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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 Wyszkowska, 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

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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

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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

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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), 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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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)

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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

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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

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☐ 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.

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BANK OF TRANSDISCIPLINARY CHALLENGES

INCLUDING AMMENDMENTS ON THE ASSUMPTIONS

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

20th 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 (≥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

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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: _____ **Numba 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
[ ] 100,000 Tsh to 500,000 Tsh
[ ] 500,000 Tsh – 1,500,000 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.
[ ] Sijawahi kukosa dawa zangu
[ ] Dawa kuisha kwenye famasi/kliniki
[ ] Kupoteza muda wakati ninapoendea kliniki
[ ] Nakosa msaada familia na ndugu
[ ] Nakosa msaada wa wahudumu wa hospitali
[ ] Nakosa msaada wa jamii
[ ] Sipati faragha ya kunywa dawa zangu
[ ] Sipati faragha nikiwa kliniki
[ ] Sipendi kunywa dawa
[ ] Dawa zinanifanya niumwe
[ ] Sijui dawa zinavyofanya kazi
[ ] Sijui muda na jinsi ya kunywa dawa kuchukua dawa
[ ] Dawa zina radha mbya
[ ] Ugumu wa kumeza vidonge
[ ] Huwa najisahau tu
[ ] Sina muda
[ ] Nyingine (jaza) _____

b. Yapi kati ya haya yafuatayo yangeweza kukusaidia kuhakikisha unameza vidonge vyako bila kukosa? Unaweza ukachagua zaidi ya kisanduku kimoja.
[ ] Kupatiwa maelezo ya wakati na jinsi ya kumeza vidonge
[ ] msaada zaidi toka kwa daktari
[ ] msaada zaidi toka kwa nesi
[ ] huduma bora na vifaa vya hospitali
[ ] msaada kutoka kwa jamii
[ ] msaada wa tabibu wa asili
[ ] msaada wa familia na marafiki
[ ] Dawa ziwe zinapatikana kirahisi
[ ] Imuda mfupi wa kusubiri kliniki na famasi
[ ] dawa mpya na bora zaidi
[ ] mifumo ya kukumbusha kupitia sms/app za simu
[ ] kutokuwepo unyanyapaa
[ ] Elimu ya VVU kwa jamii
[ ] nyingine (jaza) _____

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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 (watalaam) hawa wagonjwa wakupatie?
[ ] kupanda gari na kwenda pamoja hospitali pamoja
[ ] kusaidiana jinsi ya kuongea na daktari
[ ] kuwapasha habari za kuumwa kwangu
[ ] Kunitia nguvu kunywa dawa kama nilivyoelekezwa
[ ] kunisaidia kuweza kuwambiaa watu wengine kuhusu ugonjwa wangu
[ ] Wana kundi kwenda kufwata dawa kwa pamoja
[ ] nyingine (jaza) _____
[ ] provide drug stock-out information
[ ] kubadilishana maelezo ya jinsi ya kutumia dawa
[ ] kupewa msaada wa kimawazo
[ ] kunisadia kupata marafiki
[ ] kupambana na unyanyapaa

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

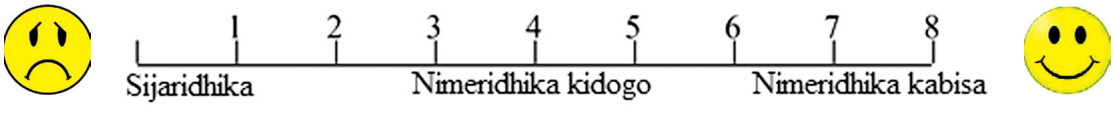
h. Je hoja yako kubwa ingekuwa nini kuhusiana na kundi la kusaidiana?

……

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 la wagonjwa la kusaidiana? Mahali ambapo kundi hili hukutana ili usiende mara kwa mara katika hospitali?
[ ] Ndiyo; [ ] Hapana; [ ] Pengine

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

[ ] mara moja kwa mwezi
[ ] wakati nikiwa mgonjwa tu
[ ] wakati nikiwa na hoja/swali/tatizo kuhusu VVU
[ ] mara moja kila miezi 6
[ ] mara moja kila miezi 3

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

[ ] Zaidi sana; [ ] Pungufu; [ ] Hakuna tofauti; [ ] Sina hakika

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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
[ ] 100,000 Tsh to 500,000 Tsh
[ ] 500,000 Tsh – 1,500,000 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.
[ ] I never missed taking my pills
[ ] pharmacy stock-out
[ ] too much time lost to pick up medication
[ ] I lack support from family/friends
[ ] I lack support from hospital staff
[ ] I lack support from my community
[ ] I don't have enough privacy to take pills
[ ] I don't have enough privacy at the clinic
[ ] I don't want to take medication
[ ] The drugs make me feel sick
[ ] I am not sure the medication is working
[ ] not sure how and when to take the pills
[ ] the medication tastes bad
[ ] difficulty swallowing
[ ] simply forgot
[ ] no time
[ ] other (fill in) _____

b. Which of the following help would make you take your pills properly? You can tick more than one box.
[ ] information on when and how to take pills
[ ] better support from doctors
[ ] better support from nurses
[ ] better hospital facilities
[ ] better community support
[ ] support from traditional healer
[ ] support from family/friends
[ ] drug more easily available
[ ] less waiting time in pharmacy/hospital
[ ] new and better drugs
[ ] automatic reminders via messages/apps
[ ] less stigma
[ ] HIV education in community
[ ] 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?

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[ ] Yes; [ ] No; [ ] Maybe
Why: _____

d. What help from a fellow (or expert) patient do you feel is appropriate to support you?

[ ] driving together to hospital
[ ] help with what to say during doctor visit
[ ] provide information about my illness
[ ] motivate me to take medication as prescribed
[ ] help me to tell other people about my illness
[ ] group member picking up medication for whole group
[ ] other (fill in) _____
[ ] provide drug stock-out information
[ ] provide information about medication use
[ ] give me emotional support
[ ] help me to make friends
[ ] tackling stigma

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

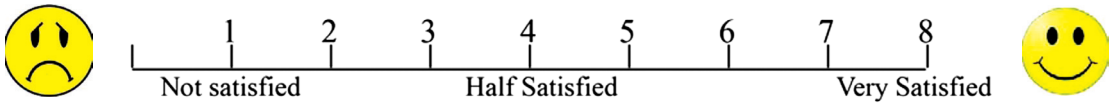
h. What would be your main concern regarding these peer support sessions? (fill in here:)

……

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)



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:

[ ] once a month
[ ] once every 2 months
[ ] once every 3 months
[ ] once every 6 months
[ ] when feeling ill
[ ] 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

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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.

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

b. Which of the following help do you think could make the patient take their pills properly? You can tick more than one box.

[ ] information on when and how to take pills
[ ] better support from doctors
[ ] better support from nurses
[ ] better hospital facilities
[ ] better community support
[ ] support from traditional healer
[ ] support from family/friends
[ ] drug more easily available
[ ] less waiting time in pharmacy/hospital
[ ] new and better drugs
[ ] automatic reminders via messages/apps
[ ] less stigma
[ ] HIV education in community
[ ] 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: _____

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d. What help from a fellow (or expert) patient do you feel is appropriate to support your patient?

[ ] going together to hospital
[ ] help with what to say during doctor visit
[ ] provide information about illness
[ ] motivating to take medication as prescribed
[ ] help to tell other people about their illness
[ ] group member picking up medication for whole group
[ ] other (fill in) _____
[ ] provide drug stock-out information
[ ] provide information about medication use
[ ] give emotional support
[ ] help to make friends
[ ] tackling stigma

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.) Do you think some patients would be interested in becoming such an expert patient?

[ ] Yes; [ ] No; [ ] Maybe

f. Would you be willing to advice and educate the expert patients?

[ ] Yes; [ ] No; [ ] Maybe

g. If yes, how often would you be willing to advice expert patients?

[ ] once a week; [ ] once every two weeks; [ ] once every month

h. What would be your main concern regarding these peer support sessions? (fill in)

_____

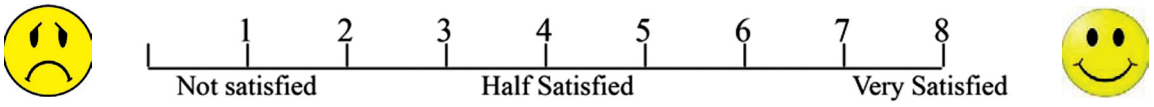
_____

DRUG DELIVERY

a. How much time does it take in total for a patient to get his medication from the clinic? (from leaving home until returning back home).

[ ] less than 1 hour; [ ] 2-4 hours; [ ] 4-6 hours; [ ] >6 hours

b. How do you think patient feel about how long it takes to pick up their medication? (draw a cross on the scale)



c. Do you think patients would consider joining a local peer support group, where they would receive their medication, so that they don't have to pick up their medicines at the hospital so often?

[ ] Yes; [ ] No; [ ] Maybe

d. How often do you think a doctor's visit is necessary?

[ ] once a month
[ ] once every 2 months
[ ] once every 3 months
[ ] once every 6 months
[ ] when feeling ill
[ ] when having concerns/issues about HIV

e. Would you think your patients would be more or less likely to take their drugs if they didn't have to visit the hospital as often?

[ ] More; [ ] Less; [ ] No difference; [ ] Unsure

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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."

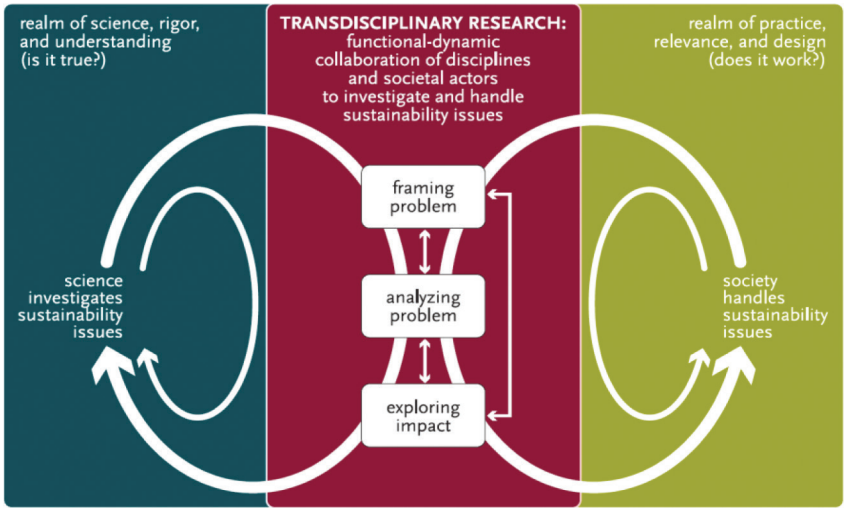

Figure 1. The transdisciplinary research process. C. Pohl *et al*

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.

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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.

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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.

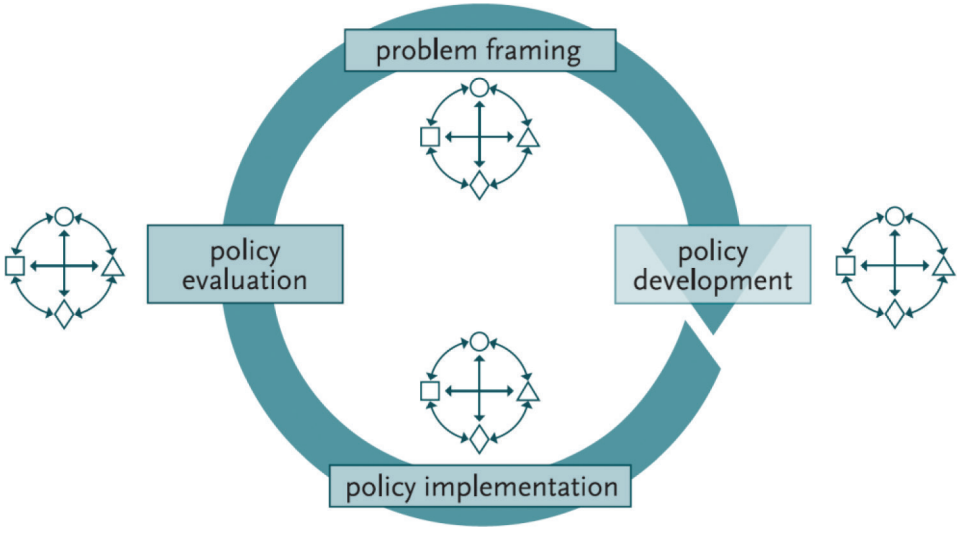

Figure 2. The four most general stages in the policy cycle. C. Pohl *et al*

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?

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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

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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.

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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)

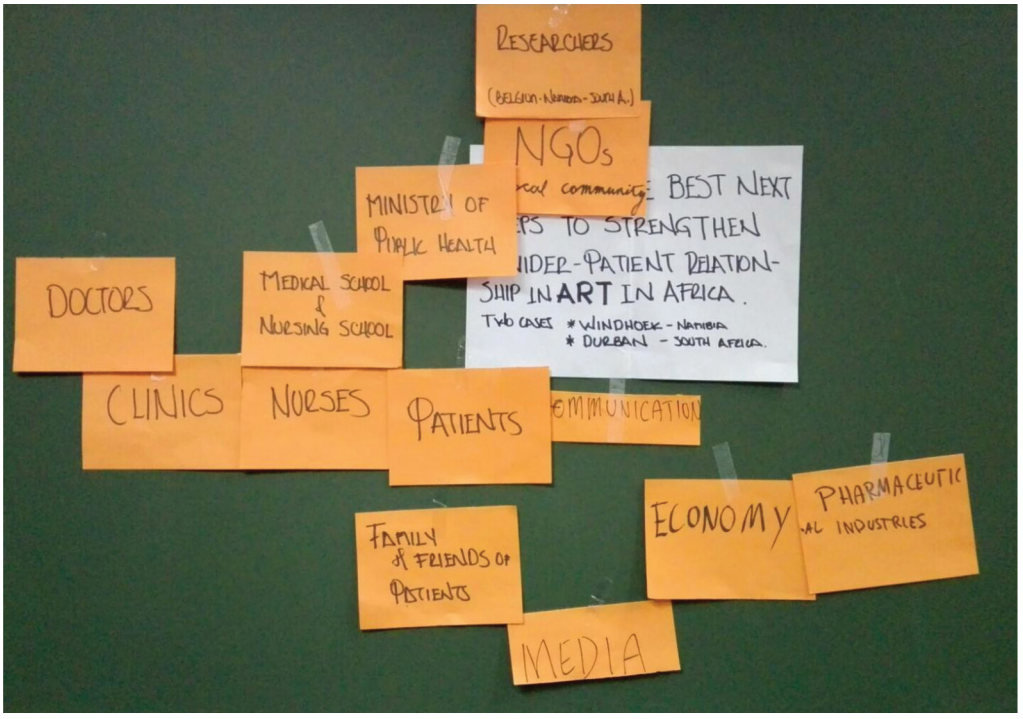

Figure 3. Output of the actor constellation workshop on this challenge

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)?

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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 Sangeda (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."

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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