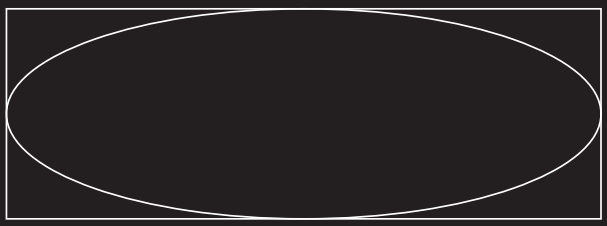
Foreign Bodies

give / take
lose / make
voice



Foreign bodies

Foreign Bodies is an untraditional curriculum designed for PhD candidates and initiated in Maastricht, NL in partnership with the University of Maastricht's Philosophy of Public Health deptartment and the Jan van Eyck Academie (a multiform institute for fine art, design, and reflection).

Foreign Bodies takes a single and specific 'care' project and places it into a 'culture' context: so that knowledge may travel both inside and outside traditional methods of research and communication towards unintended audiences.

The first Foreign Bodies project took place in February/March 2015.

Participants

KARISA SENAVITIS and KEVIN O'NEILL are a design/research partnership called Will Work for Good (WWFG). They initiated Foreign Bodies while at the Jan van Eyck Academie. Recently they were part of a multi-year program developing outcome-driven global public health initiatives. Their current research is an ongoing collection of texts, images, and playlists, sorting out the sounds of subjectivity and unregulated design practices of big biodata.

LLOYD AKRONG is a PhD candidate at the University of Maastricht. He is focused on the collaborative processes and the policies of clinical trials: questioning whose voices are silenced and whose voices are heard. He engages in field research during clinical trials of Malaria + HIV trials initiated in the UK and executed in Tanzania and Ghana.

Theme

The theme acts as a guide for identifying and questioning: levers to access, infrastructures for encounters, methods of knowledge generation + sharing, and the languages and standards of research.

give / take
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Phase 1

Senavitis and O'Neill programmed screenings, readings and workshops based in design research that were open to the residents of the Academie. It worked to build understanding of each other's worlds: Akrong's in the "soft" science of medical ethics research where he is interested in clinical trial participants influencing forms of governance, and WWFG's as "design thinking" consultants interested in formulating new questions for those designing high risk groups. This immersion period was helpful in approaching complex issues and theory with very different methods.

Program

——Group reading of *Taking Voice Lessons* by Greg Bordowitz
——Give/Take/Lose/Make Voice presentation by Karisa Senavitis and Lloyd Akrong

——Screening of *The Falls* by Peter Greenaway
——Group reading of *Woman, Sabotaj, and Underground Food Economies in Haiti* by Myron Beasley
——Workshop and presentation on design research by Femke Herregraven
——Group reading of *Ethical Encounters: the other, others and strangers* by Sara Ahmed
——Workshop and presentation on political optics + prejudice by Regula Stampfli

Outcome

The first phase confirmed that there is an interest in issues of care among the culture community (15+ of the 35 Van Eyck participants attended events or signed up for updates); and that scientific research could, when informed by art/design methods take on other directions or inquiries. New questions were raised: Whose actions and voices are we paying attention to? How is consent understood in different

cultures? How does the physical infrastructure enforce who listens and who speaks? How does data reinforce/diminish prejudices? What can an image tell you?

The output of this phase was a visual exercise based upon some field photographs taken during Akrong's clinical trial visits.

signs of infra–structure: direct + indirect

Set #1
Between Access and Participation

img01
Clinical trials are meant to be a way to provide access to essential medicines and health care. In this case, access to such services was literally on the other side of a guarded door. Those coming to this healthcare institution had to explain to the guard what they were doing there and in a very realistic way, he was the gatekeeper of who was allowed to enter and who was not. Being involved with the clinical trial was shown to be a way to easily access the premises as mentioning it literally led to doors being opened.

img02
There was great contrast between the space provided for people to wait to either see the regular hospital staff or for those waiting to see staff that were a part of the clinical trial. In the clinical trial waiting area, there were several benches provided, and importantly roofs that provided shelter from the sun, which could be quite intense at times. The visual makes one think about the non-medical related benefits that come along with being part of a trial.

Lloyd Akrong provided img01-02 and their descriptions as a starting point for the Q&A, which is an amalgamation of many voices + conversations shaped to read like a two person conversation.

Q— *How does local infrastructure reflect the international system?*

A — The resources for care are limited unless there is benefit to the markets funding international trials. Clinical trials can benefit scientists I am friends with, researchers I admire, and the doctor who plans her holiday time for volunteerism. Their theories, grants, and altruism contribute to imbalanced treatment. I am also benefiting from the results of the trial: they will make my healthcare experiences safer or my choices broader. In a way, my healthcare spending will repay the cost of the perks received to participants here.

Q— *What are similar structures applied at the European end of the system? Can you make a comparison?*

A — **img03** below reminds me of **img01**. It is the Institute for Tropical Medicine in Antwerp. It fits in discreetly with its surroundings: with its neutral, manicured exterior. The only sign of people was a bicycle out front. I wonder how the students and scientists inside, the ones who come from all over the world to study here, find this place? It seems like you have to be "in the know." How do people in Belgium connect with those in Nepal and Burkina Faso? And why Belgium? I imagine the Institute's origins are colonial ties to Congo. But I am not really sure. The wall does not appear to be there for security purposes. It looks mainly decorative and easily scalable. Not that that's necessary. The gate is open and unguarded.

img03

Set #2
Preventing Access to Participation

img04
On one particular day during my fieldwork, there was an annual research meeting planned, with presentations given to members of the institute staff, special guests from the supporting institutions abroad, and a couple members of government. Although the focus of this meeting was on the scientific work being done at the institute, although the need to have actors from a wide range of groups represented was reiterated several times, it was interesting to note that there was a lack of representation from members of public groups (i.e. community board representatives, patient groups, or patients themselves) present at the meeting. With this photo I thought how the course of conversation could have evolved during the day if the empty chair was filled with voices from public groups or trial participants.

img05
The field station visited in Tanzania was an interesting place for a couple reasons. First, it had a mock hut set up towards the back of the grounds where they were testing anti-mosquito technologies. It showed that they were not only hosting foreign clinical trials, but were engaged in the actual science of developing locally relevant technologies for the local community. Secondly, even though it was conducting research meant to benefit the local community, the station itself seemed geographically distant from local communities.

Lloyd Akrong provided img04-05 and their descriptions as a starting point for the Q&A, which is an amalgamation of many voices + conversations shaped to read like a two person conversation.

Q— *How do short distances and inconspicuous obstacles reveal broad and far-reaching structures and systems?*

A — Exclusive locations and limited times of engagement consolidate power and narrow the range of outcomes and promises geared towards local communities. This ensures the process is not impeded, so my friends will get their trials done in a timely fashion and the outcomes can impact the international health community more directly than if there was more emphasis placed on regional needs and priorities. The empty chair and the central station are in the interest of international visitors (more convenient to reach from the airport) and the institutions they represent. This small logistical accommodation represents a larger commitment, ensuring my countries' financial investments and health outcomes will be prioritized and protected. When things get personal they get messy. It is easier to administer methods to the exclusion of those making sacrifices or most personally effected.

Q— *What are similar structures applied at the European end of the system? Can you make a comparison?*

A — **img06** below reminds me of **img04**. The TB and HIV landscape analysis meeting was supposed to take place in Tanzania, during a conference. But the conference got postponed so our meeting happened in Beerse, Belgium. We spent two days, here, at the home of the late Paul Janssen— one of the most prolific drug discoverers of the 20th century. Today, 5 of his discoveries are included on the WHO Essential Medicines list. There's no real signage or anything to speak of -- it looks like a nice private residence. Now it's used by Janssen for intimate executive meetings. It was very isolated… set back off the street. Chauffeurs came and left so there weren't even cars parked on site. The grounds were constantly being maintained— for purely cosmetic reasons.

img06

img07 below reminds me of **img05**. This is a break-out group during a visioning workshop to form teams in global public health initiatives. It took place in a Mechelen convention center. I remember thinking management took the whole "white space thinking" a bit literal. The room was like entering some brutalist vision of heaven. They had to play a game where only the person holding the marker could speak. So maybe they were just shamed into submission by the HR tricks, and that's why the conversation was stunted. I noticed the people from the business and policy side were almost all white. The only people of color tended to be scientists doing research for therapies and compounds. The event was mostly attended by people based in North America and Europe… anywhere further and it wasn't a justifiable travel expense. But most of the initiatives discussed were really for markets in South America and Asia Pacific. Some wanted to include Africa but there was push-back from the leaders saying this was the realm of charity and not the mission of their group. It seems like the one empty chair stood for a lot of missings.

Q— *Bringing together the left and right images from the comparison exercise, do we get a stereo image? Are the similarities only formal?*

A — Some comparisons seem to reinforce the preconception that research happens in Africa and planning/reflection happens in Europe. At every stage of public health governance we can see infrastructure + logistics are used as tools to limit access and exclude voices. We can also see that with greater distance between groups, it becomes less obvious (you do not see who is left outside the gate, you can't compare services side by side).

img07

Q — *What other infrastructures restrict access?*

A — The context of conversations has a direct impact on the kinds of communication taking place. An interview with the same person would be very different if it took place in a medical facility or a restaurant. Often times, people want to anticipate your motivation and respond accordingly – you might not get an honest answer in a very official setting. Many participants have questions or ideas they might not be comfortable addressing directly to experts. They'd prefer to speak to a peer, like a former participant. When entering a new setting, sometimes it's best to just be around and visible for a few days so people are used to seeing you before launching into investigations. You will have very little access to participants initially. I could look for informal infrastructures that act as access points.

When medical journals have expensive subscription fees it limits the access of research findings. Many participants in clinical trials cannot afford to access the publications nor have the technical means to do so. The language used in publications limit audiences too. The ethical standards and scientific protocols have a limiting effect on publishing content/methods – going beyond the familiar can limit your potential outlets for publishing and therefore your audience. But you could also see it as a chance to consider less tradition outlets for communication.

Visas and passports limit who gets to attend which conference, etc. And I'm also thinking about technologies… who has a good phone connection gets to have a stronger voice on the conference call. I notice people often put themselves on mute during conference calls. This can be a kind of withholding or refusal. It can also be accidental and have damaging consequences. In the same vain, if you participate in fancier remote kinds of conferencing, like a 'global connect,' then only people with that kind of infrastructure/technology have full access to communication. Maybe I'm fixating on remote conferencing but time differences also limit access. The more time zones need to be incorporated, the more difficult it is to schedule a conversation and so one region always has to compromise or be compromised.

Q — *Could you reproduce this exercise in other contexts?*

A — Yes, I could see it being useful in certain workshop settings or even incorporated into my presentations. I would not provide the answers but allow the group/audience to respond with their own.

The second month we conducted skype interviews with public healthcare experts. By speaking with stakeholders in pharma, academia, and ngo's, many observations were made and new insights were gleaned. The interviews were all conducted via skype.

Program

——Guy Nuyts, Senior Director of Pricing and Access at Janssen Pharmaceuticals, BE
——Rafaella Ravinetto, Head of Clinical Trials Unit of Switching the Poles Clinical Research Network at the Institute of Tropical Medicine in Antwerp
——Jayasree K Iyer, Head of Research at the Access to Medicines Index Foundation, NL
——Jaqueline Broerse, Head of Science and Communication at the Athena Institute, VU University Amsterdam

Outcome

The interviews identified other stakeholders, contradicting policies, issues with ethical standards, and the opposing thinking different sectors continue to enforce while recognizing they must work together. Our methods demonstrated an 'impartial' convener like the culture/arts sector could offer a platform for dialogue where less guarded conversations can occur than those happening within the healthcare field.

The output of this phase was an assessment of commonalities and discrepancies that emerged from the interviews, which influenced Akrong's next phase of fieldwork (for instance: connecting with traditional/tribal medicine trials to compare local vs international methods. See the following:

Quotes

What we heard from the voices shaping biomedical research policy:

"Now there's also hurdles, and so we are not supposed to hear from them. We are not supposed to know, actually, who's in the clinical trial."

— Guy Nuyts

"The research is not finished when I have the results; the research is really finished when the product is available to the people in need, which is really nicely said and not really easily done."

— Rafaella Ravinetto

"I don't think we've solved that, and if we don't solve that, then there are going to be voices, significant voices, that are going to be unheard."

— Jayasree K Iyer

"As being irrelevant – as being a subject, instead of a person."

— Jacqueline E W Broerse

Commonalities

Everyone agrees that more voices need to be heard. Pharma needs to hear more from doctors and patients but conflict of interests keeps them apart. And this is something everyone struggles with: how to convene parties together in a fair and productive way?

Everyone is lagging behind in consent procedures for populations new to research practices. Research in a community should have local benefit and impact the local health system – but this is not a clear message. And post trial access for clinical trial participants lacks clarity in guidelines, responsibility and obligations. From an academic perspective to get the funds to conduct local assessment of custom/language/ etc. would require convincing the donor and the donor would be convinced by updated regulation standards. Regulation issues remain in academic discussions and don't impact global guidelines. Although the regulations are adapted/ interpreted by all parties depending upon the setting/context. An important limitation of ATMI is its index bases ethical ratings on these outdated standards.

Clinical trials in resource limited settings have unique ethical issues that may not be addressed formally but exist due to "indirect benefits" like travel money and access to free care + check ups.

Generics are produced at high qty and lower cost, sometimes pre-patent expiration, to serve poor populations. The issue of counterfeit drugs distracts from the efforts needed to protect patients from "legal counterfeit": under-regulated drugs approved for market that may cause harm or death.

Patients are critical of what is measured in clinical trials and want to be informed on final outcomes and debriefed on intermediary results.

Stigmas, norms, and comfort with what is familiar + proven limit organizations appetite to change their operating/business models.

Discrepancies

Accountability is slippery and changed in every conversation. Everyone seems to think they should be developing broader partnerships but, due to issues of misaligned incentives and distrust, most parties don't feel they would be the appropriate convener to instigate the conversation. They name another group and the group they name names another group and so on.

People within NGOs see national regulations as one way of updating clinical trial protocols. But pharma's policy in resource limited settings is determined more by the lobbying and procurement of NGOs than by any national government.

Patient empowerment is

encouraged by advocacy groups and foundations but laws/policies are in place to keep patient voice/identity at a distance.

Issues of drug access and drug quality insurance suffer the same inequities but are not measured the same.

Inquiries

How to begin with developing countries' input when measuring and planning for developing countries' health interventions? How can locals set agendas for every stage?

How to measure the effects of lobbying and publishing on access to medicines?

Lloyd is working within larger, more well-established institutions. How does he broaden his work to smaller local alternatives contributing to capacity building?

Epidemics allow researchers to gather lots of data quickly. And in emergencies there is no time for inclusive patient participatory processes or rigorous regulatory structures. So what can be designed ahead of time to ensure a response to an outbreak does not revictimize or exploit vulnerable populations?

Participants in clinical trials want peer contact. Can past clinical trial participants act as assistants to current patients to answer their questions, etc?

Community advisory boards and inclusionary policy methods often are tactics to ensure consent but how can they be developed or positioned to challenge the researches when needed?

How can an African context reshape what the idea of clinical research is about? (different meanings of self, community, etc.)

Chronic diseases build associations but what is often lacking is solidarity for diseases such as Malaria. Is patient-advocacy needed?

Knowledge co-creation is not properly acknowledged in medical ethical approval which can limit who will participate and who will publish. What opportunities could come from this categorization?

What is going on with healthcare in developing countries outside the traditional financial models and outside big pharma?

Conclusion

WWFG and Akrong drafted a proposal for a third phase of the project: where culture + care panelists convene in a two-day symposium of collective inquiry. To receive a copy of testimonial and proposal please contact: karisa.senavitis@gmail.com

Advisors

Femke Herregraven (NL) is a designer and researcher whose work traverses the contemporary realms of global finance, geopolitics, network power and information politics. Her research and speculative scenarios address the deconstruction of power structures and the exploration of possible alternatives. Her work consists of texts, printed materials, information design, games, drawings and installations. Projects include Geographies of Avoidance, Schizophrenic Assets, Taxodus, Mana-batteries, and Art Reserve Bank. Geographies of Avoidance addresses the financial offshore system and avoidance of financial regulation; Herregraven is currently working on high-frequency trading.

Dr. Regula Staempfli (BE) works as a political philosopher and lecturer in Germany, France and Switzerland (Design2Context, MAZ, Fachhochschule Nordwestschweiz, SIPB, Institute for European IEW, Frauenseminar Bodensee, EHESS Paris etc.) teaching in German, English and French. She is the author of many textbooks and various scientific articles dealing, among other issues, with democratic theory, European political decision making, women's history, design, political communications and political philosophy. She has written extensively about bioethics and policies – working along the idea of people becoming living coins (f.e.: women don't have capital but are in fact capital). And in art: We don't see things how they are, we see them how we are

Guy Nuyts (BE) is a health economist and Senior Director of Global Pricing and Access at Janssen Pharmaceutica, a wholly owned subsidiary of Johnson and Johnson. His work focuses on price and reimbursement policies for infectious diseases, vaccines and global public health. Guy's work also involves the development of access policy and new access models. Guy has worked on several initiatives over the years focused on increasing access; including the formation of a Hepatitis C coalition in Romania. He is always going against the mainstream, and interested in rethinking healthcare and developing social entrepreneurships.

Rafaella Ravinetto (IT) works at the Institute of Tropical Medicine in Antwerp, as head of the Clinical Trials Unit and coordinator of the Switching the Poles Clinical Research Network. She holds a Pharmacy Degree from the University of Torino (Italy) and a Postgraduate Diploma in Tropical Medicine from the Antwerp Institute of Tropical Medicine (Belgium). After a seven-year experience as a Clinical Research Scientist in the private pharmaceutical sector, Ravinetto worked as a pharmacist in emergency and development programs in the Balkans and in Africa. In 2002, she joined Médecins Sans Frontières (MSF), following various dossiers focusing on access and quality of medicines and performing regular field assessments, mainly in Africa and Latin America. She is also an expert panel member of GlobalHealthTrials.org and the promoter of Quamed, a Network hosted by the ITM to develop and promote evidence-based strategies and policies for building universal access to quality medicines, and a lecturer on subjects related to quality of medicines and clinical research standards. She was the president of the Italian branch of MSF (2007-2011). Her main areas of interest include North-South collaborative clinical research and research ethics, particularly in relation to resource-constrained settings and vulnerable populations.

Jayasree K Iyer (NL) is a specialist in global health and neglected tropical diseases for the Access to Medicines Index. She leads the Research team at the Foundation and is responsible for the Index and stakeholder relations. She holds various postgraduate degrees (Masters and PhD) from Singapore and the Johns Hopkins School of Hygiene and Public Health. She has a career in malaria and neglected tropical disease research and development and in public-private partnerships strategy. She has worked for various non-government organizations, academic institutions and was part of the founding team of a diagnostic service company in the US. Jay was recently responsible for creating, negotiating and managing public private partnerships in R&D for medicines for global health. She is an avid writer of various technical and research reports, book chapters and reviews, along with strategy papers for medicines for developing countries and solutions for neglected tropical diseases.

Prof. Dr. Jacqueline Broerse (NL) is professor of 'innovation and communication in the health and life sciences, in particular addressing issues of diversity and social inclusion' at the Athena Institute, VU University, Amsterdam. She holds a master's in Biomedical Sciences and her doctorate at the VU University with a thesis on participatory approaches to research priority setting in developing countries. Her research is focused on methodology development for realizing a science-society dialogue in new and emerging (system) innovations in the health and life sciences. She has developed methodologies

to facilitate patient participation in health research and care, and to realize multi-stakeholder participation in national health policy. She has, amongst others, been involved as advisor and facilitator in four interactive policy-making trajectories of the Dutch Ministry of Health, Welfare and Sports. She is a member of the International Advisory Board of the Dutch Royal Tropical Institute and a member of the working group patient participation of the Dutch Clinical Trial Foundation. Furthermore, she has been appointed Principal Investigator at the Centre for Society and Genomics.

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Foreign Bodies #1
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Van Eyck, multiform institute for fine art, design and reflection in Maastricht, NL.
Lex ter Braak, Director, Van Eyck
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