniki	<input type="checkbox"/> Nyingine (jaza) _____
<input type="checkbox"/> Sipendi kunywa dawa	

b. Yapi kati ya haya yafuatayo yangeweza kukusaidia kuhakikisha unameza vidonge vyako bila kukosa? Unaweza ukachagua zaidi ya kisanduku kimoja.

<input type="checkbox"/> Kupatiwa maelezo ya wakati na jinsi ya kumeza vidonge	<input type="checkbox"/> Dawa ziwe zinapatikana kirahisi
<input type="checkbox"/> msaada zaidi toka kwa daktari	<input type="checkbox"/> Imuda mfupi wa kusubiri kliniki na famasi
<input type="checkbox"/> msaada zaidi toka kwa nesi	<input type="checkbox"/> dawa mpya na bora zaidi
<input type="checkbox"/> huduma bora na vifaa vya hospitali	<input type="checkbox"/> mifumo ya kukumbusha kupitia sms/app za simu
<input type="checkbox"/> msaada kutoka kwa jamii	<input type="checkbox"/> kutokuwepo unyanyapaa
<input type="checkbox"/> msaada wa tabibu wa asili	<input type="checkbox"/> Elimu ya VVU kwa jamii
<input type="checkbox"/> msaada wa familia na marafiki	<input type="checkbox"/> nyingine (jaza) _____



c. Sehemu nyingine duniani ‘wagonjwa wataalam’ waliosomeshwa na wanatauluma wa afya, wanatoa msaada kwa wenzao wagonjwa. Hawa huongoza “makundi ya kusaidiana”, hivyo kusaidiana katika maisha yao. Je unaona kuwa hili ni wazo zuri?

Ndiyo;  Hapana;  Pengine

Kwanini (sababu): \_\_\_\_\_

d. Msaada wa aina gani ungependa (wataalam) hawa wagonjwa wakupatie?

kupanda gari na kwenda pamoja hospitali pamoja  provide drug stock-out information

kusaidiana jinsi ya kuongea na daktari  kubadilishana maelezo ya jinsi ya kutumia dawa

kuwapasha habari za kuumwa kwangu  kupewa msaada wa kimawazo

Kunitia nguvu kunywa dawa kama nilivyoelekezwa  kunisadia kupata marafiki

kunisaidia kuweza kuwambiaa watu wengine kuhusu ugonjwa wangu  kupambana na unyanyapaa

Wana kundi kwenda kufwata dawa kwa pamoja

nyingine (jaza) \_\_\_\_\_

e. Kuwa ‘mgonjwa mtaalam’ mtu mwenye VVU atapatiwa mafunzo na wataalam wa afya katika mafunzi mafupi. Baadae kwa haiari yao watatumia elimu yao kuwasaidia na kuwaelimisha wagonjwa wenzao. Baadhi ya kazi ni kama kuwa kiongozi wa kundi, kukusanya taarifa, kugawa dawa kwa wagonjwa wengine, kuwa msomeshaji n.k. Je ungependa kuwa ‘mgonjwa mtaalam’?

Ndiyo;  Hapana;  Pengine

f. Je ungependa kuudhuria mikutano ya kikundi cha wagonjwa kusaidiana mara kwa mara, inayoongozwa na ‘mgonjwa mtaalam’?

Ndiyo;  Hapana;  Pengine

g. Mara ngapi ungekuwa radhi kuhudhuria mikutano ya vikundi vya wagonjwa kusaidiana ?

mara moja kwa wiki;  mara moja kila wiki mbili;  mara moja kila mwezi

h. Je hoja yako kubwa ingekuwa nini kuhusiana na kundi la kusaidiana?

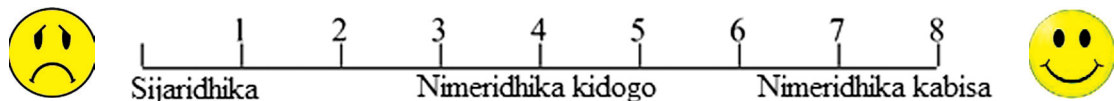
.....

## UTOAJI WA DAWA

a. Je kwa ujumla unachukua mda gani kupata dawa zako? (jumuisha muda wa kutoka nyumbani mpaka utakaporudi tena nyumbani).

chini ya saa moja;  masaa 2-4;  masaa 4-6;  masaa >6

b. Unatathmini vipi muda unaotumia kupata dawa zako ? ( Zungushia kwenye skeli)



c. Je ugekubali kujiunga kliniki kwako na kundi la wagonjwa la kusaidiana? Mahali ambapo kundi hili hukutana ili usiende mara kwa mara katika hospitali?

Ndiyo;  Hapana;  Pengine

d. Je unaonaje kama ungekuwa unaonana na daktari wako mara chache zaidi? Unadhani kumuona daktari ingekuwa muhimu:

- |  |   |
|--|---|
| <input type="checkbox"/> mara moja kwa mwezi                           | <input type="checkbox"/> mara moja kila miezi 6 |
| <input type="checkbox"/> wakati nikiwa mgonjwa tu                      | <input type="checkbox"/> mara moja kila miezi 3 |
| <input type="checkbox"/> wakati nikiwa na hoja/swali/tatizo kuhusu VVU |   |

e. Je ungejisikia rahisi zaidi kutumia dawa zako iwapo hakuna haja ya kufika hospitali mara kwa mara?

- |                                      |                                   |  |                                      |
|--------------------------------------|-----------------------------------|--|--------------------------------------|
| <input type="checkbox"/> Zaidi sana; | <input type="checkbox"/> Pungufu; | <input type="checkbox"/> Hakuna tofauti; | <input type="checkbox"/> Sina hakika |
|--------------------------------------|-----------------------------------|--|--------------------------------------|

### Peer support questionnaire (English)

Interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Patient's number: \_\_\_\_\_

Study number: \_\_\_\_\_

#### Instructions:

You are part of a pilot study to explore if peer support is acceptable to you and what your concerns could be. Your answers will help health workers to improve the care for people receiving ARVs. Please answer the following questions as truthfully as you can – tell us what you personally think, and not what you think you want us to hear. Your responses will be anonymized and not be traced back to you.

### BASIC QUESTIONS

a. What is your age?

under 20;       20-40;       40-65;       >65

b. What is your sex?

Male;       Female;       Other

c. Which is your income range?

Less than 100,000 Tsh       500,000 Tsh – 1,500,000 Tsh  
 100,000 Tsh to 500,000 Tsh       More than 1,500,000 Tsh

d. When did you first have a positive HIV test result? \_\_\_\_\_ (year)

### PATIENT SUPPORT GROUP

a. Most patients experience some difficulties taking their drugs, the reason why can vary. If you missed taking your pills, what was the main reason? You can tick more than one box.

<input type="checkbox"/> I never missed taking my pills	<input type="checkbox"/> The drugs make me feel sick
<input type="checkbox"/> pharmacy stock-out	<input type="checkbox"/> I am not sure the medication is working
<input type="checkbox"/> too much time lost to pick up medication	<input type="checkbox"/> not sure how and when to take the pills
<input type="checkbox"/> I lack support from family/friends	<input type="checkbox"/> the medication tastes bad
<input type="checkbox"/> I lack support from hospital staff	<input type="checkbox"/> difficulty swallowing
<input type="checkbox"/> I lack support from my community	<input type="checkbox"/> simply forgot
<input type="checkbox"/> I don't have enough privacy to take pills	<input type="checkbox"/> no time
<input type="checkbox"/> I don't have enough privacy at the clinic	<input type="checkbox"/> other (fill in) _____
<input type="checkbox"/> I don't want to take medication	

b. Which of the following help would make you take your pills properly? You can tick more than one box.

<input type="checkbox"/> information on when and how to take pills	<input type="checkbox"/> drug more easily available
<input type="checkbox"/> better support from doctors	<input type="checkbox"/> less waiting time in pharmacy/hospital
<input type="checkbox"/> better support from nurses	<input type="checkbox"/> new and better drugs
<input type="checkbox"/> better hospital facilities	<input type="checkbox"/> automatic reminders via messages/apps
<input type="checkbox"/> better community support	<input type="checkbox"/> less stigma
<input type="checkbox"/> support from traditional healer	<input type="checkbox"/> HIV education in community
<input type="checkbox"/> support from family/friends	<input type="checkbox"/> other (fill in) _____



c. In some regions 'expert patients', who have received training from health professionals, are supporting and educating their fellow patients. They lead and organize peer support groups, which support patients through their lives. Do you think this is a good idea?

Yes;                     No;                     Maybe

Why: \_\_\_\_\_

- d. What help from a fellow (or expert) patient do you feel is appropriate to support you?
- |   |   |
|---|---|
| <input type="checkbox"/> driving together to hospital                       | <input type="checkbox"/> provide drug stock-out information       |
| <input type="checkbox"/> help with what to say during doctor visit          | <input type="checkbox"/> provide information about medication use |
| <input type="checkbox"/> provide information about my illness               | <input type="checkbox"/> give me emotional support                |
| <input type="checkbox"/> motivate me to take medication as prescribed       | <input type="checkbox"/> help me to make friends                  |
| <input type="checkbox"/> help me to tell other people about my illness      | <input type="checkbox"/> tackling stigma                          |
| <input type="checkbox"/> group member picking up medication for whole group |   |
| <input type="checkbox"/> other (fill in) _____                              |   |
- e. To become an 'expert patient' a person with HIV will receive training by healthcare professionals in a short training program. Then they will voluntarily use their knowledge to support and educate fellow patients. Tasks could include being group leader, gathering information, distributing medication to other patients, becoming an educator etc.)  
Would you be interested in becoming such an expert patient?
- Yes;                     No;                     Maybe
- f. Would you like to attend regular peer support sessions that are led by an expert patient?
- Yes;                     No;                     Maybe
- g. How often would you be willing to attend peer support sessions?
- once a week;                     once every two weeks;                     once every month
- h. What would be your main concern regarding these peer support sessions? (fill in here:)
- .....

## DRUG DELIVERY

- a. How much time does it take in total to get your medication? (Including the time from leaving home until you return back home).
- less than 1 hour;     2-4 hours;     4-6 hours;     >6 hours
- b. How do you feel about how long it takes to pick up your medication? (draw a cross on the scale)
-     1    2    3    4    5    6    7    8    
- Not satisfied                    Half Satisfied                    Very Satisfied
- c. Would you consider joining a local peer support group, where you would receive your medication, so that you don't have to pick up your medicines at the hospital so often?
- Yes;                     No;                     Maybe
- d. How would you feel if you saw a doctor less often? I feel a doctor's visit is necessary:
- |  |  |
|--|--|
| <input type="checkbox"/> once a month        | <input type="checkbox"/> once every 6 months                   |
| <input type="checkbox"/> once every 2 months | <input type="checkbox"/> when feeling ill                      |
| <input type="checkbox"/> once every 3 months | <input type="checkbox"/> when having concerns/issues about HIV |
- e. Would you feel more or less likely to take your drugs if you didn't visit the hospital as often?
- More;                     Less;                     No difference;                     Unsure

## Peer support questionnaire (English)

Interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Doctor's number: \_\_\_\_\_

Study number: \_\_\_\_\_

### Instructions:

You are part of a pilot study to explore if peer support for your patients is acceptable to you as a doctor and what your concerns could be. Your answers will help to assess how peer support could improve the care for people receiving ARVs. Please answer the following questions as truthfully as you can – tell us what you think, we want your critical feedback. Your responses will be anonymized and will not be traced back to you.

## BASIC QUESTIONS

a. What is your age?

20-30;  30-40;  40-50;  50-65;

b. What is your sex?

Male;  Female;  Other

c. For how long have you been working in a HIV clinic?

< 5years;  5-10years;  10-20years;  >20years

## PATIENT SUPPORT GROUP

a. Most patients experience some difficulties taking their drugs, the reason why can vary. If a patient missed taking his pills, what would be the main reason(s) according to you? You can tick more than one box.

- |  |   |
|--|---|
| <input type="checkbox"/> my patients never miss taking their pills             | <input type="checkbox"/> the drugs make them feel sick        |
| <input type="checkbox"/> there are too many pharmacy stock-outs                | <input type="checkbox"/> the medication tastes bad            |
| <input type="checkbox"/> they lose too much time picking up medication         | <input type="checkbox"/> they have difficulty swallowing      |
| <input type="checkbox"/> they are not confident the medication is working      | <input type="checkbox"/> they simply forget to take the drugs |
| <input type="checkbox"/> they lack support from family/friends                 | <input type="checkbox"/> they have no time                    |
| <input type="checkbox"/> they lack support from hospital staff                 | <input type="checkbox"/> they don't want to take medication   |
| <input type="checkbox"/> they lack support from their community                | <input type="checkbox"/> they lack privacy to take pills      |
| <input type="checkbox"/> they don't have enough privacy at the clinic          | <input type="checkbox"/> other (fill in) _____                |
| <input type="checkbox"/> they do not understand how and when to take the pills |   |

b. Which of the following help do you think could make the patient take their pills properly?

You can tick more than one box.

- |  |   |
|--|---|
| <input type="checkbox"/> information on when and how to take pills | <input type="checkbox"/> drug more easily available             |
| <input type="checkbox"/> better support from doctors               | <input type="checkbox"/> less waiting time in pharmacy/hospital |
| <input type="checkbox"/> better support from nurses                | <input type="checkbox"/> new and better drugs                   |
| <input type="checkbox"/> better hospital facilities                | <input type="checkbox"/> automatic reminders via messages/apps  |
| <input type="checkbox"/> better community support                  | <input type="checkbox"/> less stigma                            |
| <input type="checkbox"/> support from traditional healer           | <input type="checkbox"/> HIV education in community             |
| <input type="checkbox"/> support from family/friends               | <input type="checkbox"/> other (fill in) _____                  |

c. In some regions 'expert patients', who have received training from health professionals, are supporting and educating their fellow patients. They lead and organize peer support groups, which support patients through their lives.

Do you think this is a good idea?

Yes;  No;  Maybe

Why: \_\_\_\_\_





## 10 REFLECTIVE STEPS: AN EXERCISE

To improve the transdisciplinary research process, a 10-step approach has been proposed by C. Pohl *et al* (Pohl *et al*, 2017). These 10 steps aim to stimulate reflections during the research process to make the obtained results more significant.

This approach is here applied to the transdisciplinary challenge “A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa”. The different steps are studied and applied at the end of the first part of the challenge after the spring semester 2017. The exercise reflects on the already performed work, and constitutes an overview and systemization of the performed work. It can serve as a basis to improve the process during further work of future teams continuing on the same challenge.

The consecutive steps are first mentioned in black text, followed by a small citation sometimes with figure from the article by C. Pohl *et al* and afterwards applied to the challenge and the performed work in blue text.

### 1 FORMULATE THE RESEARCH QUESTION AND CLASSIFY RESEARCH AS BASIC, APPLIED, TRANS-DISCIPLINARY.

“This step helps the researchers to recognize that there are two different realms (depicted in the picture), and that positioning one’s own research in the spectrum between them might cause tension.”

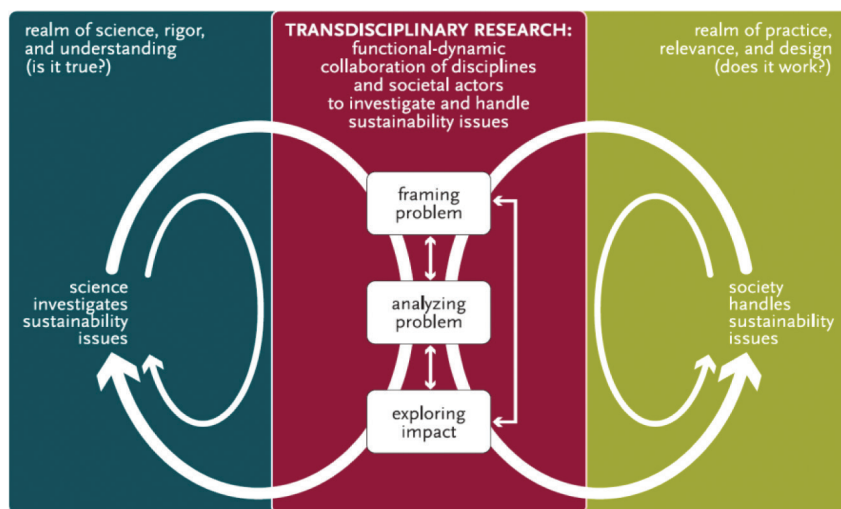


Figure 1. The transdisciplinary research process. C. Pohl *et al*

The two realms are the realm of science (research, abstract thoughts and ideas) and the realm of practice (the real situations, practicalities). The actual challenge of TD-research is to provide a link between these realms and its goal is to enable change in complex practical environments (the real world) using scientific, more abstract knowledge.

Once the problem is accepted to be transdisciplinary, the challenge is addressed in a holistic manner. Researchers with different educational backgrounds see the problem through different frameworks. Mixing these differences thought styles will produce a necessary transdisciplinary approach. (Figure 1)

#### **Applied to our challenge**

The actual research question: a way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa: improvement of the patient-provider relationship.

This research question is transdisciplinary. Taking into account the reality of practices and experiences in sub-Saharan Africa the problem will be tackled using scientific research. To work towards a solution for the problem, complex interactions in the practical situation need to be webbed and transformed to improve the situation.

## 2 DISTINGUISH BETWEEN RESEARCH QUESTION AND SOCIETAL PROBLEM; MAKE LINKS BETWEEN BOTH.

*“This step makes the researchers reflect about what the societal problem actually is, and if and how their own research contributes to solving a more general societal problem.”*

### **Applied to our challenge**

The challenge is situated in the larger context of preventing the spreading of HIVDR.

Through the following path the research will be societally relevant:

Better patient-provider relations improve the adherence of ART patients which is one of the ways of HIVDR prevention.

Through assessing the assumptions made in the challenge proposal also clear boundaries are set up to outline the scope of the challenge to study.

## 3 SPECIFY THE SOCIETAL PROBLEM IDENTIFIED IN STEP 2 AND RELATE IT TO THE POLICY CYCLE

*“This step makes researchers aware that a societal problem is dynamic, that society is heterogeneous, and that different groups may perceive problems differently. It identifies the (primary) target group(s) the research should address.”*

### **Applied to our challenge**

The patient provider relationship is differently set-up in each different hospital community. The research treats different hospital communities (the patients on ART in a hospital) as a target group and as the basis for the research. Therefore, every different hospital community represents a case study where a policy can be developed and rolled out. Note that even within each hospital community there are circumferential factors influencing only a part of that community.

THE FOUR MOST GENERAL STAGES IN THE POLICY CYCLE ARE (Figure 2):

1. **Problem framing**, when society becomes aware of a problem and disputes what the problem is about and for whom it is a problem at all.

### **Applied to our challenge**

The main problem that will be tackled is that doctors simply don't have enough time to develop a doctor-patient relationship. Therefore the patient misses “psychological care and investment” which will motivate him and comfort him in his ART therapy adherence.

2. **Policy development**, when discussions start regarding how the problem should be addressed, and what the goal of addressing the problem is. (In transdisciplinary research there is inevitable lack of clarity about the exact solution, what the outcome should look like)

### **Applied to our challenge**

The goal is twofold:

1. Shift tasks away from the doctors, so they have more time to focus on what is more important.
2. Improve the care especially in a more social way.

**3. Policy implementation**, when society discusses the policies or measures to be taken, and implements them

**Applied to our challenge**

Different approaches can be used to overcome the gap of care and investment:

- Mix skilled local health teams to increase capacity to deliver services:
  - Setting up peer patient support groups
  - Training expert patients which will take care of basic tasks
- Community participation:
  - Engage communities and people living with HIV to deliver essential basic care.

**4. Policy evaluation**, when discussions start about how far the implemented policies help to handle the problem

**Applied to our challenge**

An important question here is how to measure the impact in order to evaluate the implementation of the changes.

The ART adherence is the main parameter to monitor since that is what eventually needs to improve. Monitoring the engagement of the community in the proposed policy changes will be an important factor. Definitely always contact the different actors involved in the problem. They are a valuable source of practicalities and ideas to further improve the situation.

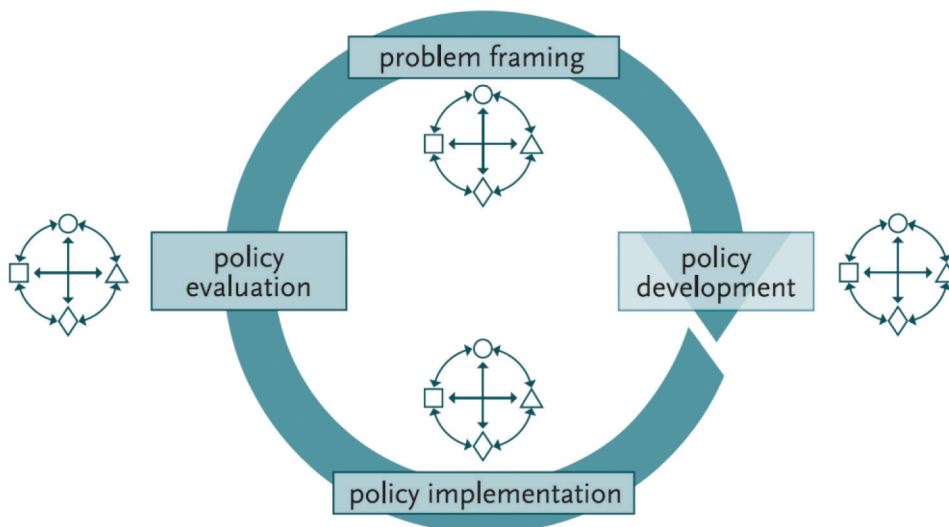


Figure 2. The four most general stages in the policy cycle. C. Pohl *et al*

**4 IDENTIFY KNOWLEDGE NEEDED BY (PRIMARY) TARGET GROUP(S); CHECK WHETHER THE KNOWLEDGE NEEDED IS WHAT RESEARCH MAY PROVIDE.**

*“This step makes the researchers reflect on different forms of knowledge their project could provide, and compare it to the knowledge needed by their (primary) target group(s).”*

**KNOWLEDGE TYPES**

Knowledge about what is (systems knowledge)

**Applied to our challenge**

What is the situation now. What is the adherence? How does the hospital community operate? What are the main problems, worries, expectations of the different groups within the hospital community? How do different factors affect the patient-provider relationship?

Knowledge about what should be (target knowledge)

**Applied to our challenge**

Where do we want to go to. What would be the ideal situation. Everyone is happily following their ART therapy.

Knowledge about how we come from where we are to where we should be (transformation knowledge)

**Applied to our challenge**

How will we improve the situation. How can we apply the new policy? Are there any regulations we need to follow? How to implement our policies in a practical way?

Good congruence between the knowledge the research provides and the knowledge demand (and expectations) of target groups is essential!

CONNECTION WITH POLICY FRAMING

1. Problem framing: systems knowledge is required to explain the problem and context.
2. Policy development: target knowledge becomes important.
3. Policy implementation: transformation knowledge is required: what kind of technical, political, educational, or economic measures should be implemented.
4. For policy evaluation systems and target knowledge are required to check whether the policy interventions changed the situation in the desired direction.

If needed, the policy cycle starts over again by examining and improving the original problem framing.

In general, all forms of knowledge are involved in each stage.

**5 IDENTIFY DISCIPLINES AND SOCIETAL ACTORS TO BE INVOLVED IN THE RESEARCH PROJECT.**

*“This step specifies and extends steps 3 and 4 to the world of societal actors and disciplinary researchers. It increases awareness of relevant expertise and decision. Actors can be useful for several reasons such as their interest, power, or expertise regarding the issue at stake or the project.”*

**Applied to our challenge**

ACTORS

- Patients
- Relatives of the patients
- Doctors
- Nurses
- Pharmacists
- Hospitals
  
- NGO: Sensoa, Project 100, HIV Justice
- Government
- WHO
- Media
- Economics
- Medical school
  
- Think-tanks
- Other HIV research groups

## NECESSARY DISCIPLINES

Systems knowledge:

- **Medical:** Doctor-patient interaction
- **Biomedical:** HIV-treatment
- Cultural development: Southern mentality
- **Humanities and social:** Social interactions within the community

Target and transformational knowledge:

- Behavioral sciences: Psychology and humanity ~ **philosophy**
- **Engineering & Economics:** Organization and structuring

The disciplines in bold are the disciplines present in the team. Of course prioritization of the disciplines as well as actors to be involved with is necessary.

A total of six to ten is a workable number of disciplines and societal actors.

## **6 POWER AVAILABLE ELSEWHERE. CLARIFY THE ROLE OF SOCIETAL ACTORS AND DISCIPLINES VIS-À-VIS YOUR OWN RESEARCH (QUESTION); IDENTIFY PATHS OF INTERACTION (INFORMING, CONSULTING, CO-PRODUCING).**

*“This step helps the researchers to place their research in a broader context by linking it to other disciplines and societal actors. Here the importance of each societal actor and discipline for their research is made explicit and the plan to interact with them is described.”*

### ***Applied to our challenge***

**To inform →**

- The WHO spokesperson requesting the challenge is informed of the progress made.

**To consult ←**

- Other research groups are requested for expert opinions.
- By using a questionnaire the patients and doctors are reached to solicit their opinion.
- NGOs are contacted to gather information about current practices.

**To coproduce knowledge ↔**

- Within the research group, different point of views are discussed.
- Local partners (A researcher and a ministry of health official, both former PhD researchers at KU Leuven) are contacted to inform the research group about the local situation and to help writing the questionnaire.

## **7 ACTOR CONSTELLATION: MODERATED ROLE-PLAY PLACING SOCIETAL ACTORS AND DISCIPLINES AROUND A RESEARCH QUESTION. THE CLOSER THE ACTORS/DISCIPLINES ARE TO THE RESEARCH QUESTION, THE MORE RELEVANT THEY ARE FOR THE RESEARCH.**

*“This step allows individuals and the group as a whole to reflect about the relevance of specific societal actors and disciplines for an exemplary research question.*

*The group critically reflects one participant’s mental picture of the most important actors and disciplines as developed in step 6: we ask for a volunteer willing to present his/her results during a 30-minute role-play session involving about ten participants.”*

It leads to:

- Role clarification. Who is the person, organization I am actually representing?
- Rethinking actor placing
  - Detection missing societal actors or disciplines.
  - Arguing about who is more important for the research
  - Discovering benefits (or harms) actors would derive from the collaboration, their reasons to be involved in the research.

### Applied to our challenge

At the start of the project a very simplified actor constellation is set-up displaying the importance of the actors with respect to solving the research question. (Figure 3)

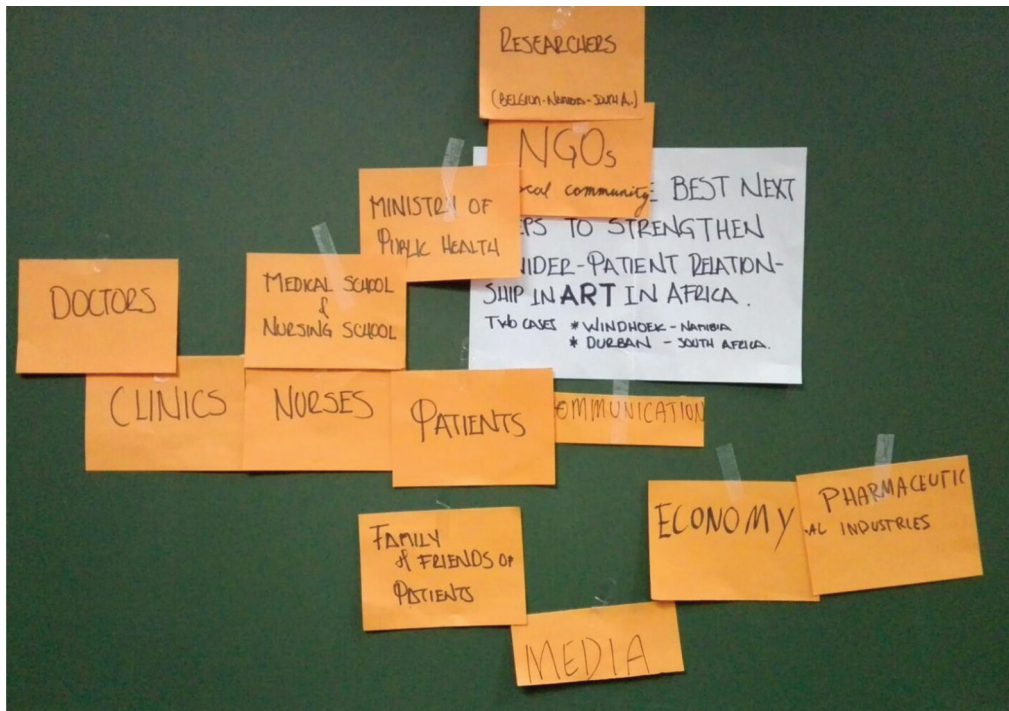


Figure 3. Output of the actor constellation workshop on this challenge

No real roleplay has been performed during the orientation of the research. However an important discussion about the relative importance of the different actors with respect to the research question has taken place. This resulted in the idea that the importance of the different actors changes depending on the stage the research is in. Because the research stage you are in determines the mindset in which you look at the research question. For example: during the policy implementation, cooperation with hospital/doctors/nurses, patients, NGO, government will be the most important. When researching different possible solutions, cooperation with think tanks and other HIV research groups is necessary. To acquire systems knowledge the hospital community and patients are the main actors to be involved with and to study.

## 8 CLARIFY EXPECTATIONS AND INTERESTS OF THE SOCIETAL ACTORS AND DISCIPLINES INVOLVED.

*“Researchers must substantiate why societal actors and other disciplines need to be involved. This makes the vague notions of involvement and interaction (see steps 5, 6) more explicit and concrete.*

*This step helps in clarifying who should be involved and why. One can learn about which scientific or societal actor carries essential knowledge for the project, who might have power to impact relevant societal decisions, or who might lose by certain societal decisions and thus needs to be involved.”*

Essential Questions are: Who initiates the interaction? Who participates? Why participation? Regarding which issues and when? By which method(s)?



### **Applied to our challenge**

- Substantive (i. e., those to be involved have relevant expertise)
  - E.g.: Contact with other HIV research teams and experts of transdisciplinary research.
- Normative (i. e., the democratic principle requires that those affected have a say)
  - E.g.: Little questionnaire for the doctors to get them involved in the idea of peer support groups.
- Instrumental (i. e., by interaction one hopes for more legitimized decisions)
  - E.g.: Contact with a government official with a patient interrogation approval.

In this project this step is implicitly achieved as indicated by the examples.

## **9 DESIGN A PLAN ON WHY TO INVOLVE WHICH SOCIETAL ACTORS AND DISCIPLINES AT DIFFERENT STAGES OF THE RESEARCH PROJECT.**

*“This step encourages reflections about who to involve/collaborate within one’s research project depending on the desired societal impacts. It helps to understand that collaboration is dynamic over time.”*

*“A detailed plan for whom to involve. No process of a complex decision problem requires a single level of interaction only; it will rather span different levels at different points in time. Therefore, the intensity of interaction between scientific and societal actors depends on the phase, goals, and content of the process and its context. And the various interaction intensities reflect the dynamic involvement of the different groups addressed.”*

*“A nuanced understanding of the interaction with other disciplines and societal actors emerges: The essential project steps and the potential or need for interacting. This helps to identify possible flaws in the project set-up retrospectively or to plan interaction for subsequent project steps. Set-up flaws may include a lack of interaction at the start of the project when aiming at a shared problem understanding, or too intense and demanding interaction with a too diverse set of disciplines or actors during intensive data analyses or during the paper-writing period.”*

### **Applied to our challenge**

A plan was formed as the project evolved. First the challenge itself was rewritten and agreed upon by the parties of interest, the project team and the person proposing the project. The context of the HIV problem was studied and different organizations involved with HIV, such as Sensoa, were contacted.

Afterwards through contact with a health department official and a biomedical researcher based in Tanzania, sub Saharan Africa, the local situation is investigated. The most important issue in the patient-provider relation is the lack of time the available doctors are able to spend with their patients (3 min /patient). Insufficient resources are available to improve of the patient-provider relationship by an increase of the number of doctors. Limited improvement in the nurse patient relation is possible.

To motivate the patient and stimulate its adherence in an effective way a different solution is researched in literature. Patient peer support groups and their positive influence on the adherence have been reported. A case study in Tanzania is proposed to investigate the effects of patient peer support groups. As a first step the willingness to participate in such a project is explored through a questionnaire. The questionnaire is designed with the help of a HIV think tank, the NGOs HIV Justice and Project100, and Dr Mosha and Dr Sangedda (local support) who have experience in conducting similar surveys and who obtained ethical approval to conduct the surveys. Eventually the results of the questionnaires will be interpreted.

To continue the challenge the team feels the need to continue the work with a new team the following year.

## **10 THINK ABOUT LESSONS LEARNED FROM GOING THROUGH STEPS 1 TO 9.**

*“This step triggers a reflection on the nine steps and their potential impact on one’s research work. It helps to identify potential weaknesses in the research project.”*

This can best be organized as a poster session, so that a lively exchange develops within the group about what everybody learned, and what impact this would have on their on-going and future research.

### ***Applied to our challenge***

There was no time to address this step, it was proposed to gather the achievements so far and prepare it for a next team on the same challenge.

### **Reference**

1. Pohl, C., Krutli, P., & Stauffacher, M. (2017). Ten reflective steps for rendering research societally relevant: While the goal of transdisciplinary research is to be relevant to society, specific instructions for accomplishing this remain implicit. We propose to improve

this situation by means of a 10-step approach aimed at stimulating explicit reflections around ways to render research more societally relevant. *GAIA - Ecological Perspectives for Science and Society*, 26(1), 43-51. <https://doi.org/10.14512/gaia.26.1.10>



## **Transdisciplinary experience in a pilot year of a new Honors Program at the KU Leuven – University of Leuven: building a team, developing and improving a transdisciplinary project through addressing a challenge on HIV drug resistance in Africa**

**Joram Dehens, Maud de Hemptinne, Michaël Galouchka, Abdus Sajud, Reinier Petrus van Otzel, Cedric Vanhoorebeeck, Małgorzata Wyszowska, Anneleen Kiekens, Jorge Ricardo Nova Blanco, Anne-Mieke Vandamme**

### **Abstract**

Challenge: A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa.

During this pilot year of the “Transdisciplinary Insights” Honors Program at the KU Leuven – University of Leuven, together with the academic staff, students have developed a methodology for working on a transdisciplinary challenge. The pilot project was structured initially in three (partially overlapping) steps: building a transdisciplinary team, building a transdisciplinary project, and gathering knowledge. The Actor Constellation, Three Types of Knowledge and Ten Reflective Steps exercises ([www.transdisciplinarity.ch/toolbox](http://www.transdisciplinarity.ch/toolbox); Pohl et al, 2017) and ‘complexity and collaborative knowledge co-creation’ (Marc Craps) workshops were very helpful for building a team and identifying gaps and steps to be undertaken to solve the challenge. It also boosted students’ creativity and team-working skills. In the coming years, more challenges will be addressed simultaneously, each by a dedicated student group, coach and stakeholders.

### **Key words**

Honors Program, student team, Transdisciplinary Challenges, Transdisciplinary Toolbox, stakeholders



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**Joram Dehens,<sup>1,2\*</sup> Maud de Hemptinne,<sup>1,3\*</sup> Michaël Galouchka,<sup>1,4\*</sup> Abdus Sajud,<sup>1,5\*</sup> Reinier Petrus van Otzel,<sup>1,4\*</sup> Cedric Vanhoorebeeck,<sup>1,4\*</sup> Małgorzata Wyszowska,<sup>1,6\*</sup> Anneleen Kiekens,<sup>7</sup> Jorge Ricardo Nova Blanco,<sup>1,7</sup> Anne-Mieke Vandamme<sup>1,7,8§</sup>**

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## Challenge

**A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa**

**Background:** The 'Transdisciplinary Insights' Honors Program was established in the academic year 2016-2017 at KU Leuven – University of Leuven by Prof. Anne-Mieke Vandamme, Prof. Griet Ceulemans and Prof. Andreas de Block and coordinated by Mr. Jorge Ricardo Nova Blanco. The academic team is responsible for lectures and workshops which provide a framework for transdisciplinary research. One of its main objectives is to bring together future researchers and entrepreneurs and familiarize them with solution-oriented transdisciplinary research. Students work in groups around a specific challenge which comes from a database compiled by the Academic team (the Bank of Transdisciplinary Challenges), with submissions from researchers at KU Leuven or elsewhere, industry, community groups such as NGOs, society members or even from the students registered on the course.

To be accepted for the database, the challenge has to require the insight of at least one discipline from each group of sciences (Biomedical Sciences, Science and Technology, Humanities and Social Sciences) as a prerequisite for reaching long-term solutions. Therefore, each team of students is composed of at least one member of each group of sciences working together

in a cooperative relationship with external stakeholders to work towards solutions for global problems. The outcome should be presented in the form of a research proposal, a scientific article, a movie, a TED talk, a poster, a blog, a prototype or any other form which is delivered in a digital medium. Additionally, it is necessary to include a synopsis (abstract) which defines the problem and the proposed solution. These materials are then submitted for publication in this journal.

**Methods:** In the academic year 2016-2017 the challenge was provided by Dr. MPH. Michael R. Jordan and concerned a drug resistance problem: “*A way to understand and instruct on best practices for delivering and accepting HIV drug treatments in Africa*” (Dehens et al, this issue). The student team consisted of 7 students from the following backgrounds: Medicine, Biomedical Sciences, Mechanical Engineering, Philosophy and Cultural Studies. The student selection responded (in part) to the requirements laid down by the challenge provider, who asked for expertise in arts, economics and business, psychology and educational sciences, social sciences, bioscience engineering, engineering technology, medicine and pharmaceutical sciences. This year’s student team was coached by Prof. Anne-Mieke Vandamme and supported by experts such as Dr. Jordan (Boston, USA), Dr. Moshia (Dar es Salaam, Tanzania), Dr. Sangeda (Dar es Salaam, Tanzania), Dr. de Oliveira (Durban, South Africa). Also, the following volunteers working with NGOs familiar with the topic provided guidance to the team: Mrs Baert (MSF, Brussels, Belgium), Mr Bernard (HIV Justice, Brighton, UK), Mr Thompson (Project 100, London, UK). Prof. Andreas de Block (University of Leuven, Belgium) provided students with an introductory lecture on transdisciplinarity (Conceptual and Psychological Issues). Prof. Marc Craps organized a workshop on complexity and collaborative knowledge co-creation (University of Leuven, Belgium). Prof. Griet Ceulemans and Mr Jorge Nova (both University of Leuven, Belgium) guided the transdisciplinary methodology through preparing exercises ([www.transdisciplinarity.ch/toolbox](http://www.transdisciplinarity.ch/toolbox)) and were responsible for collecting students’ feedback about the progress of the course. Feedback took place from students to the academic team (anonymously online after each session), from the academic team to students (during work sessions and through revising output), and between students (anonymous peer evaluation). Mrs

Anneleen Kiekens collected the output from the team to be used in the next few years of this challenge.

**Results:** The pilot project was structured initially in three (partially overlapping) steps and lasted one semester, with 2 hours of weekly sessions. The three steps were: building a transdisciplinary team, building a transdisciplinary project, and gathering knowledge. The first step was building a team (suppl. 1), where the students learned which actors were needed in the team. This started with checking the assumptions of the challenge laid down. Each student was assigned to check one of the assumptions included in the challenge through a literature study. As a result, the challenge was rewritten to reflect the research (Dehens et al., this issue). Further, the students were asked to reflect on how their expertise could be useful in order to bring the team closer to the solution and why the challenge provider had requested expertise in specific domains. An Actor Constellation exercise was performed which was found to be very effective in identifying missing actors. The team then searched for individuals who could fill these roles. In step 2 (suppl. 2), the Three Types of Knowledge exercise ([www.transdisciplinarity.ch/toolbox](http://www.transdisciplinarity.ch/toolbox)) initially caused some confusion which the students attributed to the vague and lengthy definition given by Prof. Anne-Mieke Vandamme during the exercise. This improved after the students had reformulated these definitions (suppl. 4). Through a literature review of case studies about Durban and Windhoek, the students tried to understand the current situation in hospitals in these places. The Skype calls with local experts were a big help in gaining information. The ‘complexity and collaborative knowledge co-creation’ workshop was also instrumental in further understanding the issues related to a transdisciplinary project. In step 3 (suppl. 4), knowledge regarding the patient-provider relationship and peer support was gathered in general for Africa, and more specifically for Dar es Salaam, the study site that collaborated to fill in questionnaires investigating the perceived value and acceptability of peer support (Dehens et al., this issue).

This academic year, the student group has decided to publish its work in the form of info graphics and a blog that is intended to be updated by future teams that will take over the challenge in the next academic years under the guidance of Mrs Anneleen Kiekens. Moreover, the concept “*Ten Reflective Steps*” (Pohl et al, 2017)



was retrospectively applied to the work by this team, and a document has been created for the convenience of the future group (Dehens et al, this issue). The solution to the challenge that has been reached by students is described in Dehens *et al.* (this issue).

The academic team evaluated the quality of the abstracts and the digital supplementary information to decide whether it could be submitted to the international “Transdisciplinary Insights” e-journal. In addition, in future editions of the program, there will be a small conference at the end of the academic year at which all teams will present their proposals.

**Conclusion:** During this pilot year of the “Transdisciplinary Insights” Honors Program at the KU Leuven – University of Leuven, together with the academic staff, students have developed a methodology for working on a transdisciplinary challenge. The exercises and workshops were very helpful for building a team and identifying gaps and steps to be undertaken to solve the challenge. It also boosted students’ creativity and team-working skills. This program is now ready for the next academic year, where more challenges will be addressed

simultaneously, each by a dedicated student group, coach and stakeholders.

### Supplementary materials:

1. Infographics: Building a transdisciplinary team
2. Infographics: Building a transdisciplinary project
3. Three types of knowledge – definitions
4. Infographics: Gathering knowledge

### References

1. Dehens J., de Hemptinne M., Galouchka M., Sajud A., van Otzel R.P., Vanhoorebeeck C., Wyszowska M., Mosha F., Sangeda R.Z., de Oliveira T., Bernard E.J., Thompson M., Kiekens A., Baert S., Nova Blanco J.R., Jordan M.R., Vandamme A.M. (2017). Exploring the value and acceptability of peer support in the process of improving adherence to HIV antiretroviral drugs in Tanzania, Dar-es-Salaam. *Transdisciplinary Insights* 1, 9-32. <https://doi.org/10.11116/TDI2017.1.2>.
2. Pohl C., Krutli P., & Stauffacher M. (2017). Ten reflective steps for rendering research societally relevant. *GAIA – Ecological Perspectives for Science and Society*, 26(1), 43-51. <https://doi.org/10.14512/gaia.26.1.10>



# BUILDING

A

## TRANSDISCIPLINARY

# TEAM




	
<b>CHALLENGE ASSUMPTIONS</b>	Re-writing the challenge paragraph by paragraph. Checking the assumptions to reflect on our research through an extensive literature study.
<b>UNPACKING THE CHALLENGE</b>	How can your expertise help? The challenge provider asked for expertise in a few disciplines. Each student reflected on the challenge document and thought how their expertise could be applied to providing a solution.
<b>ACTOR CONSTELLATION EXERCISE</b>	Who plays an important role in the issue, who can play an important role in the proposed solution and what expertise do we need to add to the team as a result? Exercise turns out to be an eye-opener. Following this exercise we proceeded searching for think-tanks and NGOs in Africa, NGOs in Belgium, doctor and nurse schools in South Africa and Namibia (two suggested case sites).
<b>CONTACTING NEW ACTORS</b>	We got into contact with NGOs in Belgium: SENSOA, HIV-SAM (VZW Muungano); in the UK: HIV Justice, Project 100; in South-Africa and Belgium: Médecins sans Frontières.

# BUILDING A TRANSDISCIPLINARY PROJECT


**ACTOR CONSTELLATION**

With this exercise from the previous phase: 'Building a transdisciplinary team', we began a new stage: 'Building a transdisciplinary project'. It helped us identify lacking stakeholders and what to do next.




**THREE TYPES OF KNOWLEDGE: SYSTEMS KNOWLEDGE, TARGET KNOWLEDGE AND TRANSFORMATION KNOWLEDGE**

The obstacle here was very unclear definitions. We tried in an exercise to list the different knowledge types, and ultimately we reformulated the definitions to more clearly understand these types of knowledge.




**CASE STUDIES**

What do we know about the hospitals in Durban and Windhoek? What do we need to know about the local situation?




**LITERATURE STUDY**

Because of lack of contact with the local stakeholders in Durban and Windhoek, we did a literature study on potential other cases to work with in Cape Town and Dar es Salaam. After experiencing good contacts with the government in Dar es Salaam, we decided to add only Dar es Salaam.




**EXTERNAL CONTACTS**



As a result, we added Dr. Fausta Moshia, a medical microbiologist and epidemiologist, since 2010 a Director for the National Public Health Laboratory in Tanzania, and Dr. Raphael Sangeda, a lecturer in the Department of Pharmaceutical Microbiology at the MUHAS node, to our team.

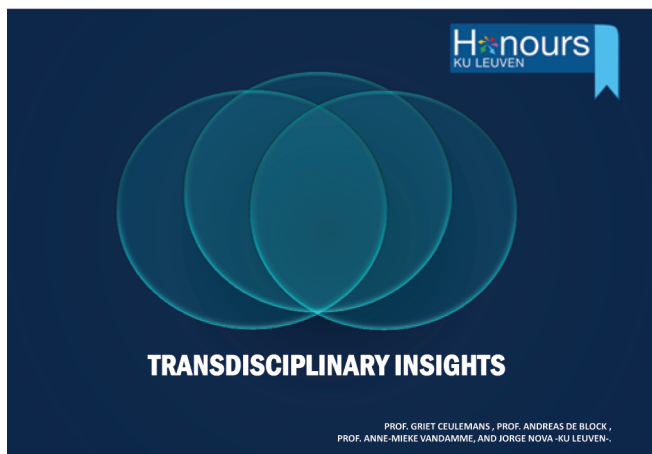


**GATHERING KNOWLEDGE**

The next phase of the project was to gather knowledge. This phase is described in a separate infographic.



 **TRANSDISCIPLINARY INSIGHTS** 



## Three Types of Knowledge Students' definitions

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<http://www.un.org/sustainabledevelopment/>



### Systems knowledge Your definition

Systems Knowledge is identifying a clearly defined problem within a given situation.

In order to identify the problem, a series of questions may be asked. These could include the following: What information do we have? Who are the stakeholders involved? What are the issues at stake? What is the key problem within this given context? Which actors in which disciplines could help solve the problem?

The first research questions that are formulated are meant to gather this systems knowledge and not to solve the problem itself, rather it aims to present the problem.

Systems Knowledge | Target Knowledge | Transformation Knowledge  
 Anne-Mieke Vandamme, March 2017



### Target knowledge Your definition

Target Knowledge comprises all possible solutions to the challenge and all insights identifying which solution will be chosen as the team's main goal.

In order to identify the solution, a series of questions may be asked. These could include the following: Who and what will be affected if the solution is implemented? What will be the implications for the broader context? Why is this solution chosen as the objective above the other possible solutions?

At this stage it is important to learn about the context, effects and consequences of the solution. Specific research questions should be formulated to gain this target knowledge before the research team settles on a proposed solution to answer the need for change.

Systems Knowledge | Target Knowledge | Transformation Knowledge  
 Anne-Mieke Vandamme, March 2017



### Transformation knowledge Your definition

Transformation knowledge is all information needed to formulate strategies to arrive at the solution to the problem.

In order to identify the strategies, a series of questions may be asked. These could include the following: What are the practicalities involved (e.g. feasibility, costs, available infrastructure, cultural barriers etc.) in the problem situation? Which key stakeholders could be involved in the overall strategy? What stages need to be completed within the given time frame?

It is the knowledge of what we can and cannot do, what will help or obstruct the implementation of the solution. Specific research questions should be raised to identify the best course of action to reach the end goal.

Systems Knowledge | Target Knowledge | Transformation Knowledge  
 Anne-Mieke Vandamme, March 2017



Anne-Mieke Vandamme, March 2017

# GATHERING KNOWLEDGE

All the steps taken during the project to gather the knowledge

- 1 FIRST CLASS (21/2/2017)**

The very first class (after introductory class) was "Conceptual and psychological issues", by Andreas de Block, which most of us found quite complicated, but very interesting
- 2 REDEFINITION (APRIL)**

Because this pilot project was only during the second semester, we evaluated what we could contribute in this short period, and redefined our goals to make it feasible. Building on the case studies, and interviews with the stakeholders, we assessed that investigating patient peer support groups would be more valuable in the short run than improving patient-provider relationship as suggested by the challenge submitter.
- 3 CASE STUDIES**

We learned from successful peer support group cases in Mozambique (Tom Decroo, PhD thesis ITG, Antwerp, Belgium). We built good contacts with Dar es Salaam, Tanzania, as a test site for exploring peer support.
- 4 NGOS THAT PROVIDED KNOWLEDGE ON PEER SUPPORT GROUPS**


We interviewed Edwin J Bernard from HIV Justice, Marc Thompson from Project 100, Saar Baert from Médecins sans Frontières.
- 5 QUESTIONNAIRE**

With these NGOs we started working on questionnaires to check feasibility of peer support in Dar es Salaam, Tanzania, one addressed to patients and one to doctors. At the test site, Fausta Moshale and Raphael Zozimus Sangeda helped us. In the beginning we gathered as many questions as possible. The next step was to eliminate irrelevant questions and shorten the form to one page.
- 6 10 REFLECTIVE STEPS**

Due to lack of time, we decided not to use the 'Ten Reflective Steps' exercise for Rendering Research Societally Relevant this year. We discovered that we had in fact implicitly used many of these steps.
- 7 WORKSHOP**

Workshop session on 'Collaborative Knowledge' by Marc Craps. We found this workshop very useful and would have liked to have this workshop earlier in the transdisciplinary research process.
- 8 FINAL STEPS**

We finalized the questionnaires and sent them out. We also prepared the final report for the new student team.

 **TRANSDISCIPLINARY INSIGHTS** 