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Editorial: The Value and Timing Context of a Living Paper

At the start of this Covid-19 pandemic, in February 2020, scientific information about the virus and the pandemic was scattered across scientific journals, pre-publication repositories, blogs and social media. We understood that scientists would benefit greatly from an overview of the evidence and its understanding by experts. Updating this understanding as papers were published, or not, and as new data became available in the same scattered way is very challenging for scientists. We decided to help our scientific colleagues by updating, on a weekly basis, a "Living Paper" that would be as complete as possible given the time constraints, and called it "Covipendium". Our Transdisciplinary Insights eJournal offered from the beginning to publish the final version of the paper, at the end of the updating road. That is how the separate section, "Living Papers", arose.

One year into the pandemic, sufficient other reliable sources of scientific information are now available such that there is no longer any urgent need to keep the Covipendium updated on a weekly basis. We refer readers to other excellent web-based initiatives, such as the WHO's Covid-19 database (https://www.who.int/emergencies/diseases/novel-coronavirus-2019/global-research-on-novel-coronavirus-2019-ncov) or the "Covid Reference" by Kamps and Hoffman (https://covidreference.com/). The last Covipendium update was issued on 20 October 2020, and it is now ready for publication in our journal (https://doi.org/10.5281/zenodo.4273202). The editorial office chose not to submit this final version to a regular reviewing process, as this would trump the purpose of the document, i.e. to be a testimony of how a living document arises and evolves. Nevertheless, reviewers were solicited and their comments published alongside the Covipendium. In this way, our readers can appreciate the opinion of other experts in the field.

Between 20 October 2020 and 2 January 2021, the time of writing this editorial, a PubMed search on the terms [SARS-CoV-2 or Covid-19] identified 28,256 new publications. In comparison with Zika, for which Pubmed identifies a total of 8,807 articles, such a large number of publications to monitor each week is insurmountable in keeping a Covid-19 living paper up to date. How can we explain the extraordinary abundance of Covid-19 publications? It would be naive to think that each paper has been written with the objective of helping the medical/scientific community better manage the pandemic. Publishing is essential to many careers, creating a perverse incentive to publish, rather than to have societal impact, in order to keep afloat in the competition for a position and funding. As Marilyn Strathern wrote: "When a measure becomes a target, it ceases to be a good measure". Undoubtedly, other incentives include the passion of researchers about their work, as well as scientific egos. The success of non-peer-reviewed publishing platforms, such as MedRxiv, has made publishing a scientific paper much easier in these troubled times when the need for rapid dissemination of information seems to take precedence over the quality

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of the content. The scientific literature on Covid-19 is therefore characterised not only by its quantity but also by its often highly inadequate quality, its incredible redundancy on certain subjects, and its shortcomings in other less-studied areas. This begs the question how we can ensure a comprehensive and critical overview of the literature for scientific researchers. The growing set of artificial-intelligence (AI) tools still needs improvements, but may progressively replace typical PubMed or Google Scholar searches, and help researchers sift through massive amounts of literature (see for instance https://www.nature.com/articles/d41586-020-01733-7).

We continue to have mixed feelings with regard to this publishing revolution. We feel the need for change in our research practices as well as our communication on infectious diseases and their control. We dream of a more virtuous scientific world, a more open-minded spirit, and better connection to the field. The Institute for the Future at KU Leuven, the founder of this eJournal Transdisciplinary Insights, believes in a transdisciplinary approach to wicked problems, as most health problems are. Knowing that more and more scientists share this holistic vision, we are convinced that renewal is underway.

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The Impact of Community Health Workers on HIV Therapy Outcome in Sub-Saharan Africa

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Abstract

In sub-Saharan Africa, the burden on HIV care givers is high. This resulted in renewed interest in community health worker (CHW) programs. We conducted a review of the literature to summarize CHWs' effects on HIV therapy outcome. We also investigated which CHW tasks might favorably impact treatment outcome.

We conducted a comprehensive literature search in PubMed, Web of Science and Embase for papers published up to October 2018. The studies included were conducted on HIV-positive adults in sub-Saharan Africa and reported biological HIV outcomes. We systematically collected data on HIV therapy outcome and CHW tasks. We used Bayesian network modelling for the analysis of CHW tasks.

We included 19 studies in total: 4 randomized controlled trials, 8 comparative cohort studies and 7 single arm interventions. In all studies, CHW interventions were beneficial or not inferior to standard of care (SOC). The more common tasks of CHWs involved an important human support component, with home visits being the most common task. Upon analysis we found indications that ART delivery, individual adherence support and frequent home visits were predictive of a successful CHW intervention, defined as improved therapy outcome compared to SOC or reaching 90% of treated patients being virally suppressed.

We found that CHW interventions are not inferior to SOC and might even be beneficial. We hypothesize that ART delivery, individual adherence support and frequent home visits are predictive of a successful CHW intervention. Further research is needed to be able to judge whether any single task or a particular combination of tasks is significantly correlated with a successful CHW intervention, or whether such tasks are context specific.

Key words

Community health workers, Baysian network modeling, HIV.

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Evidence before this study

Over the past decennia, there has been renewed interest in community health worker (CHW) programs in HIV care in sub-Saharan Africa. It is widely assumed that CHW interventions are not inferior to standard of care (SOC) in terms of antiretroviral therapy outcome, but little high-quality evidence on large-scale CHW interventions is available. In two reports, the WHO stresses the importance of community level interventions for people living with HIV. In the context of HIV and AIDS, CHWs are commonly trained to fulfil tasks in prevention, counselling, treatment support and care[4]. However, it is unclear which exact tasks of CHWs are most beneficial to improve HIV treatment outcome[13,14].

Added value of this study

With our literature review, we add evidence to the assertion that CHW interventions are not inferior to SOC. Further, we aimed to document which tasks of the CHWs are most beneficial. Although we did not find evidence of a single task or combination of tasks correlating significantly with better HIV therapy outcome, we present indications that ART delivery, individual adherence support and frequent home visits are the most important contributions of CHWs to improve biological treatment outcomes of HIV-patients.

Introduction

In sub-Saharan Africa (SSA), 25.7 million people are living with HIV. This corresponds to 70% of all people living with HIV in the world. In 2014, UNAIDS published the 90-90-90 goals, defining 3 targets by 2020: 90% of all people living with HIV must know their status, 90% of all people with a diagnosed HIV infection must receive sustained antiretroviral therapy (ART), and 90% of all people receiving ART must have viral suppression. By 2017, eastern and southern Africa reached 81%, 66% and 52% for those targets, while western and central Africa reached 48%, 40% and 29% respectively. In comparison, western and central Europe and North America reached 85%, 76% and 65% of the three targets in 2016[1].

Over the last decennia, the rapid scale-up of HIV testing and treatment proved instrumental on the road to the 90-90-90 goals, but the health care services in many SSA countries became overstretched[2]. The majority of SSA countries has a physician/population density of less than 0.5 per 1000[3]. This leaves health care staff with little time and resources to invest in patient-centered care. Nevertheless, patients with HIV often require substantial support from their health care provider to achieve optimal therapy outcomes. They need to be retained in care for their whole life and need to adhere to daily ART, a huge challenge for many patients.

As a response to the health worker shortage, there has been renewed interest in community health worker (CHW) programs[2]. The phenomena of CHWs emerged in the mid-1950s, when community members were used to render basic health services to their communities. In the early days, a CHW was not only a health care provider, but also acted as an advocate for his or her community. Although nowadays CHWs mainly focus on health issues, their strong link with the community is still of major importance for their successful implementation[4]. A comprehensive description for their relation with the community was given by Giblin[5]: 'Indigenous qualities include, in most general terms, the possession of the social, environmental, and ethnic qualities of a subculture and, in more specific terms, a sharing with a client of a verbal and nonverbal language, an understanding of a community's health beliefs and barriers to health care services, and an enhanced empathy with, and responsibility towards a community and its health service needs.' CHWs are sometimes referred to as 'cultural brokers', since they understand the sociocultural norms of the communities. As such, they can act as intermediaries between the communities and the health sector[6].

At present, there is a wide range of CHWs with an even bigger variety in health-related tasks[4]. Depending on the country, these tasks generally include: home visits, environmental sanitation, provision of water supply, first aid and treatment of simple and common ailments, health education, nutrition and surveillance, maternal and child health and family planning activities, communicable disease control, community development activities, referrals, record-keeping, and collection of data on vital events[7]. In the context of HIV and AIDS, CHWs are commonly trained to fulfil tasks in prevention, counselling, treatment support and care[4].

The positive impact of CHW programs on ART outcome in SSA is widely assumed[8]. Additionally, several recent reviews stress that optimizing existing services, such as CHW programs, are a promising way to improve adherence to ART[9–12]. However, little high-quality evidence on large-scale CHW interventions is available[4].

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In two reports, the WHO stresses the importance of community level interventions for people living with HIV. Yet, it is unclear which exact tasks the CHWs need to fulfil[13,14]. It is important to look at existing programs to learn what does or does not work. Identifying why some CHW interventions are successful and others are not is of major importance to achieve optimal health care contribution by CHWs.

We conducted a review of the literature to synthesize the effects on HIV therapy outcome of various CHW programs implemented in SSA to date. Our primary aim was to document the current knowledge on whether CHWs can contribute to improved HIV therapy outcome in SSA. Second, we aimed to investigate which tasks are commonly assigned to CHWs, and which CHW interventions might favorably impact the treatment outcome. As such, this literature review focuses on the last goal of the UNAIDS 90-90-90 goals.

Methods

Definition of CHW

In order to have a clear understanding of what a CHW is, we use the definition given by the WHO: 'community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers'[4].

Surrogate markers for HIV therapy outcome

For the measurement of HIV therapy outcome, we used the proportion of patients with undetectable viral load (VL), increase in CD4 cell count and time to treatment failure as surrogate markers. VL and CD4 cell count give us an idea of the patients' response to the HIV therapy, as the goal of the therapy is to reach and maintain VL suppression and to increase CD4 cell count. Treatment success was defined as reaching VL suppression in at least two consecutive measurements within six months of start of ART therapy, and as maintaining VL suppression during the study period; otherwise the patient was classified as having treatment failure, irrespective of CD4 count. For VL suppression we adopted the cut-offs as used by the included papers. The majority of the papers defined VL suppression as less than 400 copies per milliliter, while in some papers the cut-off was set on less than 200 copies, 500 copies or 1000 copies per milliliter. In absence of VL measurements, patients were usually classified as treatment experiencing success if the CD4 cell count increased above 200 cells per microliter of blood. In case of CD4 cell count follow-up above this threshold, a gradual increase until a healthy count is reached is indicative of good treatment response[15]. CD4 count was not used to define treatment failure.

Standard of care (SOC)

SOC was equivalent across all studies. In SOC, patients were seen at the clinic by a nurse and/or a clinical officer and/or a doctor. SOC consisted of health assessment, adherence assessment, HIV education and counselling and prescription of ART for one, two or three months. Patients then had to present to the pharmacy where ART was dispensed according to national guidelines, which were roughly similar in the various countries of the studies. In the event that the CHW intervention took place outside the clinic, patients had to visit the clinic less frequently than under SOC.

Search strategy and study selection

Between June 2018 and October 2018, we conducted a comprehensive literature search in PubMed, Web of Science and Embase. The inclusion criteria for our search were: studies had to be conducted in SSA, had to report biological HIV outcomes (viral load or CD4 cell count) and had to report on the contribution of CHWs, as described by the definition of the WHO, on HIV therapy outcome. Studies on children or on the co-pathology of HIV and tuberculosis were excluded. Ongoing trials without preliminary results were excluded. The full search strategy for each of the three databases is available in Supplement 1.

Data extraction and analysis

Data extraction from the literature was performed using a specific extraction format in Excel, including the literature reference of the study, purpose, design, intervention under study and duration, tasks of CHWs during the intervention, demographics of patients and the HIV therapy outcomes. A narrative summarizes the results of the primary analysis, in which we describe the impact of CHW interventions on biological HIV outcomes. For

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the secondary analysis of CHW tasks, we looked at the different tasks CHWs performed in each study. We studied the distribution and character of the tasks quantitatively and qualitatively. With the help of B-course[16], a program for classification and dependency Bayesian network modelling, we exploratively visualized the conditional probabilistic dependencies between a specific variable or combination of variables and successful CHW interventions. For the explorative analyses we defined a CHW intervention as successful if the CHW intervention led either to significantly better therapy outcomes compared to SOC or to at least 90% of treated patients reaching viral suppression. The data set used for the Bayesian network modelling included as variables: success of the intervention, study duration and the tasks performed by the CHWs. An extended methodology on B-course and our data set can be found in Supplement 2. For the explorative dependency model, B-course predicted if connections were likely to be directed, mutual or undefined. We manually identified whether a connection between two variables as presented by B-course was likely to be positive, negative or undefined by plotting the two variables against each other in Excel. Since B-course could not depict this type of connection, we used Kumu[17] to reconstruct the dependency model with connection types. After obtaining both the explorative classification and dependency model, we compared the two models. A narrative summarizes the results of the secondary analysis.

Results

Characteristics of included studies

The literature search resulted in 205 records, of which 26 papers were retained. After reading the full text of the papers, 8 studies were excluded. 1 study mentioned by an excluded systematic review was added since it met all inclusion criteria and had not shown up in our search. Figure 1 represents the flow chart of record and study selection.

More information on the excluded studies and on the inclusion of the additional study can be found in Supplement 3.

In total, we included 19 studies. Table A3 in Supplement 4 depicts the details of the included studies. 2 of the papers discuss large studies for which only part of the population fulfilled the inclusion criteria[18,19], hence we only included the relevant part of the population. Statistical analysis was available for the included part of the population. Of the 19 studies, 4 were Randomised Controlled Trials (RCTs), 8 were comparative cohort studies and 7 studies evaluated a single arm intervention. All the studies were conducted in Eastern Africa or South Africa, except for 1 study from Burkina Faso. Most studies were performed over an extended period of time, with the shortest study having an intervention period of 3 months and the longest study running over 8 years. Sample sizes ranged from 129 up to 6194 HIV-positive study participants. In 3 studies, research was not carried out at the time of the intervention, hence medical records were used for retrospective analysis. The total study population varied in terms of ART experience: 9 studies reported findings on HIV-positive individuals initiating ART, 4 studies targeted HIV patients on ART defined as stable, 1 study focused on HIV patients with adherence problems, and 1 study targeted both patients initiating ART and patients previously initiated. The remaining 4 studies recruited HIV-positive individuals enrolled in care, regardless of their therapy experience and adherence levels.

Effects on HIV therapy outcome

In all studies, the effects of CHW intervention on plasma VL suppression or CD4 cell count were not inferior to SOC. This conclusion is based on data from studies that compared with a comparator arm and upon comparison with other studies in case of single arm interventions, as mentioned by the studies themselves, and as confirmed by an additional meta-analysis on efficacy of CHW programs[20].

8 of the 19 studies found statistically significant effects of CHW interventions on therapy outcome in comparison with SOC (indicated with * in Table 1, Figure 2 and Table A3). Of these studies, 1 was a RCT and 7 were comparative cohort studies. 3 RCTs, of which 1 was not optimally designed to measure effects on biological outcome, and 1 comparative cohort study did not show statistically significant improvement in plasma VL or CD4 cell count. The remaining 7 studies were single arm intervention studies, hence had no comparator arm such that statistics could not be calculated.

7 of the 19 studies reported VL suppression in at least 90% of treated patients, hence reached the third target of the 90-90-90 goals (indicated with # in Table 1, Figure 2 and Table A3). Of these 7 studies, 3 had a single arm intervention, 3 were comparative cohort studies, and 1 was a RCT.

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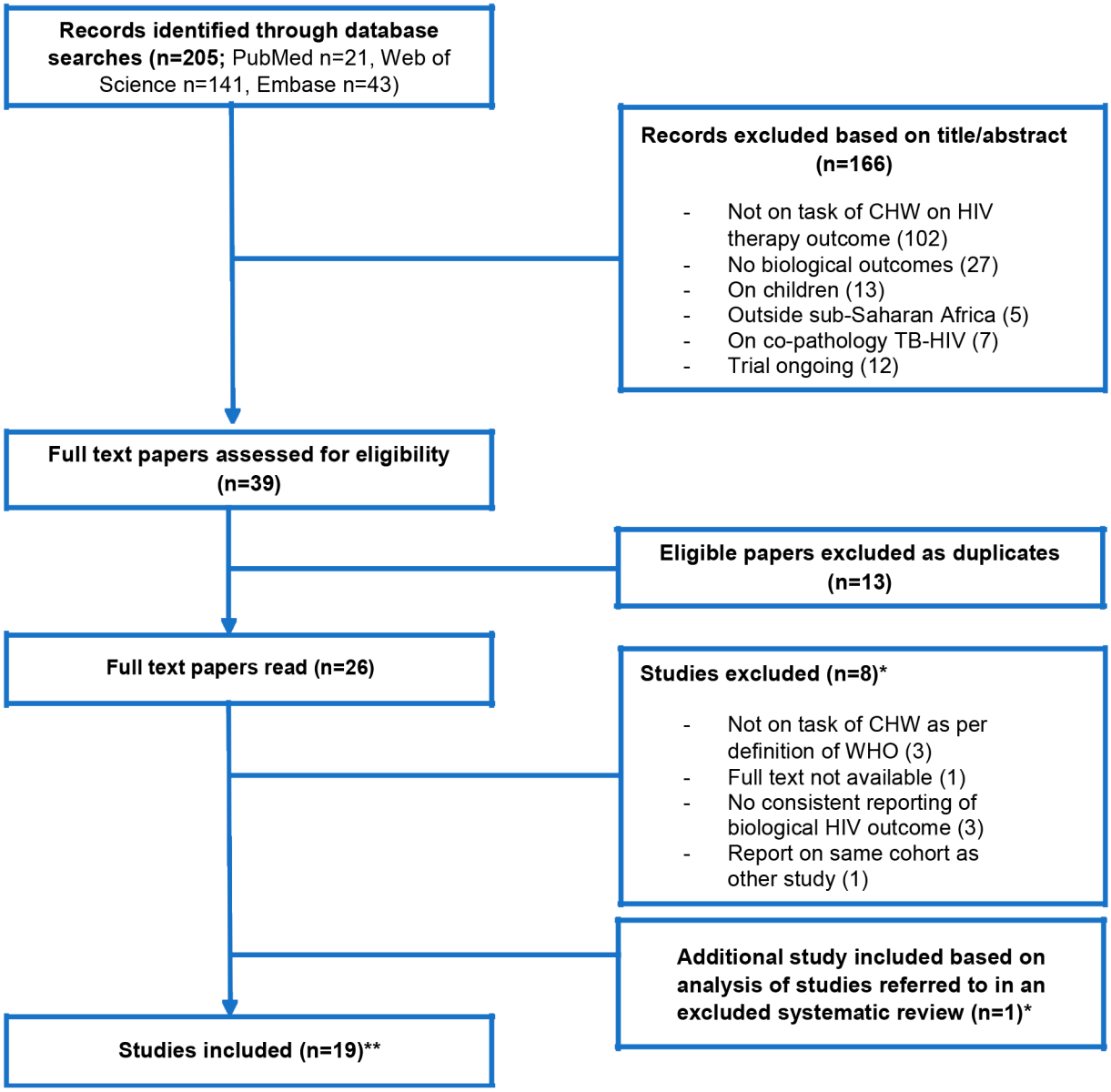

Figure 1. Flow chart of record and study selection

The number of records and the reasons for exclusion are depicted. For 2 papers, only part of the study population fulfilled the inclusion criteria. It is only this part of the study population that was included.

* cf. Supplement 3

** cf. Supplement 4

Distribution of CHW tasks

In the 19 included studies, various tasks were given to the CHWs. The tasks of the CHWs as reported in the included studies are represented in Table 1. Figure 2 shows the number of times a CHW task was performed per study outcome.

Carrying out home visits was the most common task of the CHWs. The second most common task was giving adherence support to the individual. 4 studies did not focus on the individual for adherence support but set up group adherence sessions instead[21–24]. 1 study provided both individual and group adherence support[25]. Other popular tasks were providing education and counselling and assessing the patients' health. Generally speaking, the more common tasks involved a significant human support component, whereas less prevalent tasks had a more logistic character. Conducting home visits and

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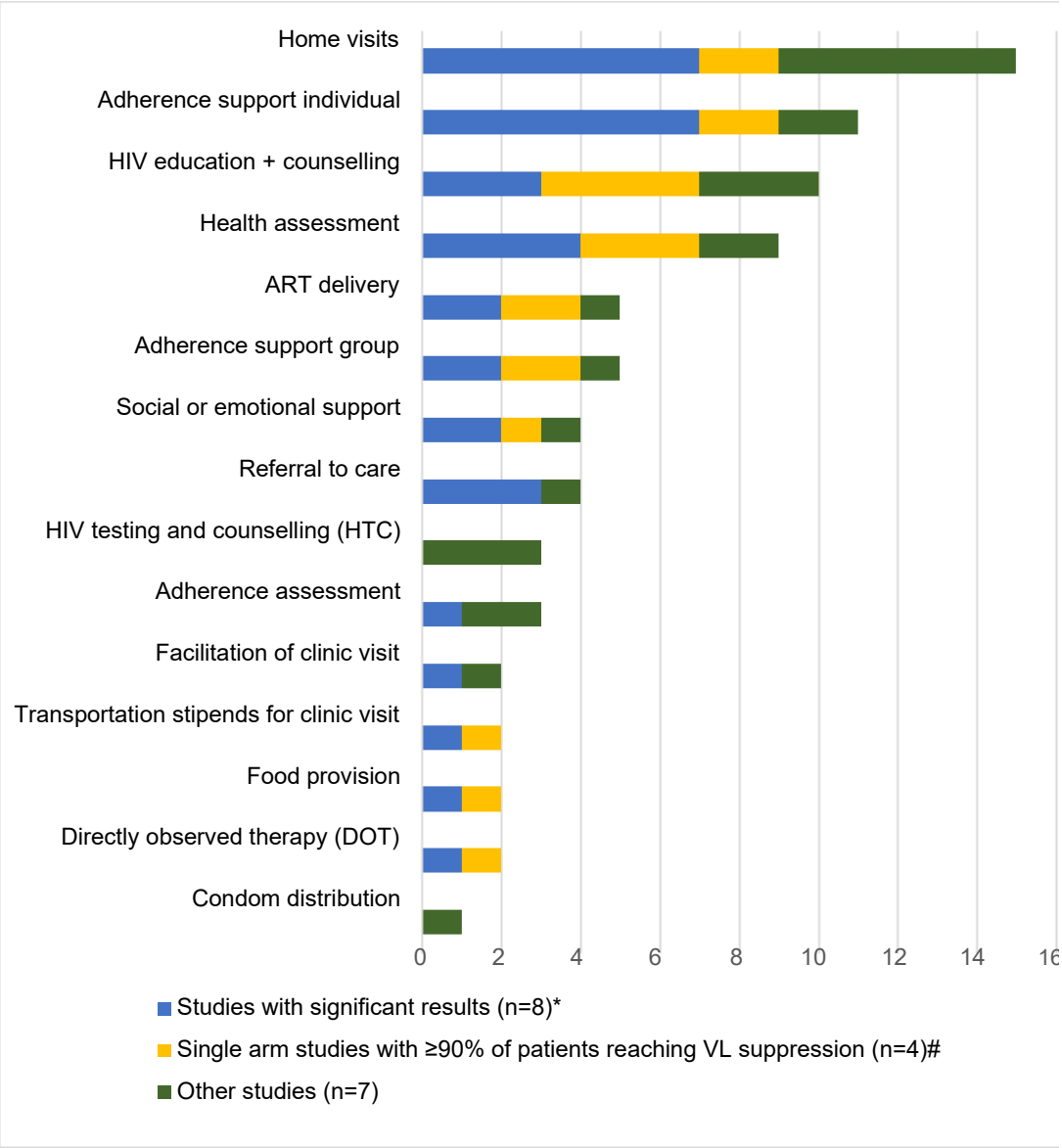

Figure 2. Number of times a CHW task was performed per study outcome
#Viral load suppression in ≥90% of patients was reached in 7 studies in total, of which 3 studies yielded significant results. Hence, these 3 studies are displayed in the category titled 'Studies with significant results'.
Abbreviations: ART = antiretroviral therapy

providing adherence support, social or emotional support, education and counselling are all tasks that require a certain amount of human interaction, time and engagement from the care provider. These tasks often help to improve the patients' well-being and self-efficacy. In all studies, CHWs covered at least one of these tasks. The more logistic tasks were often regarded as side tasks in studies where CHWs had a broad range of duties.

Whereas home visits were conducted in the majority of studies, there was a substantial variability in frequency of home visits. In studies that reported significant results or in studies with at least 90% of patients attaining VL suppression, CHWs visited the patients' home at least once a month, with a maximum visiting frequency of once a day. In the other studies, CHWs did not conduct as many home visits (cf. Table 1).

Many studies assigned a multitude of tasks to the CHWs. The median number of tasks was 4. There was 1 study in which CHWs solely had to organize the adherence support group[26]. In 2 studies the CHWs had as many as 7[27] or 8[28] tasks. The number of tasks assigned to CHWs did not impact HIV therapy outcome.

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Table 1. Tasks of the CHWs as reported in the included studies

Tasks of CHWs	Number of studies in which CHWs fulfilled the task (n=19)	Studies with significant results (n=8)*	Single arm studies with ≥90% of patients reaching VL suppression (n=4)#	Other studies (n=7)
Home visits	*15*	Achieng *(1/m)* Chang (2010)# *(8/m)* Fatti *(4/m first month, then 1/m, quarterly when stable)* Franke *(30/m)* Igumbor *(as needed)* Kipp #*(4/m)* Wouters *(4/m)*	Rich *(30/m)* Weidle *(4/m)*	Barnabas (2016) *(3/y)* Barnabas (2014) *(5/y)* Chang (2009) *(as needed)* Konate *(2 weekly visits, then 1/m)* Selke *(1/m)* van Rooyen *(3/y)*
Adherence support individual	*11*	Achieng, Chang (2010)#, Franke, Fatti, Igumbor, Kipp#, Wouters	Rich, Weidle	Chang (2009), Konate
HIV education + counselling	*10*	Chang (2010)#, Igumbor, Wouters	Grimsrud, Myer, Rich, Weidle	Barnabas (2016), Barnabas (2014), Konate
Health assessment	*9*	Achieng, Chang (2010)#, Franke, Kipp#	Grimsrud, Myer, Rich	Chang (2009), Selke
Adherence support group	*5*	Achieng, Bango#	Grimsrud, Myer	Peltzer
ART delivery	*5*	Bango#, Kipp#	Grimsrud, Myer	Selke
Social and/or emotional support	*4*	Franke, Wouters	Rich	Chang (2009)
Referral to care	*4*	Achieng, Chang (2010)#, Fatti		Barnabas (2014)
HIV testing and counselling (HTC)	*3*			Barnabas (2016), Barnabas (2014), van Rooyen
Adherence assessment	*3*	Chang (2010)#		Chang (2009), Selke
Directly observed therapy (DOT)	*2*	Franke	Rich	
Food provision	*2*	Franke	Rich	
Transportation stipends for clinic visit	*2*	Franke	Rich	
Facilitation of clinic visit	*2*	Franke		Barnabas (2016)
Condom distribution	*1*			Konate

#VL suppression ≥90% of patients was reached in 7 studies in total, of which 3 studies yielded significant results. Hence, these 3 studies are displayed in the column titled 'Studies with significant results'.

Abbreviations: ART = antiretroviral therapy; m = month; y = year

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Explorative analyses of CHW interventions

For the secondary analysis on CHW tasks, we performed explorative classification and dependency Bayesian network analyses. Since we did not have access to individual patient data, the unit included in the Bayesian network analyses was the study itself, such that connections represent differences between studies, not between patients. As mentioned in methods, we defined a CHW intervention study as successful if the CHW intervention led either to significantly better therapy outcomes compared to SOC or to at least 90% of treated patients reaching viral suppression. Given the small number of included studies and the multitude of tasks assigned to CHWs in some studies, study design is a confounding factor in the interpretation of the results. This will be illustrated with an example below.

The purpose of the explorative dependency network analysis was to uncover potential combinations of variables linked to successful CHW interventions and their dependencies. After predicting the connection types (positive, negative, undefined; directed, mutual, undefined), we reconstructed the explorative dependency model (Figure 3 and Figure 4). The original explorative dependency model provided by B-course can be found in Supplement 5 (Figure A1).

Variables directly linked with 'successful CHW intervention' were 'adherence support individual', 'HIV testing and counselling (HTC)', 'ART delivery', 'condom distribution' and 'home visits'. The types of the connections varied. The connection between 'successful CHW intervention' and 'adherence support individual' was directed and positive, hence having CHWs provide individual adherence support was predictive of a successful CHW intervention. The connection between 'successful CHW intervention and 'HTC' was mutual and opposite, hence having a successful CHW intervention predicted that HTC was not provided AND not providing HTC predicted having a successful CHW intervention. The connection between success and ART delivery was mutual and positive. The connection between success and condom distribution was directed and opposite. Conducting home visits was linked with success in a unidirectional and positive way.

In the explorative dependency network, the strongest dependencies were found between 'adherence assessment' and 'home visits', between 'health assessment' and 'adherence assessment' and between 'health assessment' and 'HIV education + counselling'. These three connections were directed and had a positive effect. If any of these connections were to be removed, this would result in a model with a probability of less than one millionth of that of the original model.

Modest dependencies were found between 'home visits' and 'successful CHW intervention' (directed and positive), between 'home visits' and 'adherence support individual' (directed and positive), between 'adherence support group' and 'home visits' (directed and opposite), between 'ART delivery' and 'adherence assessment' (mutual and opposite) and between 'referral to care' and 'home visits' (mutual and positive). If any of these connections were to be removed, this would result in a model with a probability of less than one thousandth of that of the original model.

When looking more closely at the explorative dependency model, we see that the variable 'home visits' has seven connections, of which five are modest or strong. This ratio (5/7) is higher than for other variables. The variables 'health assessment' and 'adherence assessment' have a relatively high ratio of stronger connections as well. Having a stronger connection between variables means that these two variables often appeared together in the same studies. The variables 'HIV education + counselling' and 'adherence assessment' both have eight connections, which is the highest number of connections on the map.

With the explorative classification network analysis, we aimed to investigate which variables were likely to be the strongest predictors of success of a CHW intervention. B-course indicated the variables (1) 'adherence support individual', (2) 'HTC', (3) 'ART delivery, (4) 'adherence assessment', (5) 'referral to care', (6) 'directly observed therapy (DOT)', and (7) 'condom distribution' as the best subset for predicting success of the CHW intervention. If predictor (1 or 2), (3 or 4), (5 or 6 or 7) were to be removed, the predictive accuracy of the model would go down by 17.86%, 10.71% or 3.57% respectively.

We used the knowledge from the explorative dependency model and predicted the connection types in order to interpret the predicting subset of the explorative classification model. This resulted in the following findings: (1) providing adherence support of the individual predicted success of the CHW intervention, (2) not providing HTC predicted success of the CHW intervention and vice versa, (3) delivering ART predicted success of the CHW intervention and vice versa, (4) not conducting adherence assessment predicted success of the CHW

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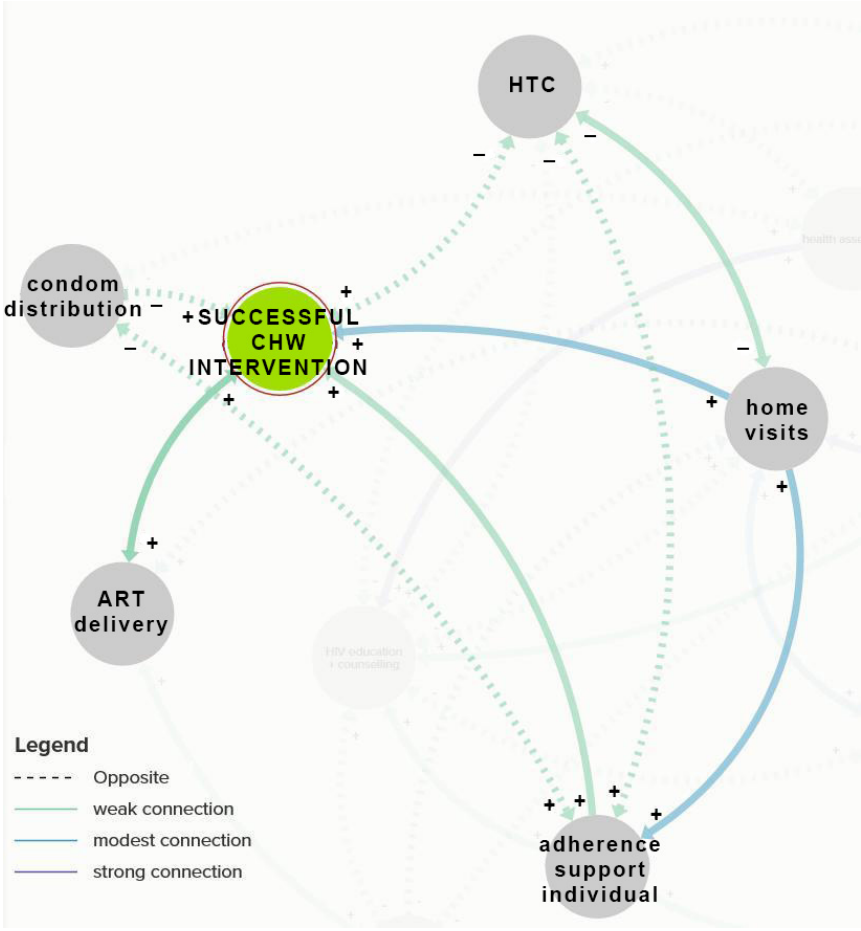

Figure 3. Explorative dependency model centered around 'successful CHW interventions'
The colors of the arcs represent the probable strength of the dependencies as indicated in the legend. Purple connections: removing such connection would decrease the probability of the model to less than one millionth of the probability of the original model. Blue connections: removing such connection would decrease the probability of the model to less than one thousandth of the probability of the original model. Green connections: removing such connection would decrease the probability of the model to less than one hundredth of the probability of the original model. The arrows indicate whether a connection is likely to be directed or mutual. The absence of arrows means that the direction of the connection could not be predicted. + and – represent the probable effect of the variables on each other. Dotted arcs represent opposite effects (+ – or – +). When no + or – is given, the dependency could not be predicted.
Abbreviations: ART = antiretroviral therapy; HTC = HIV testing and counselling

intervention, (5) conducting DOT predicted success of the CHW, (6) referring to care predicted success of the CHW intervention, and (7) not distributing condoms predicted success of the CHW intervention.

Upon comparing the explorative dependency model with the explorative classification model, we found that all the variables directly linked with 'successful CHW intervention' in the explorative dependency model, with the exception of 'home visits', were listed in the predictive subset of the explorative classification model. Conversely, 'adherence assessment', 'referral to care' and 'DOT' were indicated as predictors; however, they were not directly linked with 'successful CHW intervention' in the explorative dependency model. This means that their predictive effect is indirect through (an)other variable(s).

The models generated above have important limitations. Given the small number of included studies and the multitude of tasks assigned to CHWs in some studies, the results need to be interpreted with care. As an example, 'condom distribution' has been designated as a negative predictor for 'successful CHW intervention' in the explorative classification model. However, this connection is based on 1 study only. In this study,

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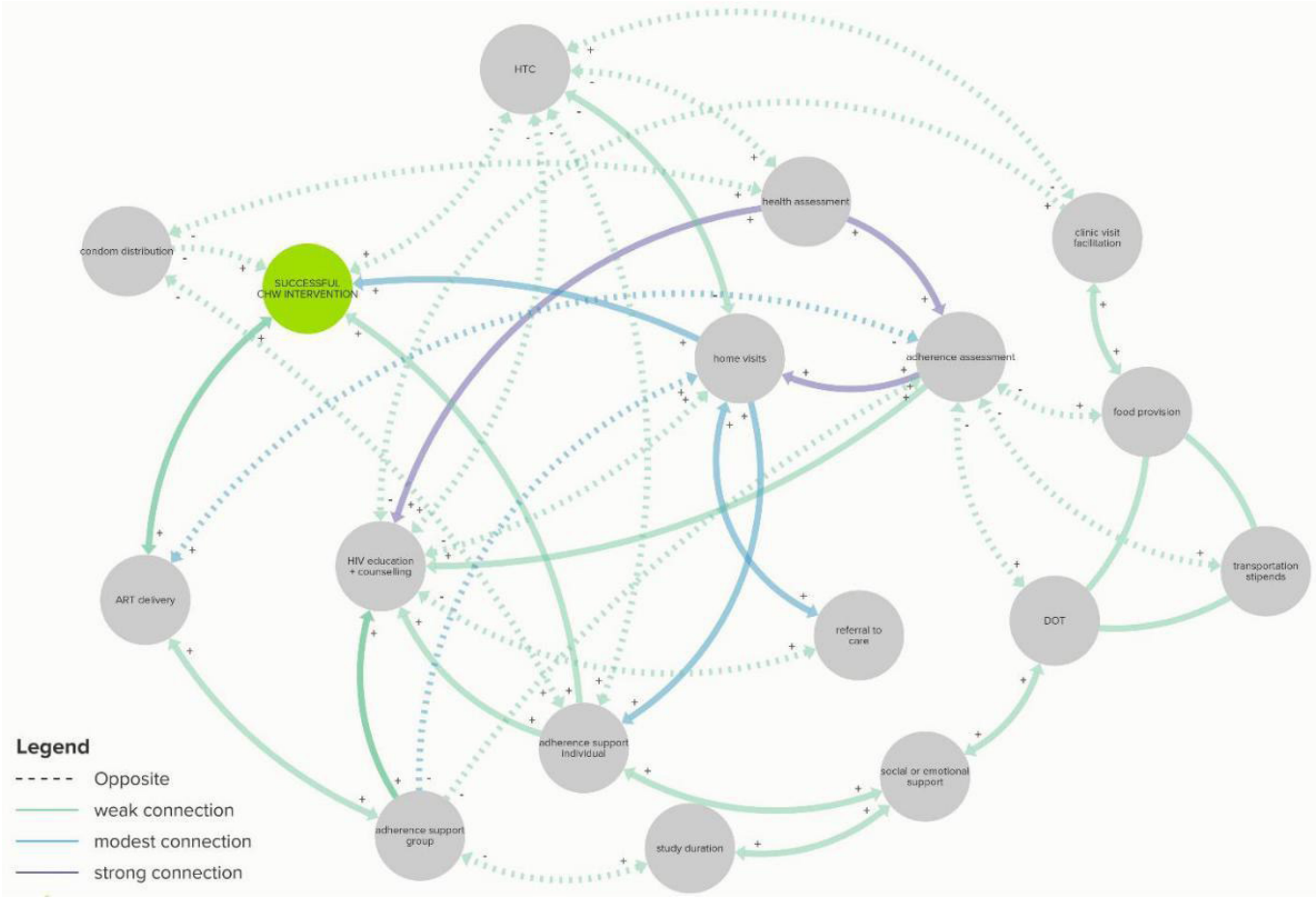

Figure 4. Explorative dependency model

The colors of the arcs represent the probable strength of the dependencies as indicated in the legend. Purple connections: removing such connection would decrease the probability of the model to less than one millionth of the probability of the original model. Blue connections: removing such connection would decrease the probability of the model to less than one thousandth of the probability of the original model. Green connections: removing such connection would decrease the probability of the model to less than one hundredth of the probability of the original model. The arrows indicate whether a connection is likely to be directed or mutual. The absence of arrows means that the direction of the connection could not be predicted. + and – represent the probable effect of the variables on each otter. Dotted arcs represent opposite effects (+ – or – +). When no + or – is given, the dependency could not be predicted.

Abbreviations: ART = antiretroviral therapy; HTC = HIV testing and counselling; DOT = directly observed therapy

condom distribution was one of the tasks and the study outcome was not successful[18].

Further, study design could also be a confounding factor in the interpretation of the results. For example, there were 4 studies that focused on stable patients. 3 of the 4 studies organized adherence group sessions with ART delivery. 1 of these 3 studies showed significant effects of the CHW intervention[21], whereas the other 2 studies maintained VL suppression in at least 90% of patients, without showing significance[22,23]. According to our definition of success, we could classify these studies as successful CHW intervention studies. In the explorative dependency model, however, we do not see a direct connection between ‘adherence support group’ and ‘successful CHW intervention’. The connection is indirect, via ‘ART delivery’. This is because ‘adherence support group’ was more frequently linked with other variables than ART delivery, hence the best way of linking ‘adherence support group’ to ‘successful CHW intervention’, with as few connections as possible, is via ‘ART delivery’. Further, of these 3 studies, both health assessment and HIV education + counselling were performed in 2 studies. However, we cannot see a link between ‘adherence support group’ and ‘health

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assessment'. Hence, a direct connection between 2 variables may be absent or present because of study design, not necessarily because of (lack of) effect. If a connection is present, but its presence cannot be attributed to study design, we can assume that the connection shows a certain effect. When we look at the variable 'successful CHW intervention', the variables 'ART delivery', 'adherence support individual' and 'home visits' seem to be positively connected independently of study design, hence we assume that these tasks are predictive of success.

Given the described limitations, the interpretation of the results is difficult, and we chose not to withhold a certain task or a particular combination of tasks as strong predictors of a successful CHW intervention.

Discussion

Over the past decennia, CHWs have emerged as the much-needed answer to the health force shortages in developing countries. The positive impact of CHW programs on ART outcome in SSA is widely assumed; however, little high-quality evidence on large-scale CHW interventions is available[4,8–12]. Furthermore, there are diverging views on what a CHW is and which specific tasks CHWs need to fulfil in order to conduct successful CHW interventions.

This literature review confirms that CHW interventions are not inferior to SOC, they can improve patient treatment outcomes, and they can contribute to reaching 90% of treated patients being virally suppressed, which is the third goal of the 90-90-90 goals. This confirms the WHO's assertion that community-level interventions for people living with HIV are feasible and must be supported[13,14]. As such, CHWs can contribute to relieving the high work load for health care workers. An important side note to make here is the possibility of bias in the published studies (unsuccessful studies may not have been published, or studies may be conducted through an intensively guided research process, resulting in results that might differ from CHW interventions done in more authentic circumstances). However, a number of difficulties have been identified in the literature, and there are also arguments to make for the equality of CHW interventions to SOC. CHW interventions usually concern stable HIV patients, who need less intensive follow-up and who may profit from more personalized CHW care, while at the same time de-burdening the health care system, leaving more time for unstable patients. The main tasks of CHWs involved an important human support component, with conducting home visits as the most common CHW task. We found indications that ART delivery, individual adherence support and frequent home visits were predictive of a successful CHW intervention, defined as improved therapy outcomes compared to SOC or reaching 90% of treated patients being virally suppressed. However, given the difficulty in interpretation of the analyses, we chose not to withhold a certain task or a particular combination of tasks as strong predictors of a successful CHW intervention.

Given the strict inclusion criteria, we reached a limited number of included studies. Although we searched for studies covering all of SSA, we found mainly studies of Eastern and Southern Africa. Of the included studies, there was a substantial number of single arm intervention studies and few were RCTs. 3 of the 4 included RCTs did not show statistically significant effects of CHW intervention on HIV therapy outcome. In 1 RCT[29] this was likely due to a design that was not optimally suited to measure effects on biological therapy outcome, in combination with limited ART supply at the clinics. The second RCT[26] ran over a very short period of time (3 months), in which the CHWs gave 3 educational sessions. Given that the study focused on patients with adherence problems, and that there was limited contact time for adherence support, the intervention might not have been comprehensive enough to show effects. The third RCT[24] gathered fewer patients than they originally aimed for and was likely underpowered. Being clinically stable on ART for a minimum of 3 months with no adherence issues was an inclusion criterion for this study. Despite being defined as stable by the study, the percentage of virally suppressed patients did not reach 90%.

For the measurement of HIV therapy outcome, we used VL and CD4 cell count as surrogate markers. As for the VL outcome, we accepted the cut-off values as used in the different studies. Although the cut-off values differ amongst the studies, this did probably not influence the trends observed. The fact that we used biological treatment outcomes might affect our ability to assess a beneficial effect of CHWs, since the most immediate effect of their intervention is considered to be improved linkage to care, which is anticipated to result in improved adherence and improved biological outcomes of treatment. As such, we might have excluded studies that only measured linkage to care or a measurement of adherence that did not involve biological outcomes. Our choice was guided by our goal to understand CHW

interventions in the context of therapy outcomes and HIV drug resistance, which is best measured with biological variables.

Regarding the tasks of the CHWs and the Bayesian network analyses, we encountered some difficulties. Given the small number of included studies and the multitude of tasks assigned to CHWs in some studies, study design became a confounding factor. Moreover, the numbers of participants involved in each study differs. Hence, the interpretation of the results is difficult. Further, it was unclear to what extent the task 'HIV education and counselling' overlapped with home visits and adherence counselling. The same applies to the task 'emotional or social support'. It might also be that the beneficial effect of specific tasks is context specific, but we had no data to address this.

As for future research, we deem it important that high-quality studies focus on which of the CHWs' tasks are most effective in terms of treatment outcomes for a particular patient population, and to explore whether some of the beneficial effects are context dependent. If other studies confirm the importance of conducting home visits, the required frequency of home visits must be studied and, additionally, how de-escalation of visits over the long-term impacts HIV therapy outcomes. Studies calculating cost-effectiveness and efficiency, as well as qualitative maintenance of the CHW intervention, with attention paid to the different CHWs tasks, are crucial to direct future interventions.

Conclusions

We found that CHW interventions are not inferior to SOC and might even be beneficial, which is in line with the assertion that CHW interventions can help to improve HIV patient care and relieve the burden on the health care system. Despite the limitations of the analyses on the CHW tasks, we found indications that ART delivery, individual adherence support and frequent home visits were predictive of a successful CHW intervention. Further research is needed to be able to judge whether any single task or particular combination of tasks is significantly correlated with success of a CHW intervention, and whether the means needed for CHW interventions justify the outcomes.

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Supplementary material

Supplement 1: Search strategies
Supplement 2: Extended methodology on B-course and data set
Supplement 3: Excluded studies and additional study
Supplement 4: Details of included studies
Supplement 5: Original explorative dependency model as created by B-course

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Supplement 1: Search strategies

PubMed

Search ((((((((((community health aides[MeSH Terms]) OR community health aide[MeSH Terms]) OR village health worker[MeSH Terms]) OR village health workers[MeSH Terms]) OR barefoot doctor[MeSH Terms]) OR barefoot doctors[MeSH Terms]) OR "community health workers"[MeSH Terms])) OR "community health workers"[Text Word])) AND ((((("HIV"[Mesh]) OR "Acquired Immunodeficiency Syndrome"[Mesh]) OR HIV[Text Word]))) AND (("Africa South of the Sahara"[Mesh]) OR ((Botswana OR Burundi OR Ethiopia OR Zimbabwe OR Mozambique OR Malawi OR Zambia OR Tanzania OR Kenya OR Uganda OR Rwanda OR Senegal OR gambia OR guinea OR sierra leone OR Liberia OR cote d-ivoire OR Burkina faso OR Ghana OR togo OR benin OR niger OR Nigeria OR Cameroon OR gabon OR congo OR angola OR Namibia OR Lesotho OR Swaziland OR Somalia OR Djibouti OR Eritrea OR sudan OR "south* africa" OR "sub-saharan Africa" OR "east africa" OR "west africa" OR "central africa")))) AND (((((viral load"[MeSH Major Topic]) OR "cd4 lymphocyte count"[MeSH Terms])) OR "viral load"[Text Word]) OR "CD4 cell count"[Text Word])

Embase

(('health aides' OR 'community health aides'/exp OR 'community health aides' OR 'community health workers'/exp OR 'community health workers' OR 'lay health workers'/exp OR 'lay health workers') AND or, AND 'health volunteers' OR 'health communicators' OR 'adherence supporters' OR 'health guides' OR 'health visitors' OR 'adherence workers' OR 'lay counsellors' OR 'health aide' OR 'community health aide' OR 'community health worker'/exp OR 'community health worker' OR 'lay health worker'/exp OR 'lay health worker' OR 'health volunteer' OR 'health communicator' OR 'adherence supporter' OR 'health guide' OR 'health visitor'/exp OR 'health visitor' OR 'adherence worker' OR 'lay counsellor') AND ('hiv' OR 'hiv'/exp OR hiv OR 'aids' OR 'aids'/exp OR aids OR 'acquired immune deficiency syndrome'/exp OR 'acquired immune deficiency syndrome' OR 'acquired immunodeficiency syndrome'/exp OR 'acquired immunodeficiency syndrome' OR 'human immunodeficiency virus infection'/exp OR 'human immunodeficiency virus infection' OR 'human immunodeficiency virus'/exp OR 'human immunodeficiency virus') AND ('viral load'/exp OR 'viral load' OR 'viral burden'/exp OR 'viral burden' OR 'viral titer'/exp OR 'viral titer' OR 'virus titer'/exp OR 'virus titer' OR 'cd4 cell count'/exp OR 'cd4 cell count' OR 'cd4 lymphocyte count'/exp OR 'cd4 lymphocyte count' OR 'cd4+ count'/exp OR 'cd4+ count' OR 'cd4 count'/exp OR 'cd4 count' OR 't4 lymphocyte count' OR 'cd4+ cell count'/exp OR 'cd4+ cell count' OR 'cd4 cell counts'/exp OR 'cd4 cell counts' OR 'cd4 lymphocyte counts'/exp OR 'cd4 lymphocyte counts' OR 'cd4+ counts'/exp OR 'cd4+ counts' OR 'cd4 counts'/exp OR 'cd4 counts' OR 't4 lymphocyte counts' OR 'cd4+ cell counts'/exp OR 'cd4+ cell counts') AND (((((('africa south of the sahara'/exp OR 'africa south of the sahara' OR 'botswana' OR 'botswana'/exp OR botswana OR 'burundi' OR 'burundi'/exp OR burundi OR 'ethiopia' OR 'ethiopia'/exp OR ethiopia OR 'zimbabwe' OR 'zimbabwe'/exp OR zimbabwe OR 'mozambique' OR 'mozambique'/exp OR mozambique OR 'malawi' OR 'malawi'/exp OR malawi OR 'zambia'/exp OR 'zambia' OR zambiaor) AND ('tanzania'/exp OR 'tanzania') OR 'tanzania'/exp OR tanzania OR 'kenya' OR 'kenya'/exp OR kenya OR 'uganda' OR 'uganda'/exp OR uganda OR 'rwanda' OR 'rwanda'/exp OR rwanda OR 'senegal' OR 'senegal'/exp OR senegal OR 'gambia' OR 'gambia'/exp OR gambia OR 'guinea' OR 'guinea'/exp OR guinea OR sierra) AND leone OR 'liberia' OR 'liberia'/exp OR liberia OR cote) AND 'd ivoire' OR burkina) AND faso OR 'ghana' OR 'ghana'/exp OR ghana OR 'togo' OR 'togo'/exp OR togo OR 'benin' OR 'benin'/exp OR benin OR 'niger' OR 'niger'/exp OR niger OR 'nigeria' OR 'nigeria'/exp OR nigeria OR 'cameroon' OR 'cameroon'/exp OR cameroon OR 'gabon' OR 'gabon'/exp OR gabon OR 'congo' OR 'congo'/exp OR congo OR 'angola' OR 'angola'/exp OR angola OR 'namibia' OR 'namibia'/exp OR namibia OR 'lesotho' OR 'lesotho'/exp OR lesotho OR 'swaziland' OR 'swaziland'/exp OR swaziland OR 'somalia' OR 'somalia'/exp OR somalia OR 'djibouti' OR 'djibouti'/exp OR djibouti OR 'eritrea' OR 'eritrea'/exp OR eritrea OR 'sudan' OR 'sudan'/exp OR sudan OR 'south* africa' OR 'sub-saharan africa'/exp OR 'sub-saharan africa' OR 'east africa'/exp OR 'east africa' OR 'west africa'/exp OR 'west africa' OR 'central africa'/exp OR 'central africa')

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Web of Science

TS=(((‘health aides’ OR ‘community health aides’/exp OR ‘community health aides’ OR ‘community health workers’/exp OR ‘community health workers’ OR ‘lay health workers’/exp OR ‘lay health workers’) AND or, AND ‘health volunteers’ OR ‘health communicators’ OR ‘adherence supporters’ OR ‘health guides’ OR ‘health visitors’ OR ‘adherence workers’ OR ‘lay counsellors’ OR ‘health aide’ OR ‘community health aide’ OR ‘community health worker’/exp OR ‘community health worker’ OR ‘lay health worker’/exp OR ‘lay health worker’ OR ‘health volunteer’ OR ‘health communicator’ OR ‘adherence supporter’ OR ‘health guide’ OR ‘health visitor’/exp OR ‘health visitor’ OR ‘adherence worker’ OR ‘lay counsellor’) AND (‘hiv’ OR ‘hiv’/exp OR hiv OR ‘aids’ OR ‘aids’/exp OR aids OR ‘acquired immune deficiency syndrome’/exp OR ‘acquired immune deficiency syndrome’ OR ‘acquired immunodeficiency syndrome’/exp OR ‘acquired immunodeficiency syndrome’ OR ‘human immunodeficiency virus infection’/exp OR ‘human immunodeficiency virus infection’ OR ‘human immunodeficiency virus’/exp OR ‘human immunodeficiency virus’) AND (‘viral load’/exp OR ‘viral load’ OR ‘viral burden’/exp OR ‘viral burden’ OR ‘viral titer’/exp OR ‘viral titer’ OR ‘virus titer’/exp OR ‘virus titer’ OR ‘cd4 cell count’/exp OR ‘cd4 cell count’ OR ‘cd4 lymphocyte count’/exp OR ‘cd4 lymphocyte count’ OR ‘cd4+ count’/exp OR ‘cd4+ count’ OR ‘cd4 count’/exp OR ‘cd4 count’ OR ‘t4 lymphocyte count’ OR ‘cd4+ cell count’/exp OR ‘cd4+ cell count’ OR ‘cd4 cell counts’/exp OR ‘cd4 cell counts’ OR ‘cd4 lymphocyte counts’/exp OR ‘cd4 lymphocyte counts’ OR ‘cd4+ counts’/exp OR ‘cd4+ counts’ OR ‘cd4 counts’/exp OR ‘cd4 counts’ OR ‘t4 lymphocyte counts’ OR ‘cd4+ cell counts’/exp OR ‘cd4+ cell counts’) AND (((((‘africa south of the sahara’/exp OR ‘africa south of the sahara’ OR ‘botswana’ OR ‘botswana’/exp OR botswana OR ‘burundi’ OR ‘burundi’/exp OR burundi OR ‘ethiopia’ OR ‘ethiopia’/exp OR ethiopia OR ‘zimbabwe’ OR ‘zimbabwe’/exp OR zimbabwe OR ‘mozambique’ OR ‘mozambique’/exp OR mozambique OR ‘malawi’ OR ‘malawi’/exp OR malawi OR ‘zambia’/exp OR ‘zambia’ OR zambiaor) AND (‘tanzania’/exp OR ‘tanzania’) OR ‘tanzania’/exp OR tanzania OR ‘kenya’ OR ‘kenya’/exp OR kenya OR ‘uganda’ OR ‘uganda’/exp OR uganda OR ‘rwanda’ OR ‘rwanda’/exp OR rwanda OR ‘senegal’ OR ‘senegal’/exp OR senegal OR ‘gambia’ OR ‘gambia’/exp OR gambia OR ‘guinea’ OR ‘guinea’/exp OR guinea OR sierra) AND leone OR ‘liberia’ OR ‘liberia’/exp OR liberia OR cote) AND ‘d ivoire’ OR burkina) AND faso OR ‘ghana’ OR ‘ghana’/exp OR ghana OR ‘togo’ OR ‘togo’/exp OR togo OR ‘benin’ OR ‘benin’/exp OR benin OR ‘niger’ OR ‘niger’/exp OR niger OR ‘nigeria’ OR ‘nigeria’/exp OR nigeria OR ‘cameroon’ OR ‘cameroon’/exp OR cameroon OR ‘gabon’ OR ‘gabon’/exp OR gabon OR ‘congo’ OR ‘congo’/exp OR congo OR ‘angola’ OR ‘angola’/exp OR angola OR ‘namibia’ OR ‘namibia’/exp OR namibia OR ‘lesotho’ OR ‘lesotho’/exp OR lesotho OR ‘swaziland’ OR ‘swaziland’/exp OR swaziland OR ‘somalia’ OR ‘somalia’/exp OR somalia OR ‘djibouti’ OR ‘djibouti’/exp OR djibouti OR ‘eritrea’ OR ‘eritrea’/exp OR eritrea OR ‘sudan’ OR ‘sudan’/exp OR sudan OR ‘south* africa’ OR ‘sub-saharan africa’/exp OR ‘sub-saharan africa’ OR ‘east africa’/exp OR ‘east africa’ OR ‘west africa’/exp OR ‘west africa’ OR ‘central africa’/exp OR ‘central africa’))

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Supplement 2: Extended methodology on B-course and data set

B-course is a web-based data analysis tool for Bayesian Network modelling, in particular dependence and classification modelling. We used both modelling types for our analysis.

Dependency modelling means searching the model of probabilistic dependences of the variables, in which the model searches for a maximal number of correlations with a minimal number of links. Dependencies are represented qualitatively by directed acyclic graphs between variables. Uncertainty about goodness of the network found is expressed by analyzing the importance of individual arcs, by observing how much the probability of the model is changed by removing the arc. For our data to be of use, we discretized the continuous variables (duration of the study and frequency of home visits) as indicated in our data set. In the case of a RCT or comparative cohort study, we also included the comparison arm in the data set. The comparison arm always equaled SOC.

For classification modelling, we had to indicate one classification variable. Since we aimed to investigate which variables contribute to the success of a CHW intervention, we chose 'studies with successful results' as our classification variable. B-course provided us with a list of variables which, according to the data set, were correlated with our classification variable.

Table A1. Data set used for Bayesian Network modelling

Studies with successful results	Duration of study (short ≤ 6 months=0;long>6months=1)	Home visits (0/12m=0; <12/12m=1;≥12/12m=2)	Adherence support individual	Health assessment	HIV education + counselling	Adherence support group	ART delivery	Social or emotional support	Referral to care	HTC	Facilitation of clinic visit	Adherence assessment	DOT	Food provision	Transportation stipends for clinic visit	Condom distribution
1	0	2	1	1	0	1	0	0	1	0	0	0	0	0	0	0
1	1	0	0	0	0	1	1	0	0	0	0	0	0	0	0	0
1	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
0	1	1	0	0	1	0	0	0	0	1	1	0	0	0	0	0
0	1	1	0	0	1	0	0	0	1	1	0	0	0	0	0	0
0	1		1	1	0	0	0	1	0	0	0	1	0	0	0	0
1	1	2	1	1	1	0	0	0	1	0	0	1	0	0	0	0
0	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
1	1	1	1	0	0	0	0	0	1	0	0	0	0	0	0	0
0	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
1	1	2	1	1	0	0	0	1	0	0	1	0	1	1	1	0
0	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
1	1	0	0	1	1	1	1	0	0	0	0	0	0	0	0	0
1	0		1	0	1	0	0	0	0	0	0	0	0	0	0	0
0	0	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
1	1	2	1	1	0	0	1	0	0	0	0	0	0	0	0	0

Studies with successful results	Duration of study (short ≤ 6 months=0;long>6months=1)	Home visits (0/12m=0; <12/12m=1;≥12/12m=2)	Adherence support individual	Health assessment	HIV education + counselling	Adherence support group	ART delivery	Social or emotional support	Referral to care	HTC	Facilitation of clinic visit	Adherence assessment	DOT	Food provision	Transportation stipends for clinic visit	Condom distribution
0	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
0	1	2	1	0	1	0	0	0	0	0	0	0	0	0	0	1
1	0	0	0	1	1	1	1	0	0	0	0	0	0	0	0	0
0	0	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0
0	0	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
1	1	2	1	1	0	0	0	1	0	0	0	0	1	1	1	0
0	1	2	0	1	0	0	1	0	0	0	0	0	0	0	0	0
0	1	0	0	1	1	0	0	0	0	0	0	1	0	0	0	0
0	0	1	0	0	0	0	0	0	0	1	0	0	0	0	0	0
1	1	2	1	0	1	0	0	0	0	0	0	0	0	0	0	0
1	1	2	1	0	1	0	0	1	0	0	0	0	0	0	0	0

For 2 studies, we did not find how many home visits were conducted[30,31]. Therefore, we left the number blank. Abbreviations: ART = antiretroviral therapy; HTC = HIV testing and counselling; DOT = directly observed therapy

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Supplement 3: Excluded studies and additional study

Table A2. Excluded studies and reason for exclusion

Assefa *et al.* (2012)[32]	To evaluate the effectiveness and acceptability of ART delivery by health officers, nurses and CHWs in Ethiopia, in comparison with ART service in hospitals based on physicians.	Not on task of CHW as per definition of WHO: in the analysis, no distinction has been made between health officers, nurses and CHWs.
Francis *et al.* (2018)[33]	To assess whether community delivery of ART is non-inferior to the standard of care in achieving viral suppression.	Full text not available.
Johnston *et al.* (2012)[34]	To describe second-line ART outcomes in a large workplace- and community-based multi-site program and to assess whether co-variates available at the time of switch predict early viral suppression on second-line ART.	Not on task of CHW as per definition of WHO: no clear description of community-based program.
Mdege *et al.* (2013)*[35]	To assess the effectiveness of task-shifting and its impact on costs of ART provision.	No consistent reporting of biological HIV outcome.
Nachega *et al.* (2010)[36]	To compare self-administered ART and treatment-supporter DOT-ART.	Not on task of CHW as per definition of WHO: self-chosen treatment supporters in this study are not CHWs.
Robbins *et al.* (2015)[37]	To examine medication adherence and key psychosocial outcomes among patients who receive either Masivukeni (multimedia technology) or standard of care counselling for ART non-adherence.	No consistent reporting of biological HIV outcome.
Vogt *et al.* (2015)[38]	To assess the impact of baseline health, patient characteristics and community support on ART outcomes	No consistent reporting of biological HIV outcome.
Wouters *et al.* (2008)[39]	To assess the impact of baseline health, patient characteristics and community support on ART outcomes	Report on same cohort as other study.

Abbreviations: ART = antiretroviral therapy; DOT = directly observed therapy

*Upon review of the studies referred to in the excluded systematic review of Mdege et al.[35], we included one additional study of Chang et al.[40]. This study was not found with the original research strategy. The research strategy as described in Supplement 1 did not cover the term ‘peer health worker’, which is the synonym for community health worker as used in the study of Chang et al.

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Supplement 4: Details of included studies

Table A3. Details of included studies

Reference	Setting	Purpose	Study design	Sample	Duration	Tasks of CHWs	Outcomes
Achieng *et al.** (2012)[25]	Kenya	To assess which program components of a program to promote adherence and retention in care during the first 6 months of ART are most effective.	Comparative cohort study: prospective	301 initiating ART	6 months	Home visits, adherence support, individual health assessment, adherence support group, clinical referral	Time to treatment failure was longer in patients participating in support groups (448 days vs. 337 days, P<0.001), pharmacy counselling (480 days vs. 386 days, P=0.002), pill counts by physicians (482 days vs. 189 days, P<0.001) and home visits (485 days vs. 426 days, P=0.024).
Bango *et al.*#* (2016)[21]	South Africa	To assess the effectiveness of lay health worker-led group adherence clubs in comparison with a nurse-driven SOC.	Comparative cohort study: retrospective	6194 stable	12 months	Adherence support group, ART delivery	Viral suppression in clubs was 99.06% (95% CI 98.82–99.27) for clubs vs. 97.20% (95% CI 96.81–97.56) for SOC.
Barnabas *et al.* (2016)[29]	Uganda	To assess whether community-based HIV testing with counsellor support (CHW clinic linkage facilitation or CHW follow-up home visits) and point-of-care CD4 cell count testing would increase uptake of ART in comparison with SOC.	Controlled trial	Randomized 2339	9 months	Home visits, HIV education, HTC facilitation of clinic visits	Roughly a third of the HIV-positive people initiated ART. Overall, 412 of the 483 participants (85%) achieved viral suppression by month 9 after enrolment, with no significant differences between interventions and SOC. VL suppression at 9 months was 51% in the group with SOC clinic referral, 52% in the group with CHW clinic facilitation and 47% in the group with CHW follow-up home visits.
Barnabas *et al.* (2014)[41]	Uganda & South Africa	To evaluate initiation of ART and viral suppression after home HTC.	Single arm intervention: implementation study	635	12 months	Home visits, counselling referral to care HTC	Of 123 ART eligible participants, 94 (76%) initiated ART by 12 months. Of the 77 participants on ART by month 9, 59 (77%) achieved viral suppression by month 12. Among all HIV-positive persons, the proportion with viral suppression (<1000 copies/mL) increased from 50% to 65% (P<0.001) at 12 months.
Chang *et al.* (2009)[31]	Uganda	To evaluate the Reach out program, an alternative AIDS care model led by nurses and peer health workers.	Single arm intervention: retrospective	360	24 months	Home visits, adherence support, individual health assessment, social support adherence assessment	Of 360 patients started on treatment, 258 (72%) were active and on therapy approximately 2 years later. VL testing demonstrated that 86% of active patients (211/246 tested) had a suppressed VL. The median CD4 increase for active patients was 197 cells per cubic millimeter (interquartile range, 108–346).

Reference	Setting	Purpose	Study design	Sample	Duration	Tasks of CHWs	Outcomes
Chang *et al.**# (2010)[40]	Uganda	To assess the effect of community-based peer health workers (PHW) on AIDS care.	Radomized controlled Trial	1336 of which 444 (33%) already on ART and 892 (67%) initiating ART	4 years	Home visits, adherence support, individual education + counselling, health assessment, referral to care, adherence assessment	No significant differences were found in cumulative risk of virologic failure (RR 0.81, 95% CI 0.61–1.08) or in shorter-term virologic outcomes (24 weeks virologic failure RR 0.93, 95% CI 0.65–1.32; 48 weeks, RR 0.83, 95% CI 0.47–1.48; 72 weeks, RR 0.81, 95% CI 0.44–1.49). However, virologic failure rates ≥96 weeks into ART were significantly decreased in the intervention arm compared to the control arm (96 week failure RR 0.50, 95% CI 0.31–0.81; 120 week, RR 0.59, 95% CI 0.22–1.60; 144 week, RR 0.39, 95% CI 0.16–0.95; 168 week, RR 0.30, 95% CI 0.097–0.92; 192 week, RR 0.067, 95% CI 0.0065–0.71).
Fatti *et al.** (2016)[42]	South Africa	To compare clinic-linked community-based adherence support (CBAS) with SOC.	Comparative cohort study: prospective	3861 initiating ART	8 years	Home visits, adherence support, individual referral to care	Amongst patients on ART for 6.5–8 years, proportions not achieving viral suppression were 11.4% and 19.4% in patients with and without clinic-linked CBAS, adjusted risk ratio = 0.47 (95% CI 0.26–0.86; P=0.015). Annual CD4 cell recovery was 15.1 cells/μL/year (95% CI 2.7–27.6) greater in CBAS patients (P=0.017).
Franke *et al.** (2013)[28]	Rwanda	To examine whether the addition of community-based accompaniment would improve retention in care, VL suppression, and change in CD4 count, relative to the national model alone.	Comparative cohort study: prospective	610 initiating ART	12 months	Home visits, adherence support, individual health assessment, social support, DOT food provision transportation, stipends for clinic visits, facilitation of clinic visits	85% and 79% of participants in the community-based and clinic-based programs, respectively, were retained with VL suppression at 1 year. Community-based accompaniment was protective against death or loss to follow-up during the first year of ART (hazard ratio, 0.17; 95% CI 0.09–0.35; P<0.0001). Individuals receiving accompaniment were more likely to be retained with a suppressed VL at 1 year (risk ratio: 1.15; 95% CI 1.03–1.27; P=0.01).
Grimsrud *et al.*# (2015)[22]	South Africa	To describe the implementation of CACs at a large, public-sector facility.	Single arm intervention: implementation study	2113 stable	12 months	Health assessment, adherence support group, ART delivery	After 12 months in a CAC, 6% of patients were lost to follow-up and fewer than 2% of patients retained experienced viral rebound.
Igumbor *et al.** (2011)[30]	South Africa	To establish the extent of impact of PA support on patient retention in care, adherence to ART and clinical treatment outcomes.	Comparative cohort study: retrospective	540 initiating ART	6 months	Home visits, adherence support, individual HIV education	The proportion of patients with unsuppressed VLs at 6 months was higher among those without PAs (42%) when compared to the frequency of unsuppressed VLs among patients with PAs (24%; P=0.001). Patients at health facilities with PA services remained in care for longer periods (P=0.001).
Kipp *et al.** # (2012)[43]	Uganda	To test the hypothesis that a health-center community-based ART program can provide a high standard of care and can produce outcomes equivalent to a physician-centered ART model.	Comparative cohort study: prospective	385 initiating ART	24 months	Home visits, adherence support, individual health assessment, ART delivery	Successful ART treatment outcomes in the health-center community-based cohort were equivalent to those in the hospital-based cohort after two years of treatment in on-treatment analysis (VL suppression, 93.0% vs. 87.3%, P=0.12), and in intention-to-treat analysis (VL suppression, 64.9% vs. 62.0%, P=0.560). Patients in the health-center community-based cohort were more likely to have VL suppression compared to hospital-based patients (adjusted OR=2.47, 95% CI 1.01–6.04).

Reference	Setting	Purpose	Study design	Sample	Duration	Tasks of CHWs	Outcomes
Konate *et al.* (2011)[18] Part of population that fulfilled inclusion criteria	Burkina Faso	To measure treatment outcomes in enhanced program of care.	Single arm intervention: implementation study	169 initiating ART	36 months	Home visits, adherence support, individual HIV education, condom distribution	47 of 169 HIV-seropositive women initiated ART. 6 months after ART initiation, 79.4% of 34 women had an undetectable plasma VL. This rate was sustained at 18 months (80%, n=30), and 36 months (81.8%, n=22).
Myer *et al.*# (2017)[23]	South Africa	To compare effectiveness of CACs with services of primary health clinic on VL, for postpartum women on ART.	Comparative cohort study: prospective, self-chosen (pilot study)	129 post-partum women stable	6 months	Health assessment, adherence support group, ART delivery	There were no differences in VL<1000 copies/mL at 6 months postpartum between women choosing primary health care services (88%) vs. adherence clubs (92%; P=0.483).
Peltzer *et al.* (2012)[26]	South Africa	To assess how a lay health worker led group on ART adherence training might impact on adherence to ART, in comparison with SOC.	Randomized controlled trial	152 adherence problems	3 months	Adherence support group	Adherence information knowledge increased significantly in the intervention condition in comparison to the SOC, while adherence motivation and skills did not significantly change. There was no significant difference in CD4 cell count, with an increase from 308, σ=210 at baseline to 317, σ=183 post-intervention in the intervention arm and an increase from 264, σ=170 at baseline to 308, σ=156 post-intervention in SOC (P=0.412).
Rich *et al.*# (2012)[27]	Rwanda	To describe outcomes from a community-based ART program.	Single arm intervention: retrospective medical record review	1041 initiating ART	24 months	Home visits, adherence support, individual health assessment, social support, DOT food provision, transportation stipends for clinic visit	Two years after community-based ART initiation, 961 patients (92.3%) were retained in care, 52 (5%) had died, and 28 (2.7%) were lost to follow-up or had defaulted. Of the 275 with testing at their 2-year anniversary, 232 (84.4%) had <40 copies/ml and 268 (97.5%) had <500 copies/ml.
Selke *et al.* (2010)[24]	Kenya	To assess whether community-based care delivered by people living with HIV/AIDS, aided by an electronic decision support tool, could replace clinic-based HIV care.	Randomized controlled trial	208 stable	12 months	Home visits, health assessment, ART delivery, adherence assessment	After 1 year, there were no significant intervention-control differences with regard to detectable VL (10.5% for the intervention group, 13.5% for the control group, P=0.65), mean CD4 count (404 (265–527) for the intervention group, 358 (240–522) for the control group, P=0.50), decline in Karnofsky score, change in ART regimen, new opportunistic infection, or pregnancy rate.
van Rooyen *et al.* (2013)[19] Part of population that fulfilled inclusion criteria	South Africa	To pilot HBCT with point-of-care CD4 count testing and follow-up visits to facilitate linkage of HIV-infected persons to local HIV clinics and uptake of ART.	Single arm intervention: implementation study	137 initiating ART	6 months	Home visits, HTC	Among the 132 participants not on ART at baseline, 61 were eligible for ART, of whom 36 initiated ART during the study. HIV VL decreased by 0.49 log10 copies/ml (P=0.009). For the 12 participants eligible for ART (CD4 =<200 cells/mL) at baseline who were not on ART, 11 initiated ART and mean VL decreased by 3.23 log10 copies/mL (P<0.001).
Weidle *et al.*# (2006)[44]	Uganda	To assess adherence to antiretroviral therapy in a cohort of HIV-infected people in a home-based AIDS care program.	Single arm intervention: implementation study	987 initiating ART	13–23 months	Home visits, adherence support, individual counselling	Most participants achieved a VL <1000 copies/mL: 894 (98%) of 913 participants in the second quarter and 860 (96%) of 894 in the fourth quarter.

Reference	Setting	Purpose	Study design	Sample	Duration	Tasks of CHWs	Outcomes
Wouters *et al.** (2009)[12]	South Africa	To investigate how immunological and virologic responses to ART are influenced by patient characteristics, health literacy, baseline CD4 cell count, baseline VL, and three forms of community support (treatment buddy, CHW, support group).	Comparative cohort study: prospective	268	24 months	Home visits, adherence support, individual HIV education, emotional support	Baseline health and all three community support initiatives had a positive effect on ART outcomes after 6 months; after 12 and 24 months, community support emerged as the most important predictor of treatment success. There were no significant between-group differences. 76.4% of patients were classified as treatment successes (CD4 cell count =>200 cells/mL and VL <400 copies/mL) after 24 months of ART. At 12 months, all three community support measures were positively associated with the 1-year treatment outcome. Patients with a treatment buddy had a greater chance (β=0.17, P<0.001) of treatment success than patients who lacked such support. The services of a CHW significantly increased a patient's chance of treatment success by 0.16 standard deviations (P<0.01).

*Statistically significant effect of CHW intervention on biological HIV outcomes in comparison with SOC. #VL suppression in at least 90% of patients

Abbreviations: ART = antiretroviral therapy; SOC = standard of care; HTC = HIV testing and counselling; VL = viral load; CACs = community-based adherence clubs; PA = patient advocate

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Supplement 5: Original explorative dependency model as created by B-course

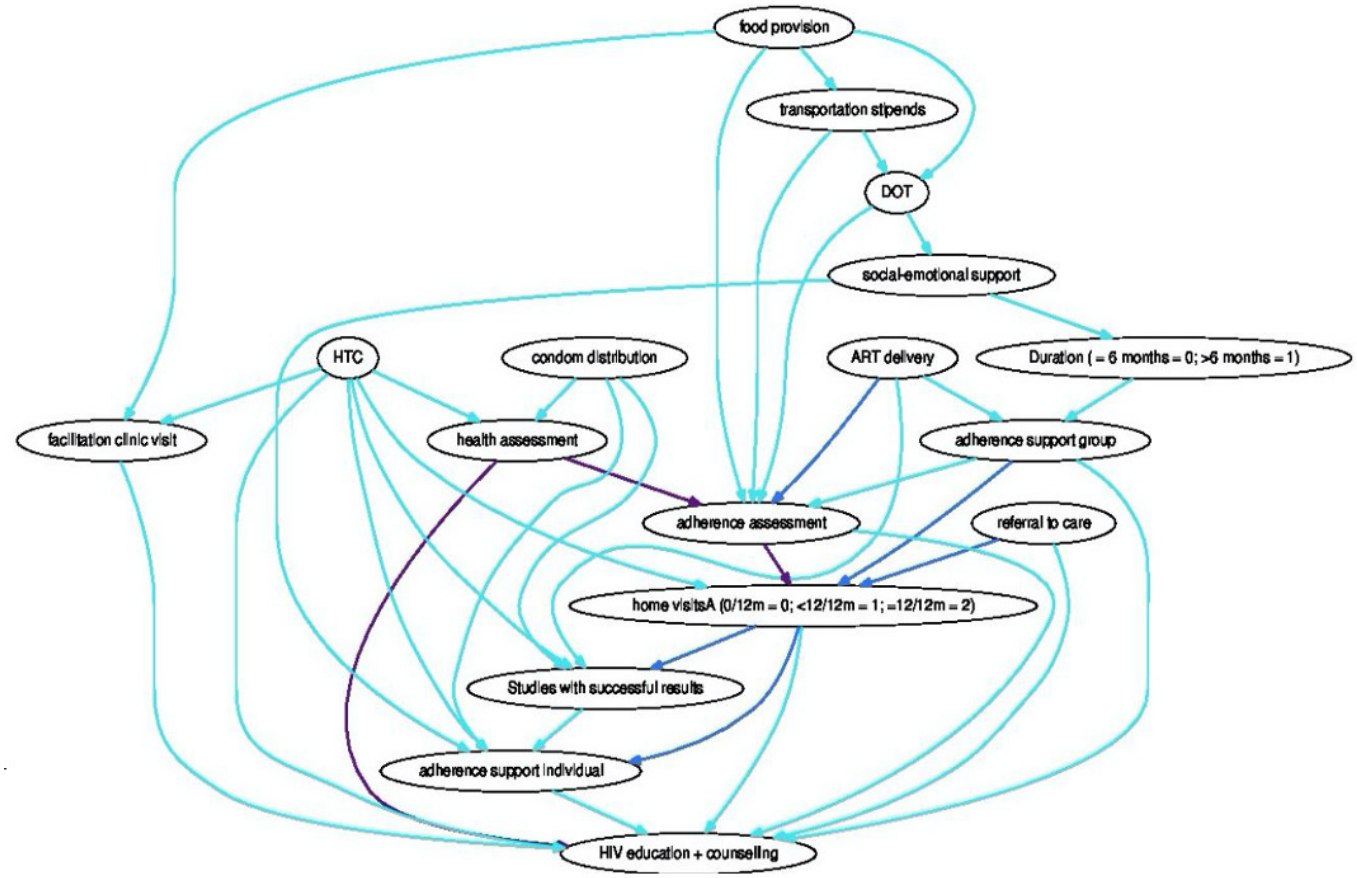

Figure A1. Original explorative dependency model as created by B-course
The darker the arcs, the stronger the connection between the variables. Purple connections: removing such connection would decrease the probability of the model to less than one millionth of the probability of the original model. Dark blue connections: removing such connection would decrease the probability of the model to less than one thousandth of the probability of the original model. Light blue connection: removing such connection would decrease the probability of the model to less than one hundredth of the probability of the original model. The direction of the arrows is meaningless.

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Co-creating a Young Persons' Guide to a Sustainable Future: Analysis of Learning Steps in a Transdisciplinary Honours Course

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Abstract

The Covid-19 crisis reveals that our expanding human population and globalised economic system create unprecedented risks, such as massive new health threats that impact our social and economic wellbeing. In the current era, called the Anthropocene, human activity disturbs life-supporting planetary processes. Surviving the Anthropocene, therefore, requires 'unlearning' the model that brought us here. This model treats nature as a mere resource for humans to exploit with a view to technological progress and economic growth, and serves unrestrained human population increase. This has disturbed the human–nature balance to such a degree that we now have the potential to eliminate all human life. Current crises make us understand we need a regenerative vision of the future, building on new kinds of knowledge, values, skills, and attitudes.

Universities are still grounded in a linear model of research and education, with disciplines studying separate domains of reality without grasping how new, more complex system behaviour emerges from the interaction among those fields. In response to this changing context, the Institute for the Future at KU Leuven runs an Honours Programme Transdisciplinary Insights, offering group learning through real societal challenges and innovative teaching practices. The challenge we present and discuss here tackled the question of how to prepare young people, the leaders of tomorrow, for this complex world (Supplement 1). What are the potential building blocks of an educational trajectory towards a more sustainable future? The challenge was inspired by a theoretical analysis of increasing complexity and its implications for research and education (Snick, 2020).

During one academic year (2019–2020) the authors all took part in this challenge, as students and as a coach. In this article we evaluate our learning experiences. The hypothesis underlying our challenge was that co-creating a vision of a possible future, inspired by emerging regenerative social and economic initiatives, allows students to develop new skills and capacities that the traditional educational approach does not offer. Our learning path involved boot camps with a series of workshops, reading scientific books, watching a documentary, (walking) meetings, field visits, design exercises,

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co-creative workshops, and group discussions. In this article, we evaluate how these helped us foster our response-ability for co-creating a life-sustaining civilisation. Our findings show that unlearning the old paradigm takes time and that empowering young persons to contribute to a sustainable society requires learning with the head, heart, hands, and hope. These insights can be inspirational to all societal actors who understand that we urgently need to move towards a 'new normal' and that the university has a vital role in this transition.

Key words

Sustainable higher education, co-creation, complexity, transdisciplinarity, Honours Programme, Anthropocene

1. Introduction: framing the challenge

Societal challenges today are so complex that no single discipline can bring solutions without triggering unplanned feedbacks that disturb balances and cause problems elsewhere; the economic and social fall-out of the Covid-19 lockdown is a case in point. Finding sustainable solutions depends not only on a transdisciplinary approach that integrates dimensions of health, social wellbeing, economics, and technology but also on a vision of what a sustainable post-corona world – a 'new normal' – could look like. Experts agree that challenges like climate change, biodiversity loss, or geopolitical conflicts are far more life-threatening than Covid-19. However, despite repeated warnings and political agreements, humanity has not taken the necessary steps to crush those curves. In the first two months of the lockdown, CO_2 emissions were reduced by a mere 8 per cent, so the bulk of the effort – to reduce the remaining 92 per cent to avoid what scientists call a 'hothouse' scenario (Steffen et al., 2018) – is still ahead of us, requiring measures that are much more drastic than the current ones (Overshootday, 2020).

The good news is that the pandemic has shown that when the stakes are perceived as high, humans can adapt their lifestyles, show empathy and cooperation, and accept radical policies. Since the lockdown measures were taken with great urgency, however, the economic system did not have time to adapt sufficiently, and the fall-out in terms of income loss is tremendous. Since other threats on the horizon will be much more devastating than the Covid-19 outbreak, and no vaccine can protect us against the sixth extinction or a runaway climate, we must change course immediately. We have to learn how to thrive in a volatile, uncertain, complex, and ambiguous world. That means we can no longer prepare the leaders, researchers, and entrepreneurs of tomorrow by applying the educational models of the past.

Young people are well aware of the threats we face. Thousands of them take to the streets to ask for urgent government action. At the same time, they find it hard to imagine what a more sustainable life could look like. There is a profound gap between *knowing* the current model is no longer valid and *feeling capable* of building a viable alternative, just as there is a gap between knowing one should change one's habitual lifestyle and effectively changing it. Current higher education does not aim to bridge that gap (Kiekens et al., 2016, p. 188). Almost all parameters in terms of climate conditions, availability of materials, biodiversity, and social organisation are shifting at rates unseen in history (McNeill & Engelke, 2014). In such a context, trying to prepare students for the future is like aiming at a moving target. Educating young people for a world of uncertainty changes the role of the teacher. Since the future cannot be extrapolated from the (unsustainable models of the) present, the experience and knowledge of older generations have to be validated against unknown future parameters; there is no 'truth' out there about what the world will be like in ten years, since that also depends on the choices humanity will make. Education for sustainability, therefore, is intimately linked with making the best possible choices. That implies letting go of the familiar, embracing (cognitively as well as emotionally) the openness and uncertainty of the future, and taking responsibility for the planet. This ability to respond to this new reality appears to depend on three crucial capacities.

1. The ability to **relate to the reality of the planet** (Latour, 2017). This is not just a matter of 'knowing the facts' but implies understanding the deep and urgent relevance of these facts for your own life. Recognising that our current lifestyles and production systems transgress planetary boundaries and threaten human survival is knowledge of a different order than memorising the amount of CO2 in the atmosphere today compared with the last 800,000 years. It means accepting (intellectually and emotionally) that the ideas about human progress we took for granted for many centuries may now be up for revision (Ceulemans et al., 2019, p. 85). It means reconnecting with nature, which our civilisation treats as a resource for consumption rather than

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as the source of all life. Recognising the magnitude of the current problems and understanding that the crises we see today are, in fact, symptoms of a deeply unstable way of life is a first step towards changing our dominant system of sense-making and choice-making (Hall, 2018).

2. The ability to **make sense of the emerging complexity** of the world (Chapman, 2015). Scientists call the current epoch the Anthropocene, meaning that human activity alters life-supporting processes on the planet. That human progress would lead to the potential collapse of all life on Earth was not planned or foreseen. To understand where we went wrong, we need to study how our systems (traditionally the subject of social sciences and humanities) and biophysical processes (the domain of natural sciences) mutually impact each other in non-linear ways. Now that planetary boundaries have been transgressed and human survival is at risk, the separation of man and nature, or social and natural sciences, no longer makes sense. Students must learn to understand that from the intense interaction between natural and human spheres, mediated by our economic and technological systems, a new planetary system is emerging, with features and behaviours not seen before in human history. That requires complex systems thinking, the capacity to understand the dynamics of co-evolution between humans and the rest of nature we depend upon. As human systems impact planetary health, we need to develop collective intelligence and humility that realign us with nature (Crist, 2019; Gorissen, 2020).
3. The ability to **make responsible choices *and* put them into effect** in the real world. Since the leading cause of the current problems is human *behaviour* undermining the life-supporting processes on Earth, education for sustainable development must go beyond abstract or theoretical knowledge and must involve the capacity to change human-made systems. Instead of further destroying life on the planet, we must start regenerating it. Education is not just about learning facts but has to inspire young people with the values and the empathy that can reconnect us with nature (Haraway, 2016; Meadows, 1994). Sustainability education firstly means helping students to understand and experience how they can help to achieve that. It inspires them to embrace a new vision of the future and fosters a change of attitudes. Young people need a perspective that inspires them to take action and develop a sense of response-ability (meaning being called upon as well as having the ability to respond). They should feel empowered to think critically and propose alternative pathways for society. Sustainability education therefore also implies taking the first steps towards real change and action. Education must let them experience how, by engaging with societal actors (e.g. via service learning or living labs in territorial contexts), they can become part of and contribute to emerging alternatives. This may give them the hope and conviction that they can make a difference. Sustainability education cannot solely focus on problems while blaming humans, as this elicits reactions of fear, denial, or discouragement. It requires an inspiring learning context that gives them hope (Lipton, 2008).

There is a growing understanding that the complexity of the current problems makes it impossible for any single discipline to offer long-term solutions. Moreover, science alone cannot bring about a safer world unless other stakeholders – entrepreneurs, citizens, financial and political decision-makers – contribute to a systemic shift. Therefore, a transdisciplinary research setting is increasingly accepted as a precondition for learning to adapt to today's global changes. 'In an ideal world, researchers and stakeholders who implement research would have access to knowledge from many disciplines. However, in reality, most researchers work primarily in a limited number of disciplines and in institutions in which knowledge is increasingly becoming specialized into sub-disciplines. Typically, research studies do not go deeply or broadly enough into the fundamental determinants of problems. As a result, many interventions only have a weak impact' (Gibbs et al., 2018, p. 4).

Due to the strong institutionalisation of its traditional, discipline-based paradigm, the university is very slow in advancing a transdisciplinary approach to current complex issues. Mainstream higher education, embedded in the old paradigm and in the vision of civilisation that brought us to the current crises, does not provide students with the vision, skills, knowledge, attitudes and behaviours needed for this transition. Several pioneering projects have been developed, yet the institutional barriers to adopting them and integrating them into mainstream curricula are high. Therefore, a specific strategy to overcome these obstacles and foster the transition is needed as well.

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2. Hypothesis: a YPGF challenge as a fertile context for learning sustainability

In such a pedagogical context, honours programmes (also called talent programmes) offer unique opportunities. They offer extracurricular learning tracks that can be designed with more flexibility than Bachelor's and Master's degree curricula. At KU Leuven (Belgium), the Institute for the Future (IF), founded as a collaboration between three science groups (social, biomedical and natural sciences), offers an Honours Programme in Transdisciplinary Insights (TDI) in which students from different disciplines work on a real societal challenge, proposed and accompanied by a coach.

In the framework of this Honours Programme, we explored an innovative educational approach to preparing young people for the complexity of the future, called 'The Young Persons' Guide to the Future' (YPGF). The project explored the idea that building a learning trajectory around the co-creation of a vision for the future can offer fertile ground for the complex kinds of learning needed to tackle the challenges of the 21st century. Donella Meadows, a leading systems thinker on sustainability, states that *vision* is the most vital step in any policy process; however, this is almost entirely missing from our whole culture. Nevertheless, building a responsible vision of a sustainable world is a skill that can be developed, like any other human skill (Meadows, 1994).

In this article we present our experiences as a case study on learning for sustainability in higher education. We will discuss the various steps of the programme and evaluate to what degree and how they contributed to our increased sense of response-ability for the survival of life on Earth. From a methodological perspective, it is important to underline that this project was not designed as a quantitative hypothesis-testing experiment comparing the learning outcomes of this (experimental) group with those of a control group. As our team consisted of only three students and a coach, we cannot draw any statistically valid conclusions, but we present our analysis as a qualitative study that may open perspectives for further projects to build on. The insights we present here are based on an evaluation of the students' experience with this pedagogical approach. To chart our evaluations in a structured way, we use a 5-point Likert scale, both to get an overall measurement of sentiment around the pedagogical experience and to collect specific data on factors that contributed to that sentiment. In addition, some comments offer qualitative data that allow for a more nuanced understanding of the scores. The graphs below are intended as visual aids to support the text, but are not used for statistical data processing (e.g. in terms of average scores, standard deviations or correlations).

The YPGF challenge was proposed in the context of the Honours Programme Transdisciplinary Insights (TDI), which is open to third-year Bachelor's and Master's degree students from all disciplines. The programme is also open to PhD students and accredited (under certain conditions) by the doctoral schools. The programme started with (mandatory) introductory boot camps for all TDI students, two full days of workshops about wicked problems, sustainability, systems thinking, responsible research and innovation and actor constellations. The rest of the programme was proposed by the coach in dialogue with the student team. Exchanges with coaches from other challenges were proposed every week, but teams mainly worked independently from each other on their challenge[1]. The students of the YPGF team held a weekly meeting of about two hours and organised one full-day team activity. Some of the activities (e.g. reading books, watching the documentary, or producing the video) required homework.

For a general description of the challenge that was originally submitted by the coach to the TDI Honours Programme staff, see Supplement 1. During the academic year – partly due to the Covid-19 pandemic which blocked all activities from mid-March on – the final phase of producing actual chapters of the YPGF had to be abandoned. When evaluating the project, therefore, the focus is more on the process ('how did working on the YPGF help us to develop the capacities we need for the transition to a sustainable system?') than on the product ('what specific visions of future systems did we come up with?'). After all, the challenge was not to describe what the future will or should look like, for that is not something science can determine but depends on a public debate about the kind of society we want (and the kind of research that can contribute to that) (Jasanoff, 2018). The challenge forced us to 'stay with the trouble' and learn how to feel responsible and empowered without any illusion of controlling the complexity of human–nature co-evolution; the pandemic increased our awareness of that. 'In fact, staying

1 See https://rega.kuleuven.be/if/challenges (accessed 7 June 2020).

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with the trouble requires learning to be truly present, not as a vanishing pivot between awful or edenic pasts and apocalyptic or salvific futures, but as mortal critters entwined in myriad unfinished configurations of places, times, matters, meanings' (Haraway, 2016, p. 1).

The challenge was to co-create a vision of the future that takes into account the complexity of the current world and our responsibility as humans for (destroying or saving) life on the planet. It is not a work of imaginary science fiction but is based on empirical input from existing initiatives that experiment with alternative approaches, creating wellbeing for communities while remaining within planetary boundaries. Rather than developing an abstract theoretical vision, our challenge was to describe the future as a landscape or country to which one can really travel. This format allowed us to focus on separate themes without overlooking the connection between them; the way food is produced and consumed in a community, for example, will be thoroughly influenced by the money system it uses. A travel guide aims to raise the curiosity of travellers; if the YPGF could depict a sustainable future in that kind of format, young people may feel inspired to 'travel there' and join in the co-creation of a sustainable future. Just like with a travellers' guide, the YPGF does not describe what you *will* experience on your trip, as travellers can go to different places, meet different people, or engage in different activities. However, it gives you a kind of compass, a framework for knowing where to look for more sustainable, future-proof alternatives.

Asking ourselves what would be the first thing one looks at in a travellers' guide, we decided to work on the themes of food and money. In the current system, money is a strong driver of economic extraction – using humans and nature as 'resources' for making money. Therefore, we were encouraged by the coach to recognise the money system as a social construct that can be redesigned, rather than as a 'given' system, to be accepted as such. We learned about the emerging landscape of local currencies that serve community goals, and decided to make that our focus. If transactions are facilitated by a currency that is designed for fair and sustainable exchanges, the economy looks totally different than if bank money is the only option you have. Due to the lockdown measures, we were unable to finalise these chapters, as they were to be co-created with various actors working on those themes. We made a video about our learning path and the many regenerative initiatives we encountered while working on our challenge (Supplement 2). We also published a reflection in the Ecological Citizen, a journal on ecocentrism (Grancitelli, Himpens, Smeers, & Snick, 2020a); a Dutch translation of this article was published in a Flemish online magazine (Grancitelli et al., 2020b).

Even if writing (chapters of) a travel guide was proposed as the challenge, its purpose was to explore a new way of educating young people for a more sustainable world. Testing innovative learning processes was the real aim of this challenge. The value of the YPGF scenarios is not that they allow us to identify the specific requirements for a sustainable world, but that they push us to think in new, creative ways about what a hopeful future might look like and understand in a profound, experiential way what we can do to bring it about. The 'hypothesis' was that the type of learning experiences this challenge (creating a vision for the future) offers can prepare us for an uncertain future. Our experiences in this honours programme allowed us to put this idea to the test.

3. Evaluating the building blocks of the TDI programme – YPGF challenge

In the next section, we critically analyse the various steps of the programme to elucidate if and how they contributed to our learning experience. To do this, we had group discussions, filled out a survey about the various activities we did, and wrote reflections about our personal learning experience. The aim of this survey was not to obtain standardised and quantitative results; it asked for both quantitative (Likert scale) and qualitative answers. The quantitative data thus gathered do not allow for statistical analysis, but give a quick scan of the participants' opinion of the various learning steps. The qualitative questions are more idiosyncratic, allowing the reader to understand on a more personal level how the programme has triggered new insights, skills, motivations, and attitudes.

The student team of the YPGF challenge came from three different disciplines: a Master's student in Business Economy, a Master's student in Multilingual Communication, and a PhD candidate in Biomedical Sciences (all of them at KU Leuven). The coach holds a PhD in Philosophy of Education, and is a researcher in sustainability, focusing on transdisciplinary research, responsible research and innovation, sustainable finance and STEAM education. In the following section, we present the results of the survey. For each question, we present the quantitative evaluation followed by the

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qualitative data. We do not distinguish between the answers given by the Master's students and those of the PhD student; although it would be interesting to see if the two groups respond differently to this pedagogical approach, it would require a more in-depth method of investigation.

For every question, we first present visually how the team scored the various learning steps as a first 'quick scan', followed by some comments explaining this score. The graphs below display on the vertical axis the score per building block of the programme; scores allowed the students to express their satisfaction with each block. Every item on the scale ranges from 1 to 5, balanced on both sides of a neutral option (score 3). On this scale, 1 is the lowest and 5 the highest possible score, although the actual scale labels vary depending on the activity; the specific labels for each question are given with each graph. The horizontal axis shows the respective score of the respondents, resulting in graphs showing a maximum of three scores per learning activity; some items only display only one or two scores because not all activities were attended by all three learners.

3.1. Did the project meet students' expectations for the Honours Programme?

The first question allowed the students to evaluate the programme in general. The question was: 'Why did you want to join the YPGF challenge, what motivated you to take on this extra workload? In what sense did it meet your expectations (or not)?' (Graph 1)

All students felt that the YPGF challenge offered (more than) what they had expected from an honours programme in transdisciplinary insights.

Comments: *'Why this score?'*

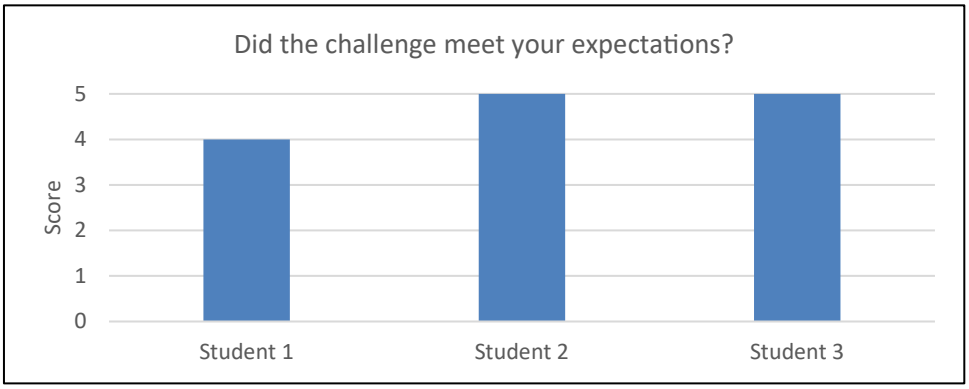
I intentionally sought out a project that didn't relate much at all with what I do in my PhD research. The TDI programme was a chance to step out of my comfort zone and seek out personal development relating to subjects that really matter to me but that I don't get to work on in my job. I liked the YPGF because I firmly believe most of our energy needs to be directed at young people if we want to make the planet a better place, and because it was quite a broad subject with many diverse things to learn about.

The project exceeded my expectations by bringing about a change in how I look at the world and the issues we face. It also fell a bit short in the sense that I would have liked to have had a bit more of a finished product to deliver.

I decided to join the TDI programme to improve on my teamwork. At first, the challenge itself did not really matter to me as long as I could work with several students from different academic domains. Although we were only a small team, we did learn a lot, which is why I feel that the programme did exceed my expectations nevertheless. I am convinced that working on this challenge has changed my views for the better.

Besides the fact that the coach's presentation was very motivating and inspiring, the main reason for joining the project was that I was looking for a place where I could meet and exchange with people who shared the same 'vision' («*une soif d'un futur différent*»). I had no particular expectations; I had an open-minded approach to learn as much as possible.

An additional point of attention is that we lost some time in the first months of the project due to frequent



Graph 1. Answers to the question 'Did the programme meet your expectations?'
Scores ranging between 1 = 'not at all,' and 5 = 'more than expected'

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changes in the team; of the original seven participants, four dropped out for various reasons. Some of the students who quit possibly never saw the TDI challenge as a learning process that required the active co-creation of knowledge among different disciplines. They seemed to see it more as a project to which they could apply their particular study domain. That shows that the difference between a single-disciplinary honours programme and a transdisciplinary one should be explained more clearly during the application phase. Moreover, a better briefing on the expectations and a stricter selection of students who enrol in the TDI-programme is desirable.

3.2 Relevance of the project for students' role as future citizens and professionals

All students evaluated the YPGF challenge as highly relevant for their future, as shown in Graph 2.

Comments: *'In what sense was the YPGF relevant for you as a future citizen/professional? What important things did you learn that you had not already understood from your university curriculum (or other learning contexts)?'*

During my Master's track I had missed out on the science philosophy course by going on Erasmus, which at that time I was actually glad about, because philosophy has a bad reputation in science faculties. However, I have realised the relevance of learning about the history of scientific thinking frameworks and the importance of questioning scientific methods. I also think just generally learning to place things in a complex context and asking the right questions about issues and being able to see them from multiple sides, are very important skills. In my opinion these even deserve a place earlier on, in secondary education. I think in education, a lot – if not all – of focus is placed on **what is**, when we need to be looking also at **what could be** and listening to alternative voices so that students learn to critically evaluate and acknowledge new information rather than just taking the status quo/general consensus as the only truth.

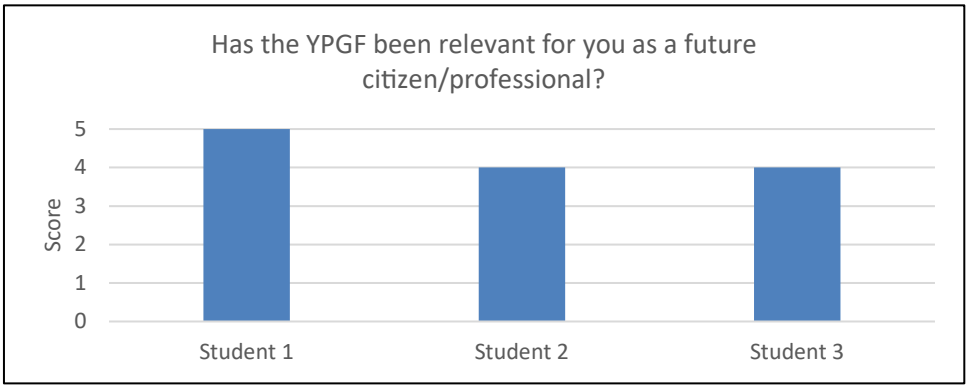
Applying the experience you gathered within your domain on a transdisciplinary wicked problem was relevant. The main lesson learned is that there is more to a problem than meets the eye, and that there are different sides to tackle a problem, for which you need peers with other areas of expertise.

I've always been sensitive to respect for humans and the environment. These are two elements that the economy instrumentalizes for the sole purpose of maximizing profit. The YPGF project has proven to me that there are communities that want to change the system, especially the economic one. YPGF also teaches you respect and integrity towards the living and non-living.

3.3 Meaningfulness of the introductory steps of the programme

Two full-day boot camps were offered to all TDI challenges together. The first one took place at the start of the programme and offered various workshops (including name games and team building activities); topics were: wicked problems, transdisciplinarity, sustainability, and systems thinking. (Figure 1)

The second boot camp took place two weeks later and offered workshops on actor constellation and



Graph 2. Answers to the question 'Has the YPGF project been relevant for you as a future citizen/professional?'
Scores ranging between 1 = 'on the contrary, it was fun but irrelevant', and 5 = 'most relevant, it makes a huge difference'

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Figure 1. Co-creative warming-up at (pre-corona) boot camp 1 for all TDI challenges

knowledge co-creation, as well as on responsible research and innovation (Snick, 2020).

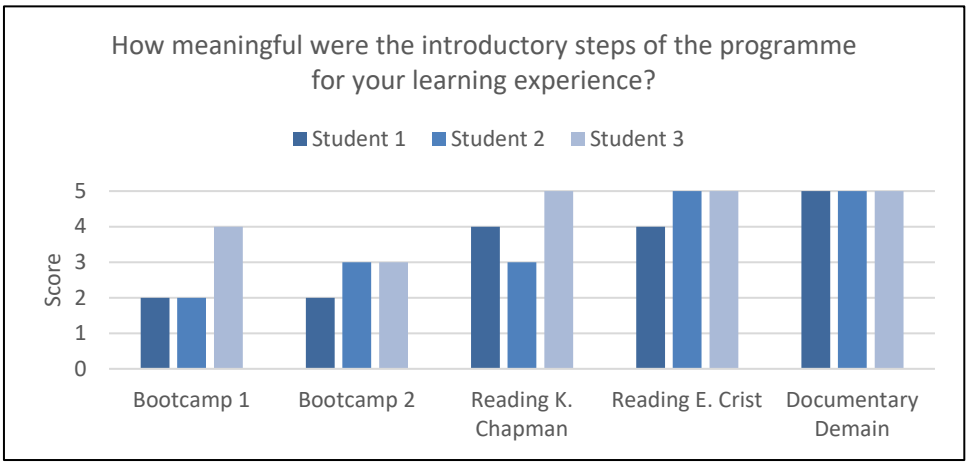
Specifically, in the YPGF challenge, the students had to read two books: one on emerging complexity and its implications for epistemology and for policy relevance (Chapman, 2015) and one on the impact of a human-centred worldview and the urgency of shifting to an ecocentric vision (Crist, 2019). The students were also required to watch the documentary *Tomorrow*, or *Demain* (Dion & Laurent, 2018).

The survey asked for an evaluation of these preparations as follows: 'The IF-staff and the coach proposed a certain framework for the YPGF rather than let you work totally "bottom-up". How meaningful were these introductory steps of the programme for your learning experience in this programme?' (Graph 3)

Comments on the scores

I felt that the boot camps were too theoretical. Since they were taking place before we had really gotten a start on our project, it wasn't really possible for us to take this information in with our project in mind and have a practical application. Therefore it felt like a bit of a waste of time. The books and documentary, however, were very informative generally and also integrated well with the rest of our work since we discussed the topics in our team meetings and related them to our challenge.

To be honest, I don't remember that much of the two boot camps, which is unfortunate. The final presentation of the first boot camp on systems thinking, for example, was too theoretical. It went too much into detail, too soon, which made it hard to keep up. I felt that I was not the only student who had trouble to keep focused. The same goes for the book written



Graph 3. Answers to the question on the meaningfulness of the preparatory steps for the YPGF challenge
Scores ranging between 1 = 'not meaningful at all, a waste of time' and 5 = 'extremely meaningful, a real eye-opener'

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by Kelly Chapman, which is, to my mind, aimed specifically towards academics from the exact sciences. The book by Eileen Crist, on the other hand, was a better fit as it was easy to read for people from all backgrounds. The best introductory step, however, was the movie *Demain* as it really opened up my eyes and made me want to learn more about the featured topics. The producers did a good job in framing the complex issues and making them understandable for 'common people.'

I remember I came back from the first boot camp excited about the adventure I had just embarked on! However, some presentations during boot camps were too theoretical but the presentation 'Complexity based, common good oriented & co-created. Responsible R&I for the Anthropocene' given by Anne Snick has been an important trigger point for shifting away from anthropocentrism. Especially the story of the 'Wiser than Vikings', which allowed me to begin the process of complex thinking (I was in a system framework which only teaches linear understanding and based on old economic models). A general comment is that inter-challenge activities over the year could have been an added value.

Concerning Kelly Chapman's book, at first, I didn't understand why I was reading it, I was also extremely struggling because it's not the kind of reading I'm used to. But after the finger exercises, discussions with our group and the second book, I understood the usefulness of this book. Nevertheless, I am thinking of rereading thoroughly some chapters in order to understand all the nuances. I think it would be interesting to ask the students to take note while reading (which I didn't do) or to ask questions at the end of some chapters to go further in understanding and complexity.

The film *Demain* is an inspiring tool for a vision of a possible future.

3.4 The pedagogical value of learning from real emerging alternatives and creative exercises

The YPGF challenge has shown that learning outside traditional university teaching settings is a good way to learn about emerging futures. Learning about complexity requires immersive experiences in contexts relevant to this aim. For mainly pragmatic reasons, most of the meetings took place in Agora, a learning centre for students and staff at KU Leuven, which offers extensive opening times, group work facilities, and a wide range of educational and digital technology, supporting all forms of social and activating learning. The first meetings, however, took place in public places, such as the Viavia café and the Wereldcafé in Leuven; the latter is a cooperative café, run mainly by volunteers, that financially supports sustainable agricultural projects in the global South. We also organised a full day of work at a location outside Leuven, including a walking meeting in the local forest. We visited cooperative zero-waste shops that sell (mainly) locally produced organic food. (Figure 2)

Figure 2. Visiting emergent alternative approaches to food and business

A recurrent creative activity was doing 'finger exercises', challenging us to approach 'normal' events from a new framework. We had to rephrase daily news items using an ecocentric lens: how would this event feature in the YPGF? When, for example, farmers in the Netherlands protested against environmental regulations that reduce their profits, we re-wrote that as (in an ecocentric future) 'farmers protest to demand government support for agro-ecology and local currencies, so they are no longer forced to torture nature for money.' Figure 3 below shows some more examples of finger exercises (coming from the coach or the students themselves).

One activity – a co-creative workshop on sustainable finance with a focus on community currencies – was organised by the coach for the Club of Rome-EU; this took place at the Triodos Bank in Brussels and involved ten experts and fifty participants of eight nationalities. One member of our team was invited to attend this workshop (hence the graph below shows only one response).

During one meeting, a professional designer (Adriaan Debruyne, Apollo18) gave a two-hour workshop on how design processes can be helpful in organising

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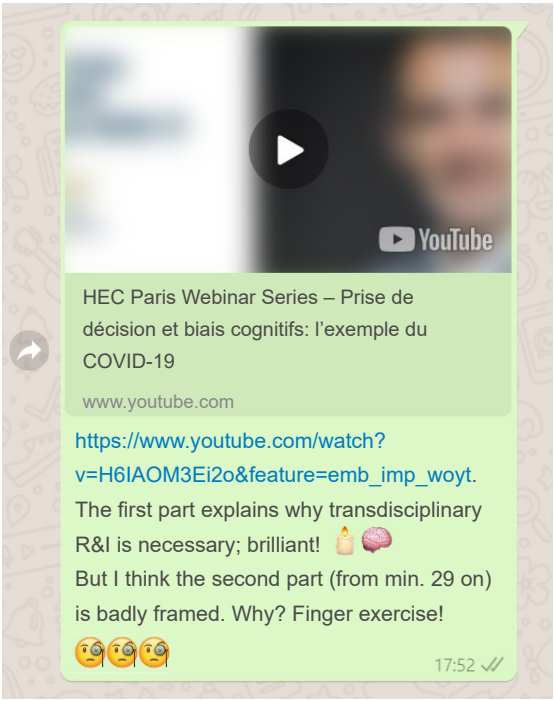
Nice finger exercise this morning on the news: "the corona pandemic is bad for the business of air companies". What would a reporter in the (ecocentric) future say about the relationship between air travel and pandemics? Or about business in general?

New finger exercise: "If we can only live in balance with living ecosystems if the human population is reduced to 2 or 3 billion, this will lead to **competition**." How would you rephrase this from an ecocentric perspective?



Finger exercise: Bill Gates' speech "Global innovation is the key to achieving a return to normal" https://huzzaz.com/video/866527. What would the title be if Bill Gates had read the YPGF?

Today farmers in the Netherlands are protesting **against** environmental protection. What do they protest for in the future instead? Relevant for YPGF captions on food, economics, money…

Expert today saying that if we achieve all the 'social' SDGs (no hunger, no poverty, education, etc.) it will be **impossible** to achieve the 'planetary' ones (viz. life on land, life below water, and stable climate). What would experts say in an ecocentric future instead?

Herman Van Rompuy says 'development cooperation' must invest in the education of young talented people in the global South (SDG4) and then seek public support for their (selective) migration… because the European industry needs their talents to win the **economic war**. → What would a political leader say about SDG4 or economics in the (ecocentric, postcolonial) future?

Imagine you're running a sustainability course, and you have to evaluate a student at the final exam. The question is: "Are electric cars sustainable?" and the student says "Yes, and this can be proven scientifically by measuring the amount of CO2 an electric car emits and comparing that to the emissions of a combustion engine". In your opinion would this student 1. Fail, 2. Pass, or 3. Graduate Cum Laude?

Figure 3. Examples of 'finger exercises' on complexity, proposed by coach or students

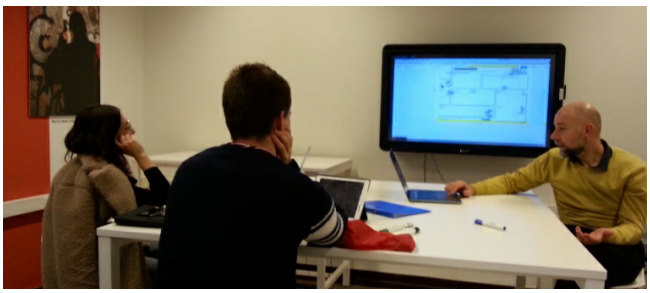


Figure 4. Workshop on design for co-creation and sustainability with a professional designer (from Apollo18).

co-creative events for sustainability; he also helped us to explore online platforms that can support 'work-in-progress projects' with iterative co-creative inputs (like the YPGF would ideally be). With his help, we prepared a co-creative stakeholder meeting (planned in Brussels); due to the Covid-19 lockdown this had to be cancelled. Two of the students attended this workshop (Figure 4) (hence the graph with the results has only two lines).

Due to the lockdown we also had to cancel a visit to a festival on emerging food initiatives in Liège ('Nourrir Liège. Festival de la transition alimentaire à Liège'[2]), where we had planned to meet stakeholders as well.

Graph 4 shows how the students evaluated the pedagogical value of these experiential and creative immersions in sites of emerging futures.

The graphs reveal that actual contacts (in field visits or workshops) with actors who explore alternative approaches (in this case, to food and money) were experienced as very valuable learning moments. Co-creative moments like team discussions, a workshop on creative design, and the finger exercises were also evaluated positively. Only the stakeholder mapping remained a difficult part of the programme throughout the project. This may partly be explained by the complexity of the challenge: on the one hand, the

2 See https://nourrirliege.be/ (accessed 7 June 2020).

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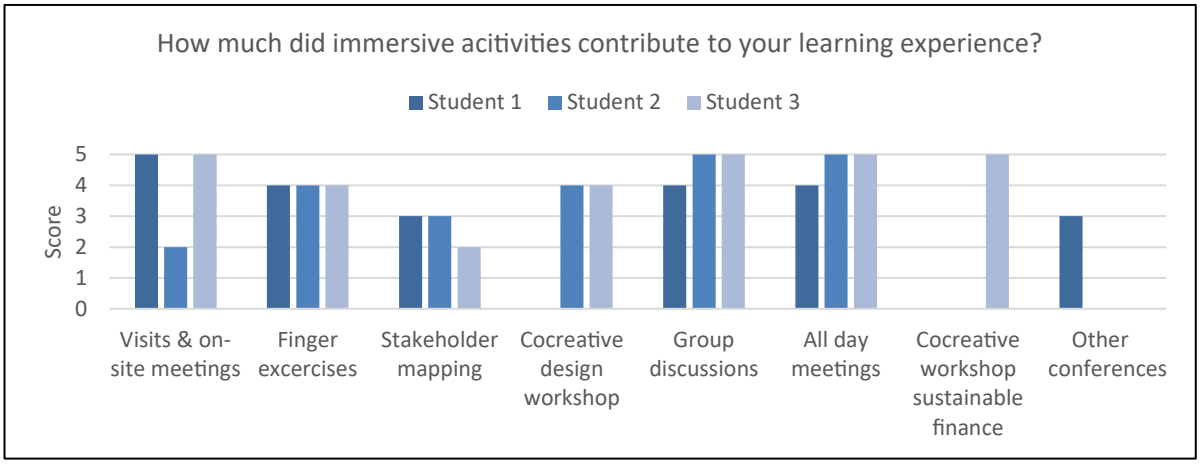
team mapped (and met) stakeholders relevant for the themes of food and money (as chapters of the YPGF); on the other hand, the target group of the project consisted of 'young persons', the leaders of tomorrow that will – hopefully – be inspired by the YPGF to approach learning for sustainability differently, and a further group consisted of actors interested in innovating higher education for sustainability. On several occasions, we made mappings in which we included those actors, but the relevance of this exercise remained vague.

The following comments were added to this question:

> I think a good example would be that shopping at the waste-free shop (very hesitantly at first, I'll admit) made me realise quite soon how easy it actually is to make lasting, meaningful changes. All you need to do is try, imperfect progress is still progress.
> It was nice that we didn't always meet in academic environments, but maybe we should have gone to other places where we could have seen even better how they try to change the current system. The very first meeting spot (Wereldcafé) was in that regard the best one.
> The finger exercises were very interesting as they point out the shortcomings of one's views and beliefs, which are important for reflection. Important as well was the safe environment for us to have the freedom to learn without being criticised for sharing 'mainstream' answers to complex problems.
> The stakeholder mapping always remained a bit vague.
> It would be enriching to organize one out of two meetings in the field (visit an alternative, participate in a workshop or a conference, etc.). This allows to be confronted with people from different generations, backgrounds, cultures, etc. with different opinions and thus to perceive the complexity of the challenge.
> I'm still not sure about the stakeholder's map, at this time, I don't see the point of it.
> Discussions with the YPGF team and at the Club of Rome-EU Workshop on the Sustainable Finance (both with a transdisciplinary perspective) allowed for a deeper understanding of the complexity involved in reaching a common and sustainable vision for the future (e.g. should there be a limit to the number of births?).

3.5 Working towards specific outcomes or deliverables

The next aspect of the programme is a response to the fact that Anthropocene conditions are the (unintended and unplanned) result of the exploitation and pollution of nature by humans: ecological destruction was driven by industrial revolutions in which science and engineering played a crucial role. Learning about sustainability, therefore, has to help students to become agents or leaders of regenerative co-evolution. That goes beyond learning theoretical facts about ecology and green technology, but requires learners to have a positive impact, not unintended or unplanned, but enabled by new capacities and value judgements. For this reason,



Graph 4. Answers to the question on the pedagogical value of experiential and creative immersions in emerging futures
Scores ranging between 1 = 'a waste of time' and 5 = 'extremely meaningful, real learning moments'

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the programme required the students to work towards specific outcomes and deliverables.

The team worked on the following outcomes.

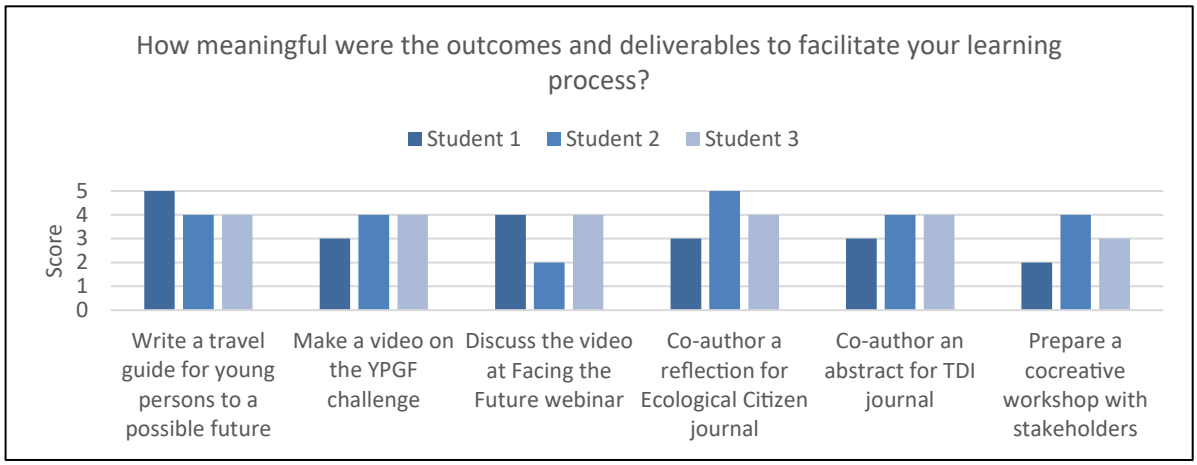
1. Producing a vision of a possible regenerative future in the format of a travel guide (the YPGF)
2. Making a five-minute video on the YPGF challenge (cf. Supplement 2)
3. Presenting the video at the online symposium 'Facing the Future' organised by the Institute for the Future (mandatory for all challenges in the TDI Honours Programme) in May 2020
4. Proposing and co-writing a reflection for the Ecological Citizen journal; Eileen Crist is involved as Associate Editor in this journal, and since her work was a crucial building block of the project, we felt submitting a reflection on our learning path was a way of paying tribute to her work; this was not a mandatory outcome, but something the team chose to do
5. Co-writing an abstract for the TDI journal (mandatory for all challenges)
6. Preparing a co-creative workshop with stakeholders as part of the transdisciplinary approach

The next question in the survey evaluated how meaningful these deliverables were for the learning process. Graph 5 shows the quantitative results.

Note that we had to abandon the co-creative workshop preparations because of the Covid-19 lockdown; this affects the evaluation (see the comments below).

These are the comments on the question about outcomes and deliverables.

I think the co-creative workshop could have been a 5 if it had actually taken place. I think all of the other ones are meaningful in the sense that actually disseminating what you've learned to an audience is in and of itself a good learning technique, just like trying to explain your subject matter to your parents when studying for an exam. In that sense the formats where feedback/discussion is possible are more helpful because they allow you to question what you've learned and potentially steer your trajectory.
The goal of our challenge was to reshape the information we gathered and make it accessible to the leaders of tomorrow. At first, this did not seem too hard. It was only after redesigning the output several times for several stakeholders that it became clear that this was no easy task. As a communication student, it was interesting to see how we changed the content to fit the needs of those varying stakeholders. The only 'bad experience' was the discussion of our video during the TDI symposium as the questions that were asked were not always relevant. The spectators were asking about technical problems, whereas our journey did not cover that aspect in detail. Then again, it may be hard to ask someone how he or she experienced a philosophical shift in ideas. Something to think about for sure.
All these tools were interesting because they forced us to summarize our ideas and start, through our



Graph 5. Answers to the question 'How meaningful was working towards outcomes and deliverables to facilitate your learning process?'
Scores range between 1 = 'a waste of time, more confusing than helpful' and 5 = 'an eye-opener or aha-moment'

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experience, telling a story to inspire people. It also allows us to receive constructive feedback and thus to improve our content. Knowing is good, but if you don't know how to spread it, your knowledge becomes useless. Unfortunately, with the pandemic, we were not able to complete our stakeholders' workshop, but I think this exercise would have been very meaningful for our project. The presentation through a video is a dynamic and personal approach, I liked it.

3.6 New insights, skills and attitudes, not formerly developed in the academic track

With the survey, we also wanted to reflect on what new insights, skills, and attitudes the team members acquired (new in comparison to the capacities developed in their former academic track). (Figure 5 and 6)

The aim of the Transdisciplinary Insights (TDI) Honours Programme is to prepare students for dealing with the complex issues of the Anthropocene; the underlying assumption is that this requires more than theoretical knowledge, but also depends on actual engagement with various stakeholders on a real societal challenge. We evaluated to what degree this year of working on the YPGF helped us develop skills, knowledge, attitudes, and feelings that will be crucial for dealing with the daunting challenges ahead of us, and that the standard academic curriculum does not address. The questionnaire inquired into the following learning outcomes.

1. Systems thinking: understanding how interactions among subsystems may create new system behaviour etc.
2. Complexity (avoiding linear ways of analysing problems)
3. Creativity (ability to picture a totally different future)
4. Transdisciplinarity: the strong conviction that innovative actors outside academia have at least as much relevant expertise for sustainable solutions as specialists do
5. Networking (awareness of people, groups or organisations that were not on your radar during your university education, but that are very relevant to your future)
6. Co-creation: understanding that you couldn't have learned this as an individual student, but that you need a team with different voices to develop 'collective intelligence'

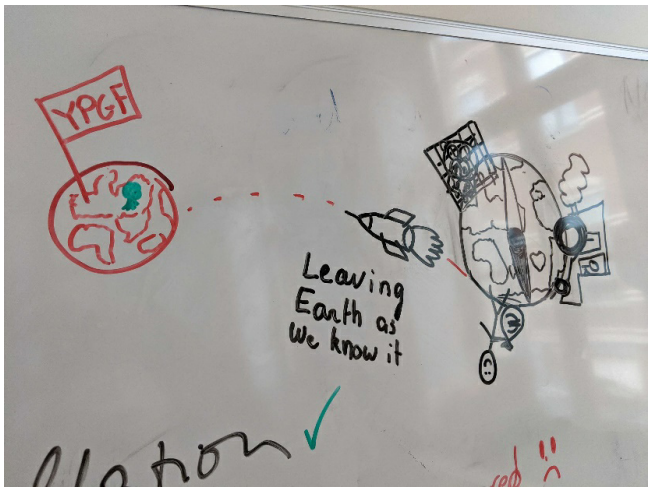

Figure 5. Co-creatively envisioning pathways towards a healthy planet

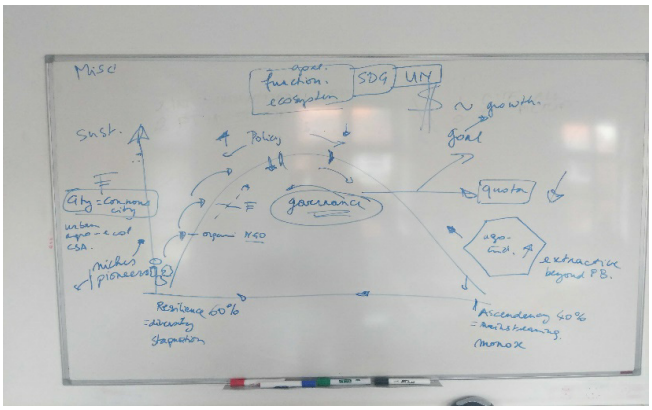

Figure 6. Workshop on Process Ecology mapping tool

7. Ecocentrism: a deep appreciation for other than human life and nature; an understanding that humans have to change their attitude…
8. Hope, inspiration, empowerment to change things, convince your friends, etc.
9. Other learnings (e.g. historical sense, lowering our baseline of biodiversity, sense of loss, etc.)

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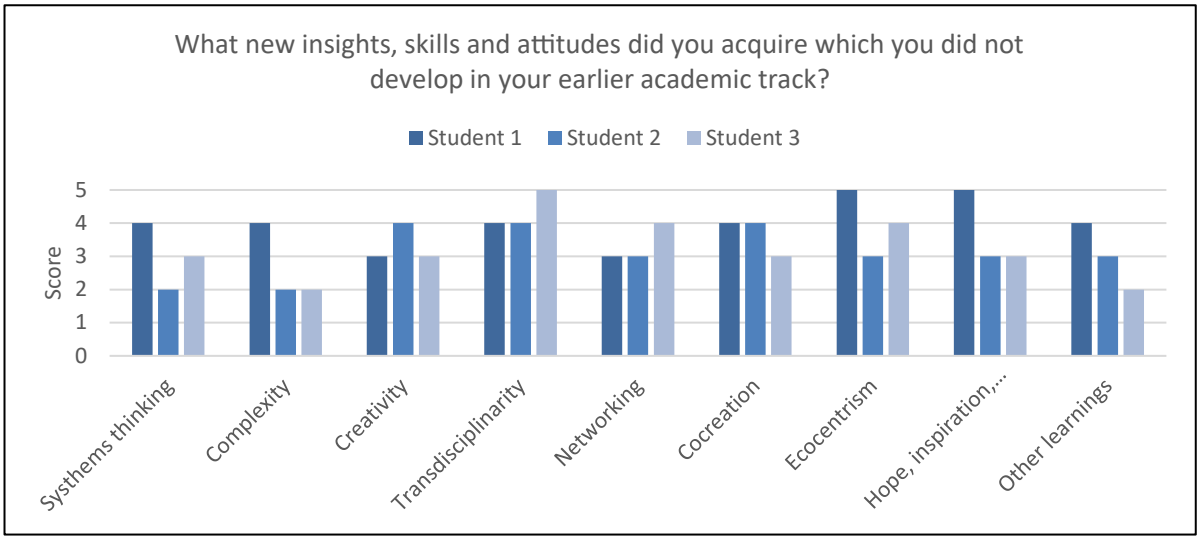
Graph 6 shows the results.

Comments on the scores:

I find that in discussions I now more often tend to also question the bigger framework that people's arguments are nested in. For example, in a discussion about capitalism vs socialism I pointed out that most arguments being made wouldn't even apply if the means/end reversal of money never happened, and if our economic system as a whole would be different. This was received as a rather radical idea, but I think it also opened some eyes to an extent.
Systems thinking and complexity were two entirely new things to me. You cannot take into account the things you aren't even aware of. To that extent, I also dealt with problems in a linear way. It is still hard to implement these tools, but at least I'm aware of them, which, I believe, is a good start.
Creativity and co-creation go hand in hand. You need others to show you how things could be different. Not everyone can invent an entirely new future for him- or herself. Everyone should be able to contribute. As the YPGF was a complex given, teamwork is really important.
For my Master's thesis on stigma towards people who use drugs, another complex subject, I feel that I am discussing it with others more often than I would have done without the TDI programme. To that extent, the YPGF has helped me to look beyond my own scope.
I've learned that there is no single answer, and the technology, as a unique tool, is also not the right one. I've learned that the success of a society is not just about power and money. I have learned that it is together, through a refocusing on healthier values and degrowth, that we can move towards a better future. As an illustration, the Covid-19 pandemic has led to a slowdown in our lifestyle, and we saved lives and decreased our environmental footprint by staying at home in our pyjamas. It is also a question of making the population accountable for its actions, including the government authorities. They are key actors to shift away from a society oriented towards capitalism and mass consumption. To take the example of Covid-19, the European Commission is encouraging countries to reopen their borders for the tourism sector and invites travellers to favour individual transport such as the car. This goes against the Green Deal (inconsistency).
The most important thing is that I learned to think differently and imagine an even more promising outcome. *To question differently: no longer ask 'How come?' or 'Why?' but rather 'Now, what if?', 'What can I do about it?'*



Graph 6. What new insights, skills and attitudes did you acquire which you did not develop in your earlier academic track? Score meaning: 1 = 'I still don't understand it'; 2 = 'I start to grasp the rough outlines of it'; 3 = 'I feel I can look with this new lens now, see both ways'; 4 = 'I tend to use this new lens (e.g. when I hear other people talk, I tend to explain this new view)'; 5 = 'It has become my new normal way of thinking'

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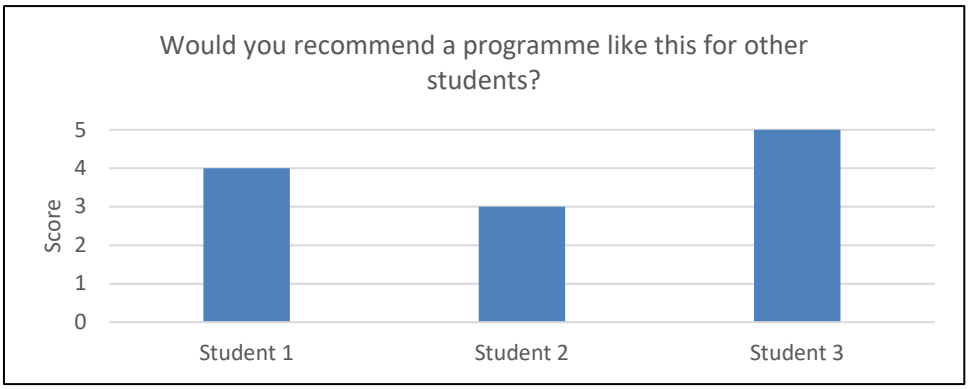

Graph 7. Answers to the question 'Would you recommend a programme like this for other students?' Scores ranging between 1 = 'No, it was just for my personal interest' and 5 = 'I think this should be a mandatory part of the curriculum for all higher education students'

3.7 Estimation of the value of this programme for other students

The YPGF team consisted of only three students, yet the challenges ahead of us concern all young people. We asked ourselves if (and under what conditions) the learning experience we had should also be made available to other students. Graph 7 shows that a complex question like this does not lead to a single answer.

The question 'Would you recommend a programme like this for other students? Why?' elicited the following reflections:

> I think it is of vital importance that students learn to understand and appreciate all that lives outside of their own study domain, since everything is interconnected.
> It is relevant for sure. However, I believe that many students simply don't care, and accept their ignorance. It would be problematic if you had members in your team who do not share your will to learn and improve yourself. Therefore I don't think this programme should be made mandatory. Nonetheless, more attention should be paid to transdisciplinarity in another way. Unfortunately, I cannot say how this should be organised. One possibility is to give a classical course such as 'Religie, Zingeving en Levensbeschouwing' ('Perspectives on Religion and Meaning'), which is taught to students from many domains at KU Leuven, to different groups at the same time and to oblige students from different backgrounds to work together on an issue. Guidance, however, is very important and it is hard for a professor to keep up with that for all groups.

> Yes, I recommend the programme! Few people see the benefit of transdisciplinary work. Moreover, this education opens up minds which is essential for the future of the planet and the living and non-living species. It is also valuable for professional and personal development.

The comments reveal that all team members find the Transdisciplinary Insights programme highly relevant for all students. However, there are doubts about how mainstreaming this programme can be achieved, which lowered the score for this item.

3.8 Role of the coach

When proposing this challenge, the coach was looking for concrete ways to innovate higher education to foster (leadership for) strong sustainability. The basic principles of this education (co-creation, transdisciplinarity) she had developed theoretically elsewhere (Snick, 2020).[3] Letting students – with backgrounds in various disciplines and inspired by (regenerative) societal actors – work together on a vision for a sustainable future in the format of a travel guide seemed a possible way to bring this new pedagogy into practice. The TDI Honours Programme offered the ideal context for putting this idea to the test. In that sense, the coach had as much to learn from the students as they could learn from her. What type of educational relationship can help young people to embark on a regenerative

3 Insights presented at the World Academy of Arts and Science 4th World Conference on Future Education https://www.youtube.com/watch?v=wII6LQlWx4M&t=57s (accessed 7 June 2020).

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learning path if the educator is no longer the person who can point the way towards a certain future?

In a context of uncertainty, all the coach can do is create learning contexts and offer learning experiences, while at the same time getting out of the students' way in their exploration of a future that radically breaks with the destructive models of the present. This begs the question of what kind of support the students need from the educator. In the context of TDI, 'creating learning contexts' meant ensuring that the complexity lens (introduced during the boot camps) was used while working on the challenge. Moreover, the coach could provide the network and contacts for transdisciplinary co-creation. The coach as a 'societal actor' proposing a challenge can be expected to know what other societal actors are working on that theme, and can create the conditions for the co-creation of knowledge by introducing the students to his or her network of relevant agents.

The second dimension of the coaching role was to facilitate the work on the co-creative challenge, which means finding the right balance between being supportive and 'getting out of the way' for students to explore their own learning pathway. In the experience of the students, it would be better to start the first months with a stronger focus on 'learning complexity', and start to work on the themes and stakeholder mapping for the challenge only later, and leave the production of materials for the last phase. This would also allow the students to work more on their own; once the coach is sure they have understood complexity and are more or less on the same level, he or she can let them figure things out for themselves. A follow-up on the students' progress once a week would then be enough.

The last question of the survey aimed to clarify 'how the role of coach differs from a teacher role, and why that is relevant or important'. A quantitative evaluation of this point seemed meaningless, as we had no idea against what baseline the 'performance' of the coach could be rated.

The table below summarises the students' feedback to the coach.

I think a coach's role is more that of a guide than a teacher. I believe self-study and also sharing our findings with each other and engaging in discussion is the most effective way of learning in this context. A teacher is someone who teaches you from his or her perspective, whereas a coach tries to teach you something by focusing on you. The role of the coach is to help a team to work bottom-up, whereas a teacher teaches in a top-down manner. A teacher would not take someone through a problem by focusing on the person, but would do so by concentrating on the issue at hand. To make lasting changes in beliefs, you need a coach. The role of a coach is to encourage and support individuals in activities. It's a more interactive and two-way exchange. Whereas the role of a teacher is mainly to teach his/her knowledge. In this project, we could have a heart-to-heart talk with our coach. Deep understanding, awareness, and humility are qualities I value in a coach.

4. Conclusions and discussion

With the caveat that this article examines the learning experiences of only three students and a coach, we can come to some cautious conclusions. The real challenge of this project was to understand what higher education should look like, given the inevitability of catastrophic developments if, in the next ten years, humanity does not change its habitual scenario. This case study allows us to move from a 'wild guess' towards an 'educated guess' concerning how higher education could innovate and prepare young persons for their roles as future leaders, professionals, and citizens in the 21st century.

The main difference between a standard academic curriculum and the learning that takes place in the Transdisciplinary Insights programme is that the former is based on separation, whereas the latter is holistic. The university was established and designed centuries ago, long before economic globalisation led to the emergence (i.e. autocatalysis; cf. Chapman, 2015) of the current, extremely complex system, which displays behaviour that cannot be understood by looking at its constituent parts separately. The changing climate is a result of human economic activity and what we call technological 'progress', although the intention of economics and technology was never 'to change the climate', so to explain those 'anomalies' a critical reflection on the underlying paradigm is required (Kuhn, 1996). In the current university, however, faculties like economics, engineering, and earth sciences are still mainly functioning within (the paradigm of) separate disciplines, using methodologies, language, methods, and tools that focus only on their subdomain. Even if several higher education staff members take initiatives

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towards embedding strong sustainability, they mostly feel that their efforts do not receive the necessary support and incentives. At a webinar on sustainable higher education (G-STIC, 2020) a student reported that in spite of the fact that his faculty offers a large variety of insights (from natural as well as social sciences) and even a course in systems thinking, this does result in a complexity lens being systematically used to analyse the issues the world is facing.

The paradigm embedded in the university splits reality into parts to be studied separately and without understanding how from their interaction new, more complex system behaviour can emerge. Humankind and nature are seen as separate realities, the first being the object of social sciences and humanities, the latter of natural sciences. It also separates man from nature in the sense that nature is not seen as the source of all (including human) life, and other species are not treated as our kin deserving our respect and care. Nature is merely framed as an object to be known, controlled, manipulated, or exploited. The 'normal' paradigm focuses on learning with the head and distrusts the heart (emotion is incompatible with true knowledge) and the hands (activism stands in the way of true science). Today, however, we understand that humankind is part of the web of life and that human discourses and actions have a profound impact on the dynamics of the planetary system. So for science to remain useful in the emerging complexity of the Anthropocene, it will have to shift to a more holistic paradigm that reconnects man with nature, reason with empathy, and knowledge with action (Lotz-Sisitka et al., 2015).

Analysing our experiences with the Transdisciplinary Insights Honours Programme, we can conclude that it offers useful learnings concerning how to foster such holistic learning.

Acquiring theoretical knowledge (learning with the head) was part of the YPGF challenge, mainly in the form of reading two (mandatory) scientific books. One book concerns the relationship between autocatalysis and epistemology (Chapman, 2015); the other one explains the impact of (human-centric versus ecocentric) cosmologies on the evolution of life on our planet (Crist, 2019). Discussing those new insights in our team was, however, the most crucial step for us to 'let it sink in' and understand at a deep level what these 'facts' mean for us as leaders of tomorrow.

The programme also called for practical learning (learning with the hands), for it required students to work on something that may contribute to a more sustainable world. In this case, the task was to draft (chapters of) a 'travel guide' to a regenerative future (as well as some concrete products like a video and publications).

A third cornerstone of the project was empathy, i.e. learning with the heart. The team was called to consider the perspectives of various stakeholders, people who are impacted by the human-made crises, and who explore alternative pathways. The fact that interacting with those actors not only widened our understanding of the crises, but also gave us hope, shows that this involved not only learning with the head, but also with the heart. Moreover, the project developed our natural intelligence, i.e. a feeling of kinship with all other species in the web of life, glimpsing the enormity of the destruction our human-centred civilisation has caused and moving towards an ecocentric attitude and a cultural paradigm of mercy and humility (Schönfeld & Chen, 2019, p. 7). The sense of 'loss' that we experienced when we learned how much biodiversity has disappeared over the last century helped us to understand that an ecocentric worldview, based on human restraint, modesty and respect for nature, is not only in our best interest as a species, but can also help us to find a new meaning in and hope for our lives. This too goes beyond a mere intellectual understanding but affects us at more personal levels.

All these learning processes are only meaningful if young people also feel capable of facing the loss of a familiar lifestyle, and are confident that a better life may be the outcome of the collapse they witness today (i.e. learning with hope). Tellingly, the documentary *Demain* (Dion & Laurent, 2018), which shows emerging alternatives in various fields, was the only preparatory activity the whole team gave the maximum score of 5 points (cf. Graph 3).

We can cautiously conclude that this holistic learning provides students with crucial capacities for building a sustainable world. As described in section 1, to be prepared for the future, one has to be able to relate to the reality of the current state of the planet, to make sense of the complexity of global evolutions, and to feel empowered to act towards a transition.

Some authors describe the current experience of collapse with that of grieving (Žižek, 2000, p. 58; de Kemmeter, 2019, p. 27). As Elisabeth Kübler-Ross describes, the first phase of grieving is denial, and this is how the psyche protects itself from the trauma of catastrophic loss. This may explain the attitude of

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the students who 'simply don't care, and accept their ignorance' (cf. comment in section 3.7). In order to adapt to reality, after the phases of denial, anger, and bargaining, people have to accept the current system is dead(ly). Only then does healing (or reconstructing a new life) become possible. While working on the YPGF challenge, the team needed time to accept the reality that 'we are dealing with a serious threat, and we'll have to change our entire way of life' (Žižek, 2000, p. 50). The team itself 'became a safe space for discussing scary issues: do we really need to rethink our entire system? Should birth numbers be limited? These questions are so daunting that just "getting the facts and figures right" does not equip us with convincing answers' (Grancitelli et al., 2020a).

Once learners can accept the reality of the current state of our planet and human responsibility for it, they can start to make sense of the complexity of current problems. They can 'unlearn' traditional reflexes and attitudes, and stop 'downloading' the habitual reactions of an egocentric civilisation (Scharmer, 2018, p. 36). The finger exercises were helpful for this. Learning to reframe societal issues from an ecocentric perspective is a powerful way to familiarise oneself with this new framework. Some of the team members started explaining this to their friends, which is a clear sign of their personal shift and enthusiasm. One of the students decided to assume the role of coach for a new team of students during the next academic year, showing 'liminal leadership' (Bateson, 2017). At the start of the programme, the team was hesitant: is it really necessary to rethink our entire system? Seeing the documentary *Tomorrow* and especially doing the finger exercises finally triggered the 'attitude revolution' from within. Once your attitude shifts towards ecocentrism, you can make responsible choices and actions with a positive impact on the planet. That can lead to a virtuous circle: when you see reality with new eyes and find hope in what you see, it is easier to find meaning in reconnecting with nature; this again leads to more restraint and respect towards nature, and natural abundance can regenerate (Gorissen, 2020).

The hopeful perspective this article paints will only become a reality if it is shared by a critical mass of young people. The key question, therefore, is if and under what conditions the learning path explored in this project can become available to all higher education students. How can the institutional barriers blocking a paradigm shift be removed? As from January 2020, the Institute for the Future is participating in STEAM+, an Erasmus+ project that explores how honours programmes can be used as labs for innovating STEM education (Science, Technology, Engineering, and Mathematics) to prepare students for the complex issues of the current era.[4]. This new project will offer opportunities to improve and test the various learnings described here and develop policy recommendations for innovating STEM education.

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List of supplements

Supplement 1: Original challenge description
Supplement 2: YPGF video
Supplement 3: Comments by Carlos Alvarez Pereira*

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Supplement 1: Original challenge description

Title of the Challenge
Young Persons' Guide to the Future (YPGF)

Key words (at least 10 words)
Sustainable higher education; complexity; transdisciplinarity; responsible research and innovation; futures; cocreation; co-evolution; Anthropocene; transition; planetary boundaries

Could you please state a specific challenge, problem or question?
Students today are still mainly educated in the linear, extractive model that since the industrial revolution brought us great wealth… but at a tremendous cost. Since the 1950s (the Great Acceleration) it is clear that the planetary and human buffers for the 'errors' in this extractive model are mostly gone; it is no longer possible to ignore those errors or put them aside as 'externalities' – as if they will disappear if you don't look. In fact they create 'unintended' rebound effects that undermine the stability of our socio-economic systems worldwide. Traditional science (and higher education) is based on the premise that the planetary system is stable (in terms of climate, soil, biodiversity, clean water, materials) and that therefore it is possible to predict (control) the outcome of an innovation in one variable (e.g. a technology or medicine) on another one (e.g. mobility or health…). Today this stable context has disappeared, and the new, emerging reality is characterized by non-linear and unpredictable dynamics. Nobody knows what the climate or the planet will look like twenty years from now. It is clear that the traditional (linear) compass for orienting ourselves in the planetary environment is no longer helpful. For the first time in human history we are leaving the stable conditions that allowed for the emergence and flourishing of agriculture and culture in general. We are entering 'uncharted territory', conditions that have never occurred previously in human history.

So the challenge is to develop a 'young persons' guide to the future' that is more adapted to this emerging complexity. No one has ever been in the future, but the developments in complexity science and systems thinking allow us to understand how life has evolved and what the basic conditions for its future development are. This understanding can offer some basic 'rules of thumb' on how to navigate this unknown territory and avoid the erroneous pathways of the past. The challenge is to translate those new theoretical insights to more or less practical – or at least understandable – guidelines for navigating the future. Those guidelines cannot describe 'what will be', but only 'what is possible', as well as under what conditions this can be made possible. The future is not some reality 'out there' to be discovered, but is cocreated by humans, at least if we understand the basic dynamics of life and co-evolution and take the responsibility for reflecting on the paths we take.

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 a specific result that you want the research group to reach?
The YPGF could be somewhat like a 'Lonely Planet' guide, which does not tell you what you will or must see or do in a city or country, but it gives you the kind of information that allows you to plan your own journey. The United Nations global agenda 2030 with its 17 Sustainable Development Goals describes a number of basic features of a future for all people on the planet (e.g. everybody has access to education and clean water…). Yet, the question how to get there – and especially how to avoid the pitfalls of the previous (linear) compass and (extractive) roadmap – is still an open question that only young people can answer, as they will be the builders and inhabitants of this new country. Ideally the YPGF will be an open sourced, common endeavour, where 'users' (or 'readers)' who come across yet another promising pathway can contribute – like Wikipedia, or like the updates you can send to Lonely Planet. Also, it ideally is made in a visually attractive way. Just like the Lonely Planet would not be useful if it contained only text and no pictures, maps or graphs, so the YPGF should also contain a lot of visualisations. This allows for learning with both brain halves and for using formats that not only touch the brain but also the heart (stories, artworks, poetry…). Just like a 'Lonely Planet guide' the YPGF could contain captions on 'how does one get around there (mobility in the

future)', 'where to stay' (housing and community development), 'what to eat and drink' (food, agriculture and water for the future), 'how to pay' (what does a sustainable financial system look like?), 'what to buy', etc. These captions will require a reflection both on 'what future we want' (ethical dimension) and on 'how can we get there' (knowledge, research and innovation dimension). Also, just like any travel guide, it should contain a lot of visual material (maps, images, graphs, pictures, maybe even short films…). How to orient oneself in the future is not something that can be described with words only, but can be 'visualised' or 'envisioned'. Different parts of our brain allow us to process visual representations and language; so using different types of representations allows us to 'use our whole brain' and be more creative. The guide might even propose games that can help the 'future traveller' to explore various scenarios.

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

Greta Thunberg, Anuna De Wever, and Kyra Gantois are convincing tens of thousands of young people to skip school and take to the streets, for they no longer believe current education prepares them for the real issues of the future. Current education does not address the complexity of current challenges, but is mainly still based on 'passing on knowledge from the past' (the premise of 'stability'). The complexity of the current challenges means they cannot be tackled by a single discipline. The YPGF is meant as a cocreated "guide" that allows young people not only to envision the future, but also to propose to their teachers really relevant questions on current knowledge that could help them to bring the desired future about, and on what errors or blind spots of the existing map need to be corrected. The challenge will, on the one hand, introduce students to the current 'state of the art' knowledge on complexity and systems thinking, as this defines the playing field for mapping the future (i.e. the evolution of life on this specific planet). On the other hand, it will allow them to critically evaluate and select what elements of current science are relevant to develop pathways into the future. Complexity and systems thinking offer a kind of language that allows us to talk about possible future scenarios, but does not determine in itself what the future will look like (in a deterministic way). Understanding the complexity of human evolution is a basic requirement for making more responsible plans for the future of humanity.

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Supplement 2: YPGF video

The YPGF video was presented at the Symposium 'KU Leuven facing the Future', webinar, 7 May 2020, and is available on https://kuleuven.mediaspace.kaltura.com/media/YPGF_Symposium+May+2020/1_ap1t75b8

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Supplement 3: Comments by Carlos Alvarez Pereira*

*Fellow of the World Academy of Arts and Science, member of the Club of Rome Executive Committee, member of the Advisory Board of the Erasmus+ project STEAM+.

'By reading this article, one can learn a fundamental lesson. For humanity the name of the game has to change: no longer expansion and growth at all costs, now it is about solving the oxymoron of human wellbeing within a healthy biosphere. To achieve that change, unlearning has to happen. The pathway to the education we need for desirable futures goes through unlearning many of the ideas conveyed by the existing educational systems.

And the lesson is learned because the article shows very well a process of transformation in the making, and one can connect with it, intellectually and emotionally. The process is substantial but not abstract because it is based on personal experiences. And it is particularly relevant in showing how learning happens: more by interacting with others than by confronting abstract notions.

Also, time is of the essence: processes take time, a full day exchanging with people involved in sustainable alternatives may be a lever, while a short meeting is not. Likewise, the whole process with the students has taken one year, not one month. That says a lot.

Gandhi famously said that speed is not relevant if we go in the wrong direction. In a world full of the anxiety of acceleration (an idea whose time is passing), this article reflects beautifully on a more sensible direction for the future of humanity.'

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A Transdisciplinary Approach to Get a Deeper Insight in the Context of Ebola Virus Outbreaks in War-torn Regions: A Comprehensive Guide for NGOs

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Abstract

Ebola virus disease is a deadly disease with mortality rates ranging from 25% to 90%. The previous outbreak in the north-eastern Democratic Republic of the Congo (DRC) posed extra challenges since it took place in a war-torn region. The roots of this conflict can be traced back to the beginning of colonization (at the end of the 19th century) and have led to struggles concerning land tenure and local identity. The political and socio-economic situation further complicated an adequate Ebola virus outbreak response. Early efforts and control strategies taken by the DRC Ministry of Health, supported by the WHO, UN peacekeepers and a number of humanitarian aid organizations eventually resulted in the tenth Congolese outbreak being controlled. However, medical NGOs encountered many obstacles, ranging from mistrust by the local population, to an unsafe working environment, lack of infrastructure, etc. This paper identifies building trust as one of the key elements for NGOs to optimize cooperation with the local population. Our data, gathered from semi-structured interviews, showed that establishing a relationship of trust with affected people and their communities is a crucial step in the Ebola virus outbreak response. This includes building a better comprehension by medical care workers of the local dynamics and cultural

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affinities. Therefore, we created a questionnaire[1] to be used by medical aid organizations to increase their understanding of the local situation from an anthropological perspective. Such an understanding will contribute to building trust between the local community and medical aid organizations working in the field. This will hopefully enable them to anticipate future problems, and do their job in a more profound and comprehensive way, incorporating the local community as a partner for success. We have summarized our conclusions in a small 10-minute video.[2]

Key words

Ebola virus, war-torn regions, conflicts, local community, transdisciplinarity, medical aid, NGOs

Introduction[3]

Ebola virus disease is a deadly disease with mortality rates ranging from 25% to 90%.[4] The outbreak in the Kivu and Ituri provinces (DRC) is the second largest outbreak recorded after the 2014–2016 Ebola virus epidemic in West Africa. Despite early efforts taken by the DRC Ministry of Health, supported by different international organizations such as the WHO, CDC, UN peacekeepers and a number of humanitarian aid organizations, and despite knowledge of previous outbreaks, the outbreak took long to be contained. Nevertheless, it was declared over on June 25, 2020. However, on July 1, 2020 a new one was already announced. The 2019–2020 outbreak studied here distinguished itself in a variety of reasons from earlier reported outbreaks.[5,6] Firstly, it took place in a war-torn region, which severely complicates the existing inadequate health care system in the region. In addition, the socioeconomic situation pushes the majority of the population to travel for trade and business with their neighboring countries in the East. And lastly there is community resistance due to distrust in the Congolese politic authorities and in any form of national or international medical support.[7,8,9]

In the past, Belgian colonial authorities changed the local structure in North and South Kivu by transplanting a large number of Hutu and Tutsi to that region for labor.[10] They appointed local chiefs, re-drew boundaries and physically separated populations.[11] As a result, many disputes arose about access to and control over land. These were in the beginning not violent, but under the former President of Zaire (now DRC) Mobutu Sese Seko, ethnicity became a mobilizing force in the competition for economic and political power.[12] So-called autochthony, defined as the natural relationship between people and their soil, is related to ideas of national citizenship and has been used to exclude Kinyarwanda speakers (Hutu and Tutsi) from certain rights. Different waves of migration dating back to the time before colonization (during the 19th century) until the Rwandan genocide in 1994 are decisive for judging people to be eligible for Congolese autochthony or not.[13]

The current conflict has three dynamics: firstly the Congolese kleptocracy, secondly the local mechanisms of land access and control, and lastly the insecure and/or lack of access to citizenship for people originating from Rwanda.[14] On top of that, the Rwandan genocide brought highly political and militarized refugees to the DRC,[15] and the two Congo Wars (1996–1997 and 1998–2003) triggered the nationality question,

1 This questionnaire can be found in Supplement I.
2 https://kuleuven.mediaspace.kaltura.com/media/Ebola+and+Conflict/1_r8n8zsbe.
3 More information about the background of the Ebola virus outbreak can be found in Supplement II.
4 WHO, "Ebola Virus Disease." Regional Office for Africa, https://www.afro.who.int/health-topics/ebola-virus-disease.
5 Aaron Aruna et al., "Ebola virus disease outbreak – Democratic Republic of the Congo, August 2018–November 2019," in *Morbidity and Mortality Weekly Report* (Centers for Disease Control and Prevention, 2019).
6 Oly Ilunga Kalenga et al., "The ongoing Ebola epidemic in the Democratic Republic of Congo, 2018–2019," *The New England Journal of Medicine* 381, no. 4 (2019).
7 F. Katembo Sikakulya et al., "Ebola in the Eastern Democratic Republic of Congo: One Health approach to infectious disease control," *One Health* 9 (2020).
8 B. Moran, "Fighting Ebola in conflict in the DR Congo," *Lancet* 392 (2018).
9 More information on Ebola virus can be found in Supplement II.
10 Henning Tamm and Claire Lauterbach, "Dynamics of conflict and forced migration in the Democratic Republic of Congo" (Oxford: Refugee Studies Centre, Oxford Department of International Development, 2010), p. 3.
11 Niamh Gaynor, "The limits to community-based conflict resolution in North-East Congo," *Community Development Journal* (2015), p. 4.
12 Koen Vlassenroot, "Chapter One: Reading the Congolese Crisis," in *Conflict and Social Transformation in Eastern DR Congo*, ed. Koen Vlassenroot and Timothy Raeymaekers (Ghent: Academia Press, 2004), p. 41.
13 Gillian Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," *Journal of African History* 58, no. 3 (2017), pp. 469, 475.
14 Vlassenroot, "Chapter One: Reading the Congolese Crisis," p. 42.
15 Ibid. pp. 46–48.

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inter-ethnic conflicts and an increase in the number of local armed groups.[16]

Currently there are over 130 local armed groups operating in North and South Kivu[17] and they use inter-ethnic problems as an argument to recruit young people and get sympathy from the affected community. Many groups are distinct anti-Tutsi, such as Mayi-Mayi, Forces Démocratiques de Libération du Rwanda (FDLR), etc. They are motivated on the one hand by the belief in securing and defending their own communities, and on the other hand by personal enrichment and criminal economic-related activities.[18] At the moment 31% of the total amount of killing people with weapons takes place in Beni.[19,20] The ongoing conflict influences the containment measures of health care workers in a number of ways. The geography and lack of infrastructure makes going out in the field a dangerous and lengthy activity. Local armed groups know the geography of the region and use this in coordinated attacks on villages and treatment centers. To prevent health care workers having to travel days through war-torn regions in order to deliver life-saving supplies and assistance, the United Nations, with the help of the European Union, has established a humanitarian air bridge.[21] However, once on the ground, health care workers are exposed to violence once again. Not being able to guarantee safety has led many humanitarian NGOs to call back their health care workers, leaving the people of North Kivu without necessary medical assistance.[22] The main outbreak containment measure – surveillance and rapid response capacities in order to respond to reintroduction events[23] – was therefore under threat. Another critical factor, indirectly linked to the local conflict, is the risk of stigmatization of survivors of Ebola virus infection. The strong stigmatization of Ebola virus disease and treatment centers, together with the mistrust created, makes any efforts by health care workers to deliver messages and increase social mobilization, community engagement and education extremely difficult.

This paper describes the work and results of a student team working on the challenge 'Ebola in conflict'[24] in the context of the Transdisciplinary Insights Honours Programme (https://rega.kuleuven.be/tdi). The team endeavored to shed some light on how NGOs can improve their medical aid by incorporating anthropological insights into their response to controlling the Ebola virus outbreak in war-torn regions. An overview of the most important actors, mistrust and the role of communication in the DRC will be discussed here. The transdisciplinary setting of this team has made it possible to tackle problems from many different perspectives, keeping in mind the Sustainable Development Goals (SDGs). Such an approach is crucial in formulating a well-founded solution for an Ebola virus outbreak in a conflict area.[25] The most crucial SDGs are here numbers 3, 4 and 17. This research seeks to contribute to the goal of combatting epidemics through universal access to safe and effective vaccines as well as through strengthening countries' capacities of risk reduction and management (goal 3.3 and 3.8). Investing in relations of trust might facilitate the spread of reliable information on prevention and also ease the distribution of vaccines. Improving the education of people (goal 4) about the risks and best ways to respond is a second vital goal. Finally, in order to create mutual trust, cooperation and 'partnership', as advocated in goal 17, are indispensable. Based on all the insights gained, an anthropological tool is proposed that could contribute to improving collaboration between international organizations and the local community.

16 Stephen Jackson, "Sons of Which Soil? The Language and Politics of Autochthony in Eastern D.R. Congo," *African Studies Review* 49, no. 2 (2007), p. 106.
17 CRG, "Congo, Forgotten: The Numbers Behind Africa's Longest Humanitarian Crisis" (Center on International Cooperation, New York University, 2019), p. 3.
18 Monica Thakur, "Demilitarising militias in the Kivus (eastern Democratic Republic of Congo)," *African Security Review* 17, no. 1 (2008), pp. 57–61.
19 CRG, "Congo, Forgotten: The Numbers Behind Africa's Longest Humanitarian Crisis," p. 7.
20 More information on the history and the current situation of the conflict can be found in Supplement V.
21 European Civil Protection and Humanitarian Aid Operations, "Democratic Republic Congo Factsheet," https://ec.europa.eu/echo/where/africa/congo_en.
22 IFRS, "Tragic attacks on responders and increased violence threaten to reverse positive gains in Ebola response, warns Red Cross," https://media.ifrc.org/ifrc/press-release/tragic-attacks-responders-increased-violence-threaten-reverse-positive-gains-ebola-response-warns-red-cross/.
23 WHO, "Recommended criteria for declaring the end of the Ebola virus disease outbreak," https://www.who.int/publications/m/item/who-recommended-criteria-for-declaring-the-end-of-the-ebola-virus-disease-outbreak
24 The challenge document can be found in Supplement III.
25 More information can be found in Supplement V: Conflict.

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Methodology

Transdisciplinary approach

A transdisciplinary approach is an integral part of this paper, and we tried to adhere to such an approach throughout all the topics we cover. The reasoning for considering this kind of approach are the inherent differences with commonly used multidisciplinary approaches. The first difference is the initial approach of a problem. In multidisciplinary approaches, problems are studied by separate teams often split into several fields of expertise. After debating all the proposed solutions, an attempt is made to formulate a consensus conclusion among all the teams. However multidisciplinarity can lead to the impossibility of formulating a consensus that satisfies all teams due to diverging interests. Similarly, interdisciplinary approaches do integrate insights from different disciplines from the start, but when this leads to implementation of measures in the field, stakeholders might oppose and the problem remains. Transdisciplinary approaches involve different disciplines from the start, but also involve the stakeholders during the research. When dealing with wicked problems, divergence of interests is always present, and a transdisciplinary approach can make this more explicit from the start, such that the researchers can consciously move beyond this divergence by creating a common understanding not only among researchers but also with the stakeholders. A transdisciplinary approach enables a team to better capture the huge complexity of a wicked problem. Since wicked problems have aspects related to different domains of expertise (researchers) or experience (stakeholders), the team addressing a wicked problem needs expertise in all these aspects, working together from the start. And lastly, the transdisciplinary approach is quite novel, not commonly used, and has the potential to expand and change drastically the approach to different wicked problems in the future.[26,27]

Actor constellation

As a research team, we started by thinking about possible actors that could be involved during an Ebola virus outbreak in DRC. In such brainstorm activities, we discussed possible actors during group sessions, combining gained knowledge and looking at it from different perspectives. Firstly, we made general actor constellations, without focusing on specific themes. We put different stakeholders in groups but also sought connections between groups of stakeholders. This allowed us to identify the contact persons for discussing a specific subject and to select the research topics that we needed to understand better through literature searches. Furthermore, after identification of the most important actors, we performed an initial literature study to deepen our knowledge about the impact of these actors. As a consequence, different major topics of interests arose spontaneously, which led to the discovery of new potential actors. In addition, the literature study enabled us to perform a more targeted and comprehensive construction of our actor constellation.

Literature study

After an initial actor constellation with our transdisciplinary team, we started a systematic review of the literature based on the actors found and their interactions. This literature review of scientific papers, anthropological studies, WHO reports and news websites led to a broad overview of the challenge. In addition, we gained more insights and knowledge about the problem and the actors involved. The insights gained served as a platform for interviewing experts from pertinent sectors, which broadened our understanding of the interconnections between new and already established stakeholders. We used this deepened knowledge to reevaluate our actor constellation and literature study. For the final literature review we prioritized studies or reports from actors from many different sectors that had experience in the field. We included independent scientific organizations, medical NGOs, the WHO and academic institutions. Based on the alignment of sources from different sectors, a consensus was established to circumvent bias from individual domains. Consequently, we excluded strongly deviating sources.

26 Sarah Gehlert et al., “Social Work in Public Health The Importance of Transdisciplinary Collaborations for Understanding and Resolving Health Disparities,” *Social Work in Public Health* 25, no. 3–4 (2010).

27 Peter Osborne, “Problematizing Disciplinarity, Transdisciplinary Problematics,” *Culture and Society* 32 (2015).

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Interviews

Based on our actor constellation, we reached out to experts in the field and local stakeholders that we identified as having an impact or being involved in this wicked problem. Other criteria were used to select actors based on domain of expertise, political and economic independency, availability and local involvement. Interviewees included virologists, industry representatives, an anthropologist, local journalists, a former NGO member and Congolese citizens. Every interview consisted of open questions and was recorded, transcribed and sent to the interviewees for final approval. All interviewed actors signed an informed consent form, allowing us to use the transcripts of their interview in our analyses for this paper. We communicated with them in a transparent way that gave them full permission to add or delete some parts in the interviews. The interviews were held on a voluntary, non-rewarded basis and could be stopped by the interviewee at any time.[28]

Questionnaire[29]

Different topics rose in the interviews, such as the need for better cooperation (instead of competition) between different levels, countries and organizations involved, or such as the importance of good transport infrastructure. Another issue was the existence of many misconceptions, resulting in hesitancy of people to go to hospitals. Moreover, when they waited too long, the chances of being cured decreased strongly, meaning that many died shortly after arriving in the hospital. This contributed again to negative perceptions among the population. Good information and communication are thus crucial for creating trust and obtaining a good anti-Ebola response. But this is severely complicated by a context of conflict (much movement of people, improper work environment for health care workers, etc.) and a troubled history and political situation (mistrust). Continuing violence, the government denying voting rights, foreign 'invasion' of health workers, etc. all further contributed to the mistrust of the population regarding health care provision. Since vaccines can only be effective if people come to the treatment centers, since this can only be achieved if they get correct and clear information, and since this information will only be accepted if people trust the sources of information, building better trust relations seemed a crucial starting point to help improve the treatment of the Ebola virus in this conflict zone of Congo. The interviews indeed showed that trust was at the core of this wicked problem. One of our interviewees, medical anthropologist Prof. Koen Stroeken, advised us to make a ready-made list of questions, which would enable medical care workers to conduct their work in a more anthropological way. We used the knowledge gathered from our interviews and literature study to construct a questionnaire that should enable NGOs to ask more specific questions in light of this wicked problem. The questionnaire covers a multitude of topics, but the silver lining in all of these questions is trust.

This paper emphasis the importance of adopting an anthropological attitude when studying complex and wicked problems. However, due to limited time, resources and funding we were unable to truly become familiar with the local perspectives, concerns and problems. Almost all stakeholders and interviewees are Western-based scholars and actors; only a few interviewees came from or worked in the region. Therefore, this paper in itself cannot be viewed as an anthropological research paper but more as coming from a social science perspective. However, with the anthropological questionnaire created from the gathered data we want to familiarize all active actors in the region with the local beliefs, customs and perspective on the Ebola outbreak. When fighting a deadly epidemic, knowledge is power, and indigenous knowledge should and cannot be ignored. The anthropological questionnaire developed is a low-threshold tool to get insight into this indigenous knowledge.

Results and discussion

Construction of an actor constellation based on empirical data

From the literature study, we identified a number of actors relevant to understand the wicked problem: 'Why had the ongoing Ebola virus outbreak still not been contained in this conflict zone?' During this process, as described in the methodology section, we progressed to the list of actors and their constellation presented in Figure 1. Given that this was an iterative process, the final central question in this figure is already informed by some of the further research described below.

28 The informed consent form can be found in Supplement VI.
29 The questionnaire can be found in Supplement I.

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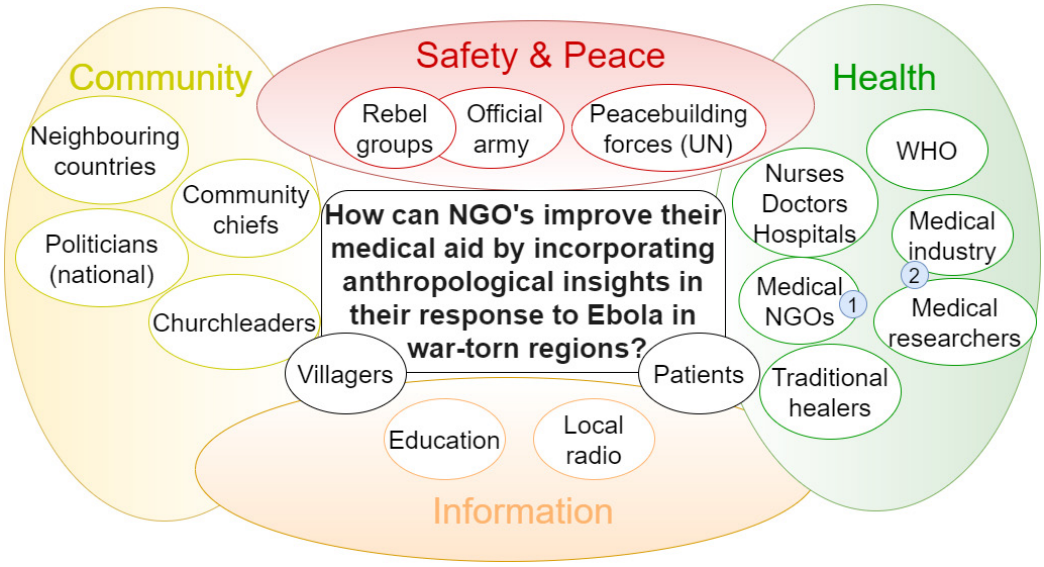

Figure 1. Schematic representation of the actor constellation. The closer the actors to the central question, the greater their impact on the wicked problem. The closer the actors are placed together, the stronger their relation. We were able to interview a few of the actors as indicated by a number, and listed in Table 1. *Four main categories of actors were defined: Safety & Peace, Health, Information, and Community.*

The local population, including Ebola virus-infected and recovered patients and non-infected people, should be key actors. In relation to them, four subgroups of actors were defined: 'safety & peace', 'health', 'information', and 'community'. Actors are placed in their predominant subgroup, although some can also be reasoned to fit into, or be linked to, other subgroups. In the following paragraphs, key considerations and arguments for all positions are explained.

Safety revolves around three main actors: the rebel groups, the official army and peacebuilding forces. As they have a direct effect on the living conditions of the whole population, they are positioned close to the center. Rebel groups and official army are intertwined, which makes it hard to draw hard distinctions between the two. In the government army, the FARDC, a lot of ex-rebels are recruited and some armed groups use official army uniforms. For the population, a clear distinction and overview of shared interests is not possible.[30] Peacebuilding forces mainly consist of MONUSCO, led by the UN. Started in 1999, the original goal was to observe the ceasefire and disengagement of forces as stated by the Lusaka Ceasefire Agreement between the DRC and Angola, Namibia, Rwanda, Uganda and Zimbabwe. In later resolutions, the mandate was expanded to include supervision and supporting the elections in 2006. Following the elections, 'MONUC remained on the ground and continued to implement multiple political, military, rule of law and capacity-building tasks as mandated by the Security Council resolutions, including trying to resolve ongoing conflicts in a number of the DRC provinces.'[31] Starting from 2010, MONUC was renamed to MONUSCO to reflect the new phase reached in the country. The new mandate focused on 'the protection of civilians, humanitarian personnel and human rights defenders under imminent threat of physical violence and to support the Government of the DRC in its stabilization and peace consolidation efforts', for which 'all necessary means were authorized'.[31] Despite being the largest and most expensive operation in the UN's history (US$ 8.7 billion), it has been seen as a complete failure. The main critique is that it neglected the root causes of the conflict, which are disputes over land and power.[32] A second critique originates from the limited results of the disarmament, demobilization and reintegration of Congolese and foreign armed groups. The MONUSCO forces themselves have been the target of attacks, both by rebel groups and dissatisfied civilians. One of the reasons is that this program represented a military and technical approach towards what

30 Information extracted from the interviews.

31 UN, "Background," https://monusco.unmissions.org/en/background.

32 Gaynor, "The limits to community-based conflict resolution in North-East Congo," p. 2.

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is essentially a political problem.[33] Another problem was that not all parties, such as the FDLR, wanted to participate. To conclude, the more local causes and effects were addressed, but the approach was lacking when it came to the broader structural causes of the problems. A strong political structure is needed to establish peace as corruption drains resources from the FARDC and police forces.

Another important category of actors is health care providers, namely traditional healers, local certified health personnel and medical NGOs such as the Red Cross and MSF. Although a clear structural organization in 11 provinces with administrative districts containing several health zones, health care commercialized and made room for a system of several actors due to disengagement of the State from regulation and financing of the health sector.[34] Traditional healers can be defined as healers whose knowledge does not originate from official certificate-granting institutions, but rather is passed on through successive generations. This does not indicate however that their methods have not evolved over the years.[35] Starting in 1999, the Congolese Minister of Health, Dr. Mashako Mamba, launched a partnership between traditional healers and medical doctors. He claims that traditional medicine is the prime source of health care for 80% of the population.[36] Traditional healers can be both health-enhancing as well as outbreak-amplifying, as in the case of the Ebola virus outbreak they wanted to support the response, but at the same time used skin cuts in their treatments, which allowed further spreading. Hewlett suggests that (inter) national health teams should provide education to healers and supply them with the necessary gear such that they can contribute in the response.[36] Medical NGOs include the Red Cross, Médecins Sans Frontières, etc., as well as projects like EBODAC, which is further discussed in the next section. Further from the center are the WHO, the medical industry (pharmaceutical companies, etc.) and medical researchers. They are in less direct contact with the patients but drive the medical response through research, supplies and initiatives.

Thirdly, a lot of information is spread through the numerous local radios that contribute to educating people. Radio is very important, but also widespread and independent. A particular radio can even spread multiple contradictory messages about the Ebola virus at the same time. In addition, several aid organizations work around educating people, and some use these local radios to spread their information.[37] Education can be a first source of information on knowledge about Ebola. Although primary level education rose from 29% in 2002 to 70% in 2014, 26.7% of children of the appropriate age are still out of school, mostly those living in rural areas. In 2016, the DRC released its Education Sector Plan for 2016–2017, in which the focus lies on expanding access and equity, improving learning quality, and improving governance and management in the sector.[38,39] A case study by the EU Capacity4dev Team identified two key features which summarize the current situation. Firstly, many schools and learning environments are unsafe due to targeting by armed groups. The current governmental education plans are insufficiently adapted to this conflict environment, and to the fragility of the country in general. Secondly, teacher salaries from the government are inadequate, precarious and are paid with big delays. This forces teachers to combine multiple (teaching) jobs, or start with private education, which deprives the public education system of high-quality teachers. In the same way that health care is commercialized, education in private schools enables inequalities.[40] In general, there are a lot of trust issues in education, as disinformation is often used to influence conflicts.[41]

33 Tamm and Lauterbach, "Dynamics of conflict and forced migration in the Democratic Republic of Congo," p. 7.

34 Belgische technische coöperatie (BTC), "Improving financial access to health care in the Kisantu District in Congo: acting upon complexity (n° 003)," https://www.enabel.be/sites/default/files/003_improving_financial_access_to_health_care_in_kisantu_district_in_dr_congo_acting_upon_complexity_en_0.pdf.

35 Barry S. Hewlett and Bonnie L. Hewlett, *Ebola, Culture, and Politics: The Anthropology of an Emerging Disease* (Belmont: Wadsworth Cengage Learning), pp. 58–59.

36 IPS, "HEALTH-CONGO: Traditional Healers Work Alongside Doctors," http://www.ipsnews.net/1999/06/health-congo-traditional-healers-work-alongside-doctors/.

37 Information extracted from the interviews.

38 Global Partnership for Education (GPE), "Democratic Republic of Congo | Global Partnership for Education," https://www.globalpartnership.org/where-we-work/democratic-republic-of-congo.

39 Ministère de l'enseignement primaire secondaire et initiation à la nouvelle citoyenneté Congo DR, Ministère de l'enseignement technique et professionnel Congo DR, Ministère de l'enseignement supérieur et universitaire Congo DR, Ministère des Affaires Sociales, Action Humanitaire et Solidarité Nationale, "Stratégie sectorielle de l'éducation et de la formation 2016–2025. RD Congo," https://planipolis.iiep.unesco.org/en/2015/strat%C3%A9gie-sectorielle-de-l%C3%A9ducation-et-de-la-formation-2016-2025-6259.

40 EU Capacity4dev Team, "Study on Governance Challenges for Education in Fragile Situations," https://europa.eu/capacity4dev/governance/documents/study-governance-challenges-education-fragile-situations-0.

41 Information extracted from the interviews.

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Lastly, both community chiefs and church leaders have a strong influence over their audience; as an example, the church tried to monitor and avoid fraud in the 2018 elections.[42] The religious landscape consists of mostly Christians (~80%) and Muslims (~12%). Contrasting with the secular nature of the DRC's Constitution, 'being openly atheist, nonreligious, or a nonbeliever would probably disqualify someone from the most important offices in political and social life'.[43] National politicians, who are based in Kinshasa, the capital city of the DRC, have less direct influence on the population living in the eastern part of the country and there exists a large mistrust from people in the north-eastern DRC towards national politics.[44] The transfer of power from Kabila to Tshisekedi seemed only a continuation of the kleptocracy of Kabila, although better hidden.[45] Tshisekedi is subject to the politics of his predecessors and Rwanda and thus does not have enough legitimacy and power to actually change the situation in the north-eastern DRC.[46] Concerning neighboring countries, Rwanda is more likely to be among the countries that provides covert support to local armed groups in the eastern regions of the DRC. Many aspects of the conflict, such as identity and land access, are deeply intertwined with Rwanda and the history they share. As a consequence, the team tried to collect information from as many of these actors as possible, in order to understand their stake in the conflict and in controlling the Ebola virus outbreak, and which approach to the Ebola virus outbreak response they might support.

There were many important actors that we could not reach, and there was expertise that was lacking in the team. The actors and experts that we could interview are listed in Table 1, and linked with the actor constellation by numbers (1,2) where applicable. All had direct experience with or expertise about the Ebola virus outbreak or the conflict, and one of the interviewees was living in the conflict zone.

Table 1. List of interviewed actors and experts with their respective disciplines

Number of interviewees	Discipline / expertise	Number of interviewees	Discipline / expertise
1	Professor of Anthropology	1	NGO employee (1)
1	Professor of Conflict	2	Local journalist
2	Professor of Virology	2	Pharma industry employees (2)
1	Congolese citizen		

Identifying trust[47] as a missing key factor for an adequate Ebola virus outbreak response

The interviews and literature study made clear that trust and communication are pivotal aspects for an effective response to the Ebola virus outbreak. Mistrust by the local population suffering from Ebola virus disease is felt towards multiple actors, both national and international. On a national level, it can be said that eastern regions of the DRC have been neglected in their rights and not listened to by the Congolese government for many years. The unstable situation was on the one hand seen by Kinshasa as a playground for motivating feelings of ethnicity to polarize people and on the other hand as some far-off problem that was not on their agenda. On an international basis, mistrust goes back as far as the colonization. The current conflict further complicates the Ebola virus response, causing international organizations to come and go, mass migrations etc. In contrast, the ninth outbreak occurring in a non-conflict zone in the Équateur province was resolved in fewer than three months.[48] In addition, the extreme exploitation of the country by both local elites and international companies, and the notorious UN interventions, only fueled feelings of fear, anger and mistrust towards many people and instances. This makes communication with the local population much harder.

42 Pierre Englebert, "Aspirations and Realities in Africa: The DRC's Electoral Sideshow," *Journal of Democracy* 30, no. 3 (2019).
43 Donatien M. Cicura, "Violence, Peace, and Religion in Congolese Society," *Peace Review* 30, no. 4 (2018).
44 Information extracted from the interviews.
45 Englebert, "Aspirations and Realities in Africa: The DRC's Electoral Sideshow."
46 Information extracted from the interviews.
47 More information can be found in Supplement VII: Trust.
48 IFRC, Emergency Plan of Action update. 2017" (July 2019), pp. 1–51.

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Political events during the Ebola virus outbreak further increased mistrust. Presidential elections in Beni and Butembo, both located in North Kivu province were suspended on 30 December 2018 because the Ebola virus epidemic would have made it unsafe. Some people claimed that the Ebola virus outbreak was used as a political reason to prevent a massive vote for a candidate chosen by the main opposition leaders.[49] This only fueled rumors that the outbreak was a political strategy or a business making the rich even richer and more powerful. Subsequently, this situation has increased community resistance and mistrust and has promoted attacks on some Ebola virus disease treatment centers by unknown persons.[50] Attacks on health care workers and Ebola virus disease treatment centers further impeded the Ebola virus outbreak response in the region.[51,52,53,54]

The combination of the above elements makes it clear that the situation in the eastern DRC is different from other regions that have coped with Ebola. Although problems such as stigmatization and lack of proper education about the subject existed in other regions affected by Ebola, the Ebola outbreak in the eastern DRC was more intertwined with the political climate of that region.[55] The sudden amount of interest that the international community had in the affected areas stood in huge contrast to the lack of interest in stopping the large number of killings that took place. It led people to think that there was a hidden political and economic agenda at play. Combined with the scars of the inability of the Congolese State and MONUSCO to protect its citizens and the violent struggle over political power, the result was a climate of distrust towards the Congolese government and international actors, including humanitarian aid workers.[56] In other words, the element of long-term violence and conflict shaped the way the internal aid workers needed to operate in the field since trust towards foreigners was wiped away by a combination of previous and current events.[57]

During the outbreak, several measures have been undertaken to rebuild a trustful relationship between the health care workers and the local population,[58] but further efforts would facilitate containment of the Ebola virus. It should be noted that the health but also the well-being of both patients and the health care workers is of the utmost importance.[59,60,61] They form the core of the response team to prevent the spread of Ebola virus disease. Their well-being is also paramount for an effective and efficient response to the health crisis that presented itself in the DRC.[62,63] Every possible solution to an Ebola virus outbreak in a conflict area should keep the SDGs in mind since neglecting them can lead to an array of new problems.

Communication to counter community resistance[64]

Communication is key, certainly in a region where mistrust and miscommunication has been an issue for decades. For health care workers operating in such an area, both strong mechanisms to spread correct information and good mechanisms to listen to the specific wishes and fears of the population are crucial. Some good initiatives are already running, such as 'edutation' programs (a combination of education and entertainment) on local radios trying to promote tolerance, the EBODAC initiative to make vaccine trials trustworthy,

49 Englebert, "Aspirations and Realities in Africa: The DRC's Electoral Sideshow", pp. 129–130.
50 Vinh-Kim Nguyen, "An Epidemic of Suspicion – Ebola and Violence in the DRC," *The New England Journal of Medicine* 380, no. 14 (2019), pp. 379–381.
51 More information on conflict can be found in Supplement III.
52 Sikakulya et al., "Ebola in the Eastern Democratic Republic of Congo: One Health approach to infectious disease control."
53 Kalenga et al., "The ongoing Ebola epidemic in the Democratic Republic of Congo, 2018–2019."
54 UN News, "Violence in DR Congo Ebola hotspot leaves people 'caught in crossfire'," https://news.un.org/en/story/2019/11/1052441.
55 WHO, "Ending an Ebola outbreak in a conflict zone" (WHO, 2020).
56 Christoph Vogel et al., "Cliches Can Kill in Congo: The country's Ebola outbreak is spreading out of control – but it's not because of a fight over 'conflict minerals'," *Foreign Policy,* 2019.
57 WHO, "Marginalised and mistrustful: listening to people who have few reasons to trust outsiders" (WHO, 2019).
58 ALIMA,"CUBE:AnewinnovationinthetreatmentofEbolaandMarburg," https://www.alima-ngo.org/uploads/831a19bc0a7022906a7773cb-8f4c36e9.pdf?_ga=2.133499785.688301221.1586642409-671771303.1586642409.
59 Sikakulya et al., "Ebola in the Eastern Democratic Republic of Congo: One Health approach to infectious disease control."
60 American Psychological Association, "Stress effects on the body," https://www.apa.org/helpcenter/stress-body.
61 P. Alhola and P. Polo-Kantola, "Sleep deprivation: Impact on cognitive performance," *Neuropsychiatric Disease and Treatment* 3, no. 5 (2007).
62 Sikakulya et al., "Ebola in the Eastern Democratic Republic of Congo: One Health approach to infectious disease control."
63 UN, "What are Human Rights.," https://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx.
64 [4] Sikakulya et al., "Ebola in the Eastern Democratic Republic of Congo: One Health approach to infectious disease control."

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anthropological initiatives to bring different people together to talk, and many more.[65]

The WHO has stressed the importance of Good Participatory Practices in emergency situations such as containing the Ebola virus outbreak. It has also created a list to help medical aid workers in taking steps towards better cooperation with local people.[66,67] However, these recommendations remain quite general and theoretical. Considering the complex circumstances in which health care workers have to operate, it might be beneficial for them to have a practical and ready-made list at their disposal. This can help them to gain a better insight into the circumstances surrounding them. The questionnaire at the end of the paper is our proposal for such a list.

In order to properly control an Ebola virus outbreak, humanitarian and health care workers should be aware and able to understand the population's habits and local culture.[68] In the case of Ebola virus, it influences the type of medical care people would like to receive, feel comfortable with and deem appropriate.[69] As Ebola virus disease has been present in the DRC for many decades, Congolese people have accumulated a fair amount of cultural knowledge on how to deal with and control the disease.[70] Accurately understanding and working with this indigenous knowledge will improve any efforts of humanitarian intervention and outbreak control, as well as creating a solid foundation for the establishment of a trust relationship. It is crucial that local communities are being listened to and are seen as equal in the development of prevention and control strategies.[71]

Development of a questionnaire aimed at guiding medically oriented NGOs to approach their field work from an anthropological perspective

Although trust and cooperation have already been stressed as important, in practice they remain elusive – within the communities themselves, towards health care workers, towards national and international governments and towards the internal community. In the documents on WHO recommendations that we consulted, there was a clear lack of a deeper insight into and affinity with cultural nuances, history and local wishes. It is of vital importance that health care workers truly interact with the communities they are working with through contextual listening. In that way power relations will be flattened and trust relationships developed. Thus, it is essential that local people are no longer seen as objects of research or in need of help, but as independent actors and subjects with equal value to the health care workers themselves.

An anthropological attitude and approach when working in an area as complicated as the north-eastern DRC is indispensable. This was the core of our incentive to make a list for medical health care workers who need to work in areas with a high level of mistrust, such as in conflict-defined areas. This questionnaire is specifically made for international health care workers to offer them different tools in order to get to know the people, the community and the area or region in which they are working better. Often NGOs work with local middlemen, but in this way the health care workers remain strangers; this is what should be overcome. To build trust and to create a space where open communication

65 UN, "What are Human Rights.," https://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx; Luisa Enria et al., "Power, Fairness and Trust: Understanding and Engaging with Vaccine Trial Participants and Communities in the Setting up the EBOVAC-Salone Vaccine Trial in Sierra Leone," *BMC Public Health* 16, no. 1140 (2016); IMI, "Of vaccines, rumours and the success of IMI's EBODAC project," https://www.imi.europa.eu/projects-results/success-stories-projects/vaccines-rumours-and-success-imis-ebodac-project; information extracted from the interviews with the pharma industry; http://www.labenevolencija.org; Yeshim Iqbal and Rezarta Bilali, "Community Radio as a Vehicle for Social Change in Conflict-Affected Settings," in *Emancipatory and Participatory Methodologies in Peace, Critical, and Community Psychology*, ed. Mohamed Seedat, Shahnaaz Suffla, and Daniel J. Christie (Springer International Publishing, 2017); Elizabeth Levy Paluck, "Is It Better Not to Talk? Group Polarization, Extended Contact, and Perspective Taking in Eastern Democratic Republic of Congo," *Personality and Social Psychology Bulletin* 36, no. 9 (2010); Julienne N. Anoko, "Communication with Rebellious Communities during an Outbreak of Ebola Virus Disease in Guinea: An Anthropological Approach," Ebola Response Anthropology Platform.

66 WHO, "Risk Communication and Community Engagement Preparedness and Readiness Framework: Ebola Response in the Democratic Republic of Congo in North Kivu" (WHO, 2018).

67 Catherine Hankins, "Good participatory practice guidelines for trials of emerging (and re-emerging) pathogens that are likely to cause severe outbreaks in the near future and for which few or no medical countermeasures exist (GPP-EP)" (WHO, 2016).

68 Clifford Geertz and L. Geertz, *The Interpretation of Cultures* (Hutchinson, 1973).

69 Barry S. Hewlett and Bonnie. L. Hewlett, *Ebola, Culture, and Politics: The Anthropology of an Emerging Disease* (Belmont: Wadsworth Cengage Learning, 2008), pp. 54–59.

70 Ibid. pp. 64–65.

71 Jon A. Leydens and Juan C. Lucena, "Listening as a Missing Dimension in Engineering Education: Implications for Sustainable Community Development Efforts," *IEEE Transactions on Professional Communication* 52, no. 4 (2009).

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can take place, medical care workers should be well known in the villages.

The questionnaire[72] that was made is a result of combining all the gathered information, our aim to enhance the SDGs and a transdisciplinary approach. As a team consisting of different backgrounds, and while learning from some of the stakeholders through interviews, we wanted this diversity to be reflected in our approach. This resulted in our aim to help medical aid workers in getting a better anthropological attitude instead of relying on external anthropologists. After all, that would only mean more different foreign people involved and would not help the medical aid workers in making themselves trustworthy. Overall this list of questions could guide NGOs in the field to improve their insights into the current situation. Our questionnaire covers a multitude of topics, of which the four most important ones are the conflict, community resistance, the impact of culture and the prevention of Ebola virus spread. This questionnaire can guide medical workers in the field towards asking the right questions to gather more in-depth insights into the situation and to gain trust. The simplicity and accessibility of the list will ensure, on the one hand, that they get a more spontaneous anthropological connection with their work field and, on the other hand, that they can start to sense for themselves whether asking a certain question is being experienced as problematic or not.

Conclusion

The present study aimed to give a deeper insight into the different layers of complexity about the Ebola virus epidemic in a conflict zone. It was clearly shown that the knowledge of the past and current history of the DRC is necessary for suggesting and providing appropriate countermeasures against the Ebola virus outbreak in this conflict zone. Without understanding these more profound structural aspects, it is impossible to create solutions. Identity, land access and the Congolese kleptocracy are still driving forces in the conflict. This is the background against which the international community, national and international NGOs, local health care systems and traditional healers are trying to deal with Ebola. The combination of all these elements is fertile ground for the creation of mistrust, rumors and community resistance. A possible solution to make the Ebola virus outbreak response more effective and more human is by gaining the trust of the communities concerned. This can only be done when health care workers themselves interact with local communities, listen to them and get to know their history and cultural nuances. The local community needs to experience their concerns being taken seriously and being heard. The questionnaire will give those medical aid workers the necessary tools to start and deepen conversations and, by doing that, build meaningful trust relationships. However, due to time constraints, insufficient resources and the absence of a local contact, our questionnaire was not constructed in a truly transdisciplinary way, since we lacked local input. We strongly advise a next transdisciplinary team to try and include this local input, in order to co-create a questionnaire based on our proposal, and make it an even more effective anthropological tool. We have summarized our conclusions in a small 10-minute video.[73]

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List of supplements

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72 The questionnaire can be found in Supplement I.

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Supplement I: Questionnaire

Questionnaire for health care workers: a comprehensive guide for NGO personnel active in resource-limited settings

Through our research it became clear that building trust and having knowledge and insight into local dynamics of society and culture is of vital importance for an efficient Ebola virus outbreak response. Yet this is often something NGOs and health care workers struggle with. The following questionnaire should be considered as a first step for health care workers in achieving this goal. For the Ebola virus outbreak response in the DRC, it focuses primarily on the control measures which can be taken to limit Ebola virus spread in conflict areas. Questions should be interpreted as a first attempt of creating an open and safe working environment in which the perspective of the local community must be prioritized. These questions should make it easier for health care workers to engage in further conversations and develop the much-needed trust relationship. Often communication between health care workers and a local community is done with the assistance of local translators. While the use of a local translator is often the only way to communicate, it creates a gap between the health care workers and local community. Local people know their setting and area better than any foreign health care worker. However, we would like to stress the vital need for close interaction between health care workers and the local community in order to reduce mistrust and promote a better understanding between them. Working with local translators creates disadvantages. For one, they often have their own prejudices and ideas concerning local beliefs and customs, especially in the ethnically diverse context of the DRC. Secondly, translators hired by the WHO or any other humanitarian actor are often educated by Western institutions, which lack indigenous knowledge. Thirdly, much information is lost in translation as translation in essence is an interpretation of something said. This questionnaire allows the third disadvantage to be tackled by asking simple and evident questions of local people. By doing so, the health care worker will be engaged at a personal level and not just a medical level. We hope that by engaging at a more personal and intimate level, building a trust relationship will be easier and the outbreak response can be tailored for every different community.

The control measures against the Ebola virus outbreak in North Kivu province are not effective enough due to a decade-long inter-ethnic conflict and unstable political situation. This situation leads to mistrust and resistance in the community. Asking difficult and personal questions of people living in extreme violence and insecurity will pose many challenges. It is of vital importance for health care workers to be sensitive about the living conditions of many people in North Kivu. Therefore, we want to point out that by no means all questions in the questionnaire should be asked at the same time or in the order written. If an interview is required or organized, the health care workers should always keep in mind the wishes and needs of the local community by asking a few questions on the control measures against the Ebola virus outbreak. This questionnaire should be seen as an anthropological tool which seeks to bring health care workers closely together with the local community. By using it, health care workers will be confronted with the local situation and this will make them think about possible prejudices and ideas of local people with regard to humanitarian aid.

1. ***Insight into personal history***
   - Family information
     - Are you married?
       ~ Polygamy is practiced in some parts of the DRC
     - Do you have children?
     - How often and under what circumstances do you see extended family?
   - Personal information
     - What is your job/responsibility within the community in which you live?
     - How has this changed over time?
     - Why has this changed?

- Where do you live?
  - How long have you lived here?
    - If fairly recently, where did you live before and why did you move?
      ~ Moving in war-torn regions is often due to violence and unsafety, sensitivity advised.
  - What are the benefits/disadvantages of the area you live now?
  - Why do you identify them as benefits or disadvantages?
    ~ Access to work, housing, agriculture, infrastructure, health care, education, community, etc.
  - How does communication with neighboring villages take place? In times of Ebola virus outbreaks, how often is there close contact?
    ~ Markets, family visits, religious gatherings, festivals, etc.

2. Insight into violence and conflict

- Impact of violence and conflict on the community
  - How has violence and conflict influenced day-to-day life in the village?
    - Are people scared to leave the house?
    - Can people still go to work?
    - Can children still go to school?
      ~ Who takes care of the children if they cannot go to school due to violence or anxiety?
  - Do you live in a closely connected community?
    - What defines a connected community for you?
    - Who can you rely on in times of violence within the community?
  - Does your community make you and your family feel safe?
  - In what way does the community try, collectively, to guarantee safety?
- Impact of violence on people's movement around the area
  - During what time in the year do people generally travel the most?
    ~ Festivities, dry/rainy season, markets, family gatherings, religious gatherings, etc.
  - Has travelling recently increased or decreased? For what reason?
  - Have people recently moved out of or into the village?
  - How often does your community come into contact with other ethnic/religious communities?
  - How often does your community facilitate foreigners?
    ~ Tourists, NGO personnel, multinational corporations, journalists, UN peacekeepers, etc.

3. Insight into cultural beliefs and practices

- Which cultural practices and beliefs are the most important to you?
- How does your community perceive the consumption of game meat?
  - How long has this been a practice?
  - How important is this practice?
  - How often do you and your family eat game meat?
    ~ Game meat can be consumed either as a delicacy or as financial solution.
- Which rites of passage does your community live by?
- What are the most important festivities in your village?
- Which religions are represented in your community?
- Which language(s) do you and your community representatives speak?

4. Insight into indigenous knowledge concerning Ebola virus disease

- How does your community identify Ebola?
  - Does your community use a different name?
  - What are the symptoms?
  - Where does it come from?

- How do you prevent it?
- How do you treat it?
- When is someone cured?
- Is Ebola virus disease perceived as a deadly disease?

– Who do ill people go to in the community?
  ~ Importance of traditional healer and perception of WHO, NGO and Ebola virus disease treatment centers.
– Have people recently fallen ill in the community?
– What does the health care system look like?
– What other diseases does your community have to face?
  ~ Malaria, TB, yellow fever, famine, etc.

5. Insight into improving prevention

– How does your community like to communicate with health care workers?
  ~ Via close personal interaction, use of telephone, SMS, radio, television, etc.
– What does your community believe health care workers are here to do?
– What is your experience with foreign health care workers?
– How can they improve their aid?
– What has foreign aid done wrong?
– How would your community like to be involved?
– How do you view the future?

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Supplement II: Ebola virus

Genome organization of the Ebola virus

The Ebola virus belongs to the genus *Ebolavirus* in the family *Filoviridae*, order *Mononegavirales*. The genus consists of six species: *Bundibugyo ebolavirus* (BDBV), *Reston ebolavirus* (RESTV), *Sudan ebolavirus* (SUDV), *Tai Forest ebolavirus* (TAFV, formerly Ivory Coast ebolavirus), *Bombali ebolavirus* (BOMV) and *Zaire ebolavirus* (EBOV). The latter is the most virulent with a mortality rate ranging from 25% to 90%. The virus is named after the Ebola river, which is near Yambuku (DRC), the village where the first reported Ebola virus outbreak occurred in 1976.

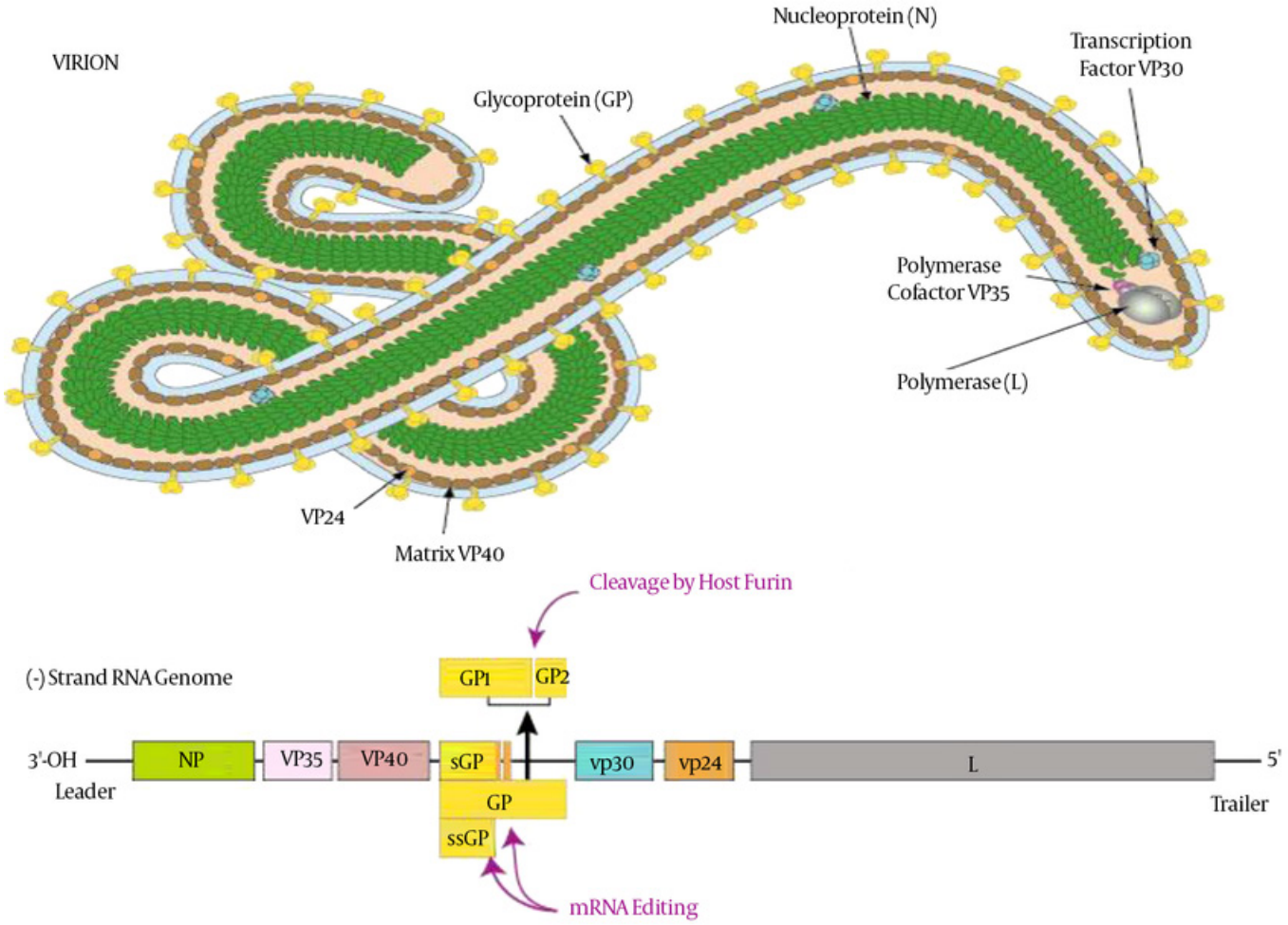

Figure A1. The Ebola virus virion. The Ebola virus is a filamentous, enveloped, non-segmented negative-sense RNA virus with genome size of approximately 19kb. The virion has a twisted thread-like shape and contains seven genes from 3' to 5': NP, VP35, VP40, GP, VP30, VP24 and polymerase L (Zawilinska et al., 2014; Kuhn et al., 2019; Kiley et al., 1982; Amman et al., 2017). Figure reprinted from Majid et al., 2016.

Clinical symptoms of Ebola virus disease

Flu-like symptoms appear after an incubation period of 2–21 days and include sudden onset of fever, malaise, headaches, vomiting, dizziness, weakness and diarrhea and later can become more severe with a petechial/maculopapular rash and hemorrhagic symptoms. Severe hemorrhagic fever leads to shock, multiple organ failure and eventually death. The virus is classified as a biosafety level 4 pathogen (Zawilinska et al., 2014; Kuhn et al., 2019; Kiley et al., 1982; Amman et al., 2017).

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Epidemiology of the Ebola virus

Ebola virus disease is a zoonotic disease. This means that the virus jumped from non-human animals to humans (e.g. due to hunting, consuming bushmeat, direct contact with infected live or dead animals). It is thought that fruit bats of the Pteropodidae family are natural Ebola virus hosts, but infection might also occur through close contact with bodily fluids of infected chimpanzees, gorillas, antelope and other wildlife. Each outbreak is initiated by an introduction from an animal reservoir, thus prevention of zoonosis by avoiding direct contact between people and wildlife would limit the amount of Ebola virus outbreaks. After the primary infection, the virus is then passed on between humans. It enters the host through mucosal surfaces, breaks and abrasions in the skin or via accidental injection. Sources of infection are direct contact with a sick person or contaminated objects used by the patient and funeral rituals. The Ebola virus is not airborne; the primary sources of infection are bodily fluids including blood, vomit, stool, breastmilk, saliva, urine, semen, etc. Moreover, intubation or bronchoscopy in hospitals causing aerosol formation might also be a way of airborne-like transmission when inhaled or ingested. Unlike other diseases, a patient infected with the Ebola virus is only infectious the moment he/she starts to develop symptoms (Zawilinska et al., 2014; WHO – Ebola virus disease, 2019).

History of Ebola virus outbreaks

So far 10 outbreaks have been reported in the DRC. The first outbreak of the Ebola virus was reported in 1976 in the DRC and Sudan. There were 318 cases with a case fatality rate (CFR) of 88% in Yambuku (DRC) and 284 cases with 53% CFR in Nzara (South Sudan) reported. These two epidemics could be attributed to two different species of Ebola virus, namely ZEBOV and SEBOV respectively.

Later, additional species of Ebola virus were discovered. An outbreak with 315 patients in Kikwit (DRC) had 250 reported deaths. In 2000 (Gulu) and 2007 (Bundibuhyo), there were outbreaks in Uganda with 425 and 149 new cases respectively; the mortality rate was estimated at 25%. In 2014, multiple outbreaks were reported in Guinea, Sierra Leone, Liberia and Nigeria. There was an estimation of 1009 cases, of which 514 patients died (del Rio et al., 2014; Rivera et al., 2016).

The outbreak related to in this study started on 1 August 2018 in North Kivu and Ituri provinces and is caused by the ZEBOV strain. It has been the second most deadly after the one in West Africa in 2014 and has reached 3453 cases, of which 2273 have died (overall mortality rate of 66%). Luckily this outbreak seems to have come to an end as no new cases were reported in the DRC between 6 and 12 May 2020, after a resurgence of the outbreak on 10 April (Sikakulya et al., 2020; WHO – Ebola virus disease, 2019; WHO – Ebola virus disease, 2020). Unfortunately a new outbreak was detected on 1 June 2020 in the northwest of the DRC. At the time of writing six Ebola cases have been detected in Wangata in Équateur province (WHO, 2020).

Challenges of the tenth Ebola virus outbreak

This tenth outbreak distinguished itself for a variety of reasons. Firstly, it took place in a war-torn region, which severely complicated the already inadequate medical aid of the health care in the region and that provided by external partners such as NGOs and the WHO. In addition, the socioeconomic situation is very unfavorable, with the majority of the population traveling for trade and business to neighboring countries in the East (Uganda, Rwanda). And thirdly, community resistance due to distrust in Congolese politics and in any external support is a big challenge to overcome. Attacks on health care workers and Ebola virus disease treatment centers markedly impeded the Ebola virus outbreak response in the region. Despite early efforts taken by the DRC Ministry of Health, the WHO, the UN, the International Organisation for Migration (IOM), the Alliance for International Medical Action (ALIMA), Médecins Sans Frontiers (MSF), DRC Red Cross National Society, the CDC, the industry and others, the number of cases increased sharply during the first year of the outbreak (Sikakulya et al., 2020; WHO – Ebola virus disease, 2020; Kalenga et al., 2019).

Ebola virus outbreak response in the DRC

On 22 July 2019, after 2.5 years, the Minister of Health of the DRC, Oly Ilunga Kalenga, resigned after the president's decision to take over the lead for the national Ebola virus outbreak response. The Ebola virus outbreak response in the DRC is currently being managed by a team of experts under the direction of Professor Jean Jacques Muyembe Tamfum, director-general of the DRC's National Institute for Biomedical Research (NIBR), who has studied the Ebola

virus and responded to Ebola virus outbreaks for more than 40 years, supported by the WHO and more than 50 other national and international partners (Kalenga et al., 2019; Wadman, 2019). The national Ebola virus outbreak response includes a package of interventions for containing and eliminating this deadly disease, such as deploying Ebola virus disease treatment centers, a surveillance system, screening of suspected cases at points of entry, contact tracing, social mobilization teams, case management and infection prevention and control, safe and dignified burials, ring vaccination (this involves vaccination of infected individuals, direct contacts of infected individuals, and contacts of those contacts), community mobilization, and free access to health care services (Sikakulya et al., 2020).

The first important factor is the fact that the medical health crisis concerning the Ebola virus in the DRC is unique and should be handled as such. Cultural habits, political disunity, superstition and regional differences in terrain, presence of violence and disparities in wealth all contribute to the uniqueness of the Ebola virus outbreak in the DRC. A second important factor is community resistance. This is one of the major reasons that health care providers struggle to limit the spread of the Ebola virus. Some people go into hiding, sometimes refusing the help of health care providers, and in worst case scenarios might even attack them (Sikakulya et al., 2020; UN News, 2019; Kalenga OI et al., 2019). One does not simply walk into communities and expect cooperation if there is a history of mistrust towards medical aid providers. This ties into the importance of building trust with local communities. This takes time and in-depth knowledge of specific communities since there is likely no one-size-fits-all approach. If trust is established, then cooperation could be gained and this will in effect make the task of limiting the spread of the Ebola virus feasible (Sikakulya et al., 2020).

Ebola virus disease treatment centers have been set up in Goma, Butembo, Katwa, Beni, Mangina and Komanda (ERCC, 2019). The clinical care teams in these centers provide patients with rehydration therapy, correction of electrolyte imbalances and nutritional support. Patients with confirmed Ebola virus disease are offered treatment according to a protocol created by the WHO for monitored emergency use of unregistered and investigational interventions. This includes three antibody-based therapies (MAb114, ZMapp, and REGNEB3) and two antiviral agents (Remdesivir and Favipavir) (Kalenga et al., 2019; WHO, 2018; Davey et al., 2018). Although these treatment centers were very helpful in the response, there are some downsides to their use. There is a risk of cross-contamination between the patients, they are poorly perceived and patients are often reluctant to go. Once they arrive, patients are cut off from the surrounding communities, which asks a lot of trust and courage of them. Furthermore, Ebola virus disease treatment centers are expensive, have slow deployment and are often situated far from the affected communities, which again potentially holds sick people back from coming. For these reasons, ALIMA and Securotec created individual treatment units, called ‘Cubes’. These are completely transparent Biosecurity Emergency Rooms that can be rapidly deployed in the heart of communities affected by the outbreak. These Cubes enable closer contact of the patients with the community and their families, which markedly reduces the threshold for seeking professional treatment (ALIMA, 2018).

A surveillance system to investigate reported alerts has been scaled up during the outbreak. More than 1000 alerts are reported daily, which results in a daily average of 280 suspected cases. However the time to identify alerts as confirmed cases remains suboptimal, with a median time of six days (Kalenga et al., 2019). Instead of referring patients to testing sites, processing and transporting the samples to laboratories and waiting for the return of laboratory results, rapid diagnostics could be deployed in a field setting, which would significantly reduce this time. These tests do not require laboratory devices and could be performed in even the most remote villages. Even though four rapid diagnostic tests have been approved, none of them are readily available and only one has been used in the current outbreak (Cnops et al., 2019; information extracted from the interviews).

Together with the Congolese Ministry of Health, the IOM implemented screenings at 80 points of entry and control, including borders with Uganda and Rwanda, bringing the cumulative number of screening tests done since August 2018 to over 170 million. Of these 170 million tests, 30 were confirmed cases. Furthermore, thermal cameras are being used at Goma airport and the Grand Barrière border crossing for rapid screening of large groups of people. These temperature screenings enabled mapping of demographic movement profiles and identification of high-risk areas (Kalenga et al., 2019; WHO – Ebola virus disease, 2019).

Contact tracing involves Ebola virus outbreak response teams that try to list and identify all people who came into contact with the patients who come to community clinics. If any of these people start showing symptoms, they can get the health care they need faster to improve their chances of survival. Contact tracing remains challenging because of poor record-keeping in community clinics and community resistance. Populations are often fearful or suspicious

towards response teams, with individuals hiding or refusing to cooperate in follow-up examinations. This leads to most of the Ebola virus cases contacts remaining unregistered (Kalenga et al., 2019; WHO, 2018). Community resistance could be overcome by social mobilization teams.

Social mobilization teams try to increase community engagement by informing them about the signs and symptoms of Ebola virus disease along with guidelines to protect themselves and their communities from it. In addition they try to explain the treatments occurring in the Ebola virus disease treatment centers. This is done by reaching the community members via radio, posters, face-to-face visits and community meetings. The social mobilization teams also help the Ebola virus outbreak response teams to engage with the communities by working with volunteers, religious leaders and community leaders. Winning the trust of the local communities is key for the successful functioning of the Ebola virus outbreak response teams. A lack of social mobilization teams, in combination with the charged political atmosphere in the region, has already translated into lethal attacks on Ebola virus disease health centers and health care workers. These attacks led to closure of treatment centers and sharp increases in Ebola virus infections (Kalenga et al., 2019; WHO, 2018).

A 'one health approach' is a recurring term that is of great importance in preventing the spread of Ebola virus. A one health approach signifies a collaboration between multiple sectors that communicate in an efficient way, aimed at the implementation of legislation, novel therapeutic strategies and policies. The main benefit of this approach is the fact that there is a unified channel formed that distributes tasks and information to the necessary actors, which in turn ablates any form of ambiguity concerning communication of regulations and jurisdiction. However this not an easy feat to achieve since conflict of interests of organizations and the sense of autonomy of local departments can complicate the implementation of the one health approach. However, international organizations that have established authority and competence in regard to health care, politics and philanthropism could play a key role in making this kind of approach work (Sikakulya et al., 2020; WHO One Health, 2017). One of the main problems that should be tackled is the lack of sensibilization around zoonoses since local people eat bushmeat, which is considered the main source of the Ebola virus. Therefore, regulations and restrictions concerning food intake could greatly improve overall health and prevent new Ebola virus outbreaks from emerging. Additionally, epidemiologists should be appointed to perform check-ups on livestock and the quality of meat on food markets. However, it should be noted that people in certain, often more remote, regions of the DRC are closely connected with and dependent on the local fauna as their main food source. Therefore, restriction or prohibition of bushmeat could lead to socioeconomic problems, which are explored in the subsection on the relation between Ebola virus outbreak prevention measures and sustainable development goals. (Sikakulya et al., 2020; WHO One Health, 2017; OHCHR, 2020; WorldTop20, 2020; CDC, 2018).

Sustainable development goals and Ebola virus outbreak prevention

It is important to take the sustainable development goals (SDGs) into account when one wants to formulate solutions in regard to Ebola virus outbreak prevention. The SDGs have been set up by the UN for the purpose of achieving a better and more sustainable future for all (https://www.un.org/sustainabledevelopment/). Measures that seem effective might create new problems when considering the context of all SDGs. A first example would be limiting mobility of the people to neighboring countries. This might seem a good idea in light of the prevention of spread of the Ebola virus, but this means that another problem is created in the process since these people need money and goods to survive. If they are limited, and thus unable to trade their goods, without re-compensation they are simply unable to survive, which would also infringe the SDGs and human rights (OHCHR, 2020; WorldTop20, 2020). Another example would be placing a ban on eating bushmeat, since this is a major source of Ebola virus outbreaks (CDC, 2018). The problem that this ban would create ties into the second SDG, namely zero hunger. Since some communities have restricted access to food, they are dependent on bushmeat; thus, if this were to be banned then some communities could face starvation, which would be an inhumane predicament (OHCHR, 2020; WorldTop20, 2020; CDC, 2018).

There is no one solution to this problem; however, the bottom line should be transparent and open communication. If the population is well informed about the benefits of screening and prevention of infection with the Ebola virus through vaccination then cooperation will come more easily since it benefits the population and fulfils their need for self-preservation and well-being. This also ties well into the goals of the SDGs (Sikakulya et al., 2020; WHO, 2018; Davey et al., 2018; OHCHR, 2020; WorldTop20, 2020).

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Mental health and well-being of health care providers

What should also be considered is the physical well-being and psychological state of mind of the health care providers. Being deployed in a war-torn region limits the possibility of interaction with residents housed in affected regions, and limits available resources and transport of persons due to the danger of being attacked. This often means that health care providers in the field are stuck for extended periods of time in dangerous locations with limited resources and communication. Not feeling safe can be linked to higher levels of stress similar to the fight-or-flight reflex since there is a continuous threat to their lives. However, the effects of fight-or-flight are prolonged for an unnatural time in this state of stress. In acute stress situations, this means a rapidly increased heart rate for a short amount of time. However, during long interventions the heart rate is unnaturally elevated for a prolonged time, which puts a heavy burden on the cardiovascular system and can eventually lead to cardiovascular problems like stroke, CVA and increased blood pressure. Another side-effect of prolonged stress situations is an excessive excretion of cortisol, which can lead to an impairment in cortisol regulation, which in turn is linked to the development of numerous physical and mental health conditions, including chronic fatigue, insomnia, burnout, depression, metabolic disorders and immune disorders. In short, residing in a state of stress for a prolonged time can result in poor mental health and physical well-being, which in turn can impair trust building (Center APAH, 2020; Kandola, 2018).

Secondly, being separated from loved ones for an extended period of time takes its toll on the mind. This can reduce morale, which can lead to less efficient aid provision. As a third argument, it could be said that the night rest of health care providers can be disturbed due to the feeling of unease and unsafety. A lack of sleep directly impacts the morale and physical ability of the person, so it is of utmost importance to pay attention to the amount and quality of night rest to be able to properly function. Sleep deprivation affects not only alertness but also long-term memory, reflexes, cognitive functioning and motivation in a negative way (Alhola et al., 2007). Last but not least, it should be mentioned that health care providers constantly need to put in effort to gain the trust of the people. This is often no easy feat and this also implies that a lot of energy is poured into trust building. This can be extremely challenging if the motives of the volunteers are being questioned, if the residents in affected areas are in denial of the existence of the disease or if infected people distrust medical facilities and thus avoid contact with health care providers (Sikakulya et al., 2020).

We can conclude that the mental and physical health of health care workers have an important impact on the quality of their work and well-being. This should certainly not be overlooked in relation to their capacity to build trust with the local community.

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Supplement III: Communication

Spreading knowledge

Good communication with the target audience is crucial for an effective treatment of Ebola virus disease. Providing correct information about the disease, the work being done and the procedures followed by aid workers are all part of that. For a discussion on the dissemination of information, the concept of Information and Communication Technology for Development (ICTD) is central. Although technology is a central element in this concept, ICTD focuses as well on the people involved and their sociocultural environments. The technological tools are called the Health Information Systems (HISs) and can include radios, books, digital devices, etc. (Walton & Derenz, 2009, 346). For the Congolese context, anthropological research has established that the most efficient HISs are generally non-written forms, as literacy levels are low. Visual communication is one alternative and can successfully spread messages through gifs (Graphic Image Formats) via social media platforms such as Facebook or WhatsApp. Even more crucial however is oral communication. The ways in which information about the Ebola virus (both correct and false) has in practice reached the people in the country are mainly through local radios, oral networks (family, friends, religious leaders) and rumors (information extracted from the interviews; Anoko, 2014; Vinck et al., 2019, 533). Many local radios exist parallel to one another. This abundance can make the medium uncontrollable, as they often broadcast different contradictory messages at the same time, but their potential should nevertheless be maximized according to the anthropological researchers of Anthrologica. Thus it is crucial that the local form of the Swahili language is used (Vinck et al., 2019, 3).

Community radios can be an important medium for bringing about social change, including violence reduction and health care improvements. They combine three assets which show their positive impact: they can reach a diversified audience; they are a form of participatory media which can actively involve local communities; and they can combine education with entertainment in ‘edutation’ programs (Iqbal & Bilali, 2017, 33–34). The latter makes it possible to mix messages which arouse local pride, such as popular music, with announcements concerning topical issues on reconciliation and public health. A good example of the participatory asset is Radio Maendeleo, which gives a platform to independent and local voices. (https://11.be/verhalen/thais-en-radio-maendeleo-geven-het-congolese-volk-een-stem). Another example shows the edutation asset: the Dutch NGO Radio La Benevolencija, which has been running in the DRC since 2006 under the name Kumbukha Kesho (Remember Tomorrow). Its aim is to help prevent new outbreaks of violence in the region and to encourage healing processes. Therefore, it provides information about resistance against manipulation, and gives psychological explanations about the background and continuation of the conflicts and the effects of trauma (Iqbal & Bilali, 2017, 36). Since 2016 it has worked in cooperation with Radio Okapi, a station led by MONUSCO, to broadcast a program on ‘Jeunes Leaders’ to stimulate dialogue instead of conflict for the then upcoming presidential elections (http://www.labenevolencija.org/drc/ongoing-projects/). The results of Kumbukha Kesho (and similar projects) in the DRC were however not always as expected, as they could also arouse feelings of grievance. This highlighted once more the importance of taking into account socio-cultural dimensions and local specificities unique to each community (Iqbal & Bilali, 2017, 40–42; Paluck, 2010).

In the context of the Ebola virus outbreak, a similar approach of ‘edutation’ was used in a project under the name EBODAC (Ebola Vaccine Deployment, Acceptance and Compliance). Contrary to the former example, this project focused only on the medical part, not on the conflicts. EBODAC ran first in Sierra Leone (2014) and was then applied in the DRC as well. It is an IMI (Innovative Medicines Initiative) program supported by World Vision of Ireland, Grameen Foundation, the London School of Hygiene & Tropical Medicine and Janssen Pharmaceutica NV. The project was developed with the aim of making Ebola vaccine clinical trials (EBOVAC) possible. Therefore, it deployed different original strategies to spread correct information about the vaccine in order to build an image of trustworthiness and commitment. In order to fight rumors, teams of social scientists which were in direct contact with both the clinical team and community workers were sent out to keep their finger on the pulse and detect new rumors so they could be countered. This happened by plainly giving correct information without explicitly denying the rumor. The community workers were then engaged to organize community meetings, to visit houses, to broadcast radio shows in local languages and to organize theatre performances. Flip charts with locally inspired drawings and short audio and video

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clips for social media platforms were used as well. Moreover, once a first vaccination was received, personal contact was continued via text messages (mainly to inform about the second vaccination) (Enria et al., 2016; www.imi.europa.eu; information extracted from the interviews).

Assembling knowledge

Both EBODAC and the La Benevolencija project cannot exist without the other side of communication: listening instead of talking, which is at least as essential. Unraveling the (hidden) fears, complaints and requests of the people involved helps to make interventions more effective. By listening to the Congolese population during the 2003 Ebola virus outbreak, it turned out that resistance to the treatment resulted from five elements: rumors, fear, mistrust, a lack of confidence in the authorities, denial of medical discourse and the desire of the local community to be autonomous. This knowledge could then inspire a locally adapted reaction. Another observation showed that social resistance to Ebola virus disease treatment depends on political configurations rather than traditional or cultural habits (Anoko, 2014, 3; Wilkinson & Fairhead, 2016). The goal of EBODAC was to gain a better insight into the socio-cultural and historical context in which the disease existed. Having a better knowledge of the local fears led for example to changes in the burial procedure. Instead of simply rejecting fears as misinformation, the project wanted to deal respectfully with local ideas. After all, they often bore within them different unspoken complaints, as for example about the power relations in the community or about the government or the UN. Detecting those and being able to report them to the relevant authorities was also part of the project (Enria et al., 2016, 6; information extracted from the interviews).

The listening suggested here entails contextual listening, since basic listening is not enough in this context, as Leydens and Lucena suggest. Contextual listening means an empathetic form of listening which does not limit itself to a first encounter with the community, but rather comprises a continued listening process. Moreover, it takes into account diverse perspectives of a wide array of stakeholders. By breaching the monologue of the aid worker, the local community is empowered and gets a sense of 'ownership' and control over the aid project. Such a participatory approach can stimulate community support for the project. It can also lay bare existing biases and challenge 'expertise' positions. This approach requires flexibility and innovative thinking, as the listening is action-oriented and thus results in adaptations according to local circumstances and obstacles. Such an approach results in Sustainable Community Development (SCD), which focuses on sustainable development with the community at the center. In addition to thinking about environmental concerns and economic growth, SCD promotes the enhancement of local social relationships (Leydens & Lucena, 2009, 360–367).

An example of such an approach occurred in the 2014 West Africa Ebola virus outbreak. During that outbreak, the WHO consulted anthropologists to establish a powerful information and communication mechanism that takes into account the local community problems, knowledge and circumstances, such as the conflictual situation in Guinea. Starting from the premise that communication is of extreme importance to gain an insight into the political, historical, social, economic and cultural context to encourage trust and commitment and to solve conflicts, the anthropologists noticed that the people who have key information are not necessarily those affiliated with institutions, let alone the state, nor those who designate themselves as leaders. Rather, they are (often ignored) people such as hunters, village birth attendants, heads of sacred forests, returned migrants, etc. These persons can have high credibility and considerable influence over their communities. A next step was to bring key actors from the community and health care organizations together in the meetings, so their perspective on the Ebola virus outbreak response could be heard. The community then voiced complaints about, amongst other things, a lack of consistency and cooperation between health care workers concerning the information they gave about the disease and their activities; lack of incentives for going to the hospital, as it was initially said there was no vaccine yet; lack of respect for local rituals; lack of means to contribute to the fight against Ebola; and lack of fair payment for cooperation. The conclusions of such a meeting are however never general or unchanging. Dialogue has always to perpetuate but, as Anoko noticed, listening and acting according to the local requests continues to be forgotten in the heat of the moment (Anoko, 2014).

Indeed, Waisbord identified some obstacles which prevent participatory communication from prevailing over informational communication. According to him, three elements are at work: bureaucratic requirements and standard procedures; the weak status of communication as an autonomous field of study and practice; and the prioritization of technical perspectives in development programs. Too often, communication in global health programs is reduced to

the role of transmitting scientific and technical knowledge in order to reach certain goals, thereby only incorporating participation once the goals are set (Waisbord, 2008). Notwithstanding, the WHO tried to prevent this slipping into oblivion of the participatory approach in emergency situations. Following the Good Participatory Practices outlined for HIV treatment, it drew up a document entitled 'Good Participatory Practice for Trials of Emerging (and Re-emerging) Pathogens that are Likely to Cause Severe Outbreaks in the Near Future and for which Few or No Medical Counter-Measures Exist' (GPP-EP). That document should stimulate community engagement during emergency interventions for contagious diseases, even though it might seem less of a priority on such occasions.

However such documents, just like the 'Risk Communication and Community Engagement Preparedness and Readiness Framework: Ebola Response in the Democratic Republic of Congo in North Kivu', remain rather general in design. Therefore, a more direct list of questions proposed in this paper might be beneficial.

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Supplement IV: Challenge document

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Dear,
Welcome to the Bank of Transdisciplinary Challenges!
This is an initiative where people concerned about the future translate their concern into a scientific challenge. The challenge typically revolves around a specific society, environment, and/or business problem or opportunity that you want to be addressed by a transdisciplinary research team.
Are you concerned about a specific theme or topic for the future?
We invite you to be part of this initiative by filling out this form and sharing your challenge with our academic team and other stakeholders.
We will inform you if your challenge is taken up by our research team, and of any further activities.
Hope to hear from you soon.
The Bank of Transdisciplinary Challenges.

SECTION 2 OF 5 – Before informing us about your challenge, we would like to know a bit more about you

First Name: **Tony**
Last Name: **Wawina Bokalanga**
E-mail Address: tony.wawina@kuleuven.be
Affiliation: **Department of Microbiology, Immunology and Transplantation. Division of Clinical and Epidemiological Virology.**

- ☐ Academia as a Researcher
- ☒ Academia as a PhD Student
- ☐ Government
- ☐ Industry
- ☐ Local Organization
- ☐ Non-profit Organization
- ☐ Society
- ☐ Other:

If you are affiliated to an organization, please fill in its name here: …
You can also include some contact details of your organization.

Would you like to receive updates about this initiative?

- ☒ Yes
- ☐ No

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SECTION 3 OF 5 – ABOUT YOUR CHALLENGE

Name of the Challenge:
Ebola Virus Disease outbreak in a war-torn region: Eastern province of the Democratic Republic of Congo.
Keywords: Ebola virus, Ebola outbreak, Ebola virus disease, Zaire ebolavirus, DR Congo.

Could you please state a specific challenge, problem or question?
The epidemic of Ebola virus disease (EVD), which is still ongoing in the Democratic Republic of Congo (DRC), is the second largest outbreak recorded so far after the 2014–2016 Ebola outbreak in West Africa. For the first time ever in the world, the Ebola virus epidemic has occurred in a war-torn region. A deep mistrust of any recommendations that reach the population through official means has hampered the eradication of the current Ebola epidemic in the DRC. The decades-old violent conflicts in the affected areas are feeding this mistrust, while also making any intervention a dangerous undertaking.
Despite the use of ring vaccination around the affected zones and implementation of countermeasures to get this epidemic under control, the number of EVD confirmed cases is still increasing over time. According to the Multisectorial National Committee against EVD on 7 October 2019, the number of EVD confirmed cases was 3092, of whom 2029 died (case fatality rate of 66%). The vaccines and medication currently deployed have not been tested in large clinical studies, which are not feasible given the rarity of Ebola outbreaks, and yet there is an urgency to deploy them during chance outbreaks, given the seriousness of the disease.
Many factors, such as a lack of adequate health care workers, poor sanitation facilities, presence of local armed groups, misperception of EVD in the local community, uncontrolled displacement of ebolavirus-infected patients, difficult contact tracing, limited telephone network coverage and lack of internet, unwillingness and community resistance, use of social and cultural practices, and lack of roads in the affected areas, promote the spread of this outbreak in the DRC.
This situation makes controlling the current Ebola outbreak an especially difficult wicked problem, with potential serious consequences should Ebola get sufficient opportunity to mutate into an even more threatening epidemic (for example if the incubation period were to be prolonged, potentially increasing the number of transmissions per infected person). There is an urgent need for different approaches to controlling this epidemic, including thoughtful intervention strategies for potential other epidemics in conflict zones.
It is of utmost importance that the DRC's government and partners quickly improve and adapt the response and countermeasures against this outbreak as they are currently not very efficient.

Would you like to add some objectives to that challenge?
The interdisciplinary group will be asked to think about new approaches and strategies for future Ebola virus outbreaks, especially in a war-torn region. Through conversations with scientists from different backgrounds or disciplines (physicians, health psychologists, sociologists, lawyers, theologians, etc.), their own literature search, and stakeholder interactions, the group is expected to suggest new strategies, for example concerning how to manage the unwillingness and community resistance.

Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?
The "one health approach" has been recognized as one of the main features of disease control and prevention strategies by many international agencies. Indeed, by working with a transdisciplinary research team (physicians, health psychologists, sociologists, lawyers, theologians, etc.) about unwillingness and community resistance during the Ebola outbreak, we will be able to overcome this challenge and suggest new approaches for future Ebola outbreaks.

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.

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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: IT, network specialists

Domain of Biomedicine:

- ☐ Kinesiology and Rehabilitation Sciences
- ☒ Medicine
- ☒ Pharmaceutical Sciences
- ☐ Other:_____

Can we contact you for getting further details of your challenge?
Yes: piet.maes@kuleuven.be; tony.wawina@kuleuven.be

Do you accept the terms and conditions for the proposition of this challenge? (See below)

- ☒ Yes
- ☐ No

Terms and Conditions

1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people and planet based on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.

2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame

3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge

4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.

5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.

6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the "Transdisciplinary Insights Course" based on the Honours programme

regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access "Transdisciplinary Insights e-Journal". Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the "Transdisciplinary Insights e-Journal" or at a "Transdisciplinary Insights Course"-related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the "Transdisciplinary Insights e-Journal" to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters' names and/or logos will be acknowledged by the "Transdisciplinary Insights e-Journal"
8. "Transdisciplinary Insights Course" reserves the right to change or update these T&Cs from time to time without prior notice to you.
Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: jorgericardo.novablanco@kuleuven.be

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?
– WHO
– Non-governmental organizations: Alima, Médecins Sans Frontières

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

If you have questions about some parts of the process, please ask them here:

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Supplement V: Conflict

Ebola virus outbreak in a conflict zone (Eastern provinces of the Democratic Republic of Congo): Analysis of the conflict and its consequences

Gillian Mathys beautifully emphasizes in her article entitled 'Bringing History Back in: Past, Present, and Conflict in Rwanda and the Eastern Democratic Republic of Congo'[1] that understanding the conflict in the eastern DRC is impossible and even dangerous without taking a good look at its history. It is embedded into a long and complicated series of events whereby local social dynamics are intertwined with larger political events.

1. Historical background of the conflict

Originally the Kivu region was one unit but now it consists of three provinces, namely Maniema, North Kivu and South Kivu. Ituri, which is located above North Kivu, was originally a part of the north-eastern province called Province Orientale and became a province only after 1999. In this area live people from many different ethnic groups. Belgian colonization changed the local structure in North and South Kivu, causing waves of migration. Already before colonization, Kirundi and Kinyarwanda speakers were living in Kivu. Between 1937 and 1955, the colonial authorities transplanted around 85000 Hutu and Tutsi to that region.[2] It was part of the colonial policy that needed to make sure that there was enough labor available. The result was that the new migrants settled on land that previously was controlled by the 'autochthonous' ethnic groups.[3] The Belgian colonial apparatus also appointed local chiefs, re-drew boundaries and physically separated populations.[4] Gillian Mathys says that this creation of chieftaincies by the colonial administrators is crucial if we want to understand the current struggles around land and political power at local level.[5] She says: 'The idea that cultural groups must coincide with a hierarchical and centralized political organization which in turn is closely related to well-delineated territory became integrated in the discursive framework of "autochthony" and has inscribed itself in the discussion about "who belongs where".'[6]

This led to many disputes about the access and control of land among different ethnic groups. In the beginning these disputes were not violent but it all changed when Mobutu Sese Seko –President of Zaire (renamed from the Republic of the Congo (Léopoldville) and later to the Democratic Republic of the Congo) – encouraged the local politicians to mobilize people based on their ethnicity.[7] The use of space and the mobility of labor was defined by internal (traditional use of space) and external (the impact of colonization) elements. After independence, land became a source of accumulation of power, which resulted in land dispossessions and alienation that led to a hardening of ethnic feelings.[8] Mobutu used *géopolitique* as his secret weapon, which means in this context the politics of geography or origins.[9] One of the consequences was that provinces could only be represented by people who could claim to be autochthon.[10] The overall result was ethnic cleansing and violent conflicts between different ethnic communities. This transformation of land disputes into ethnic conflicts had a serious impact on the existing networks of trust and cooperation because from this time the networks were organized intra-ethnically. Besides that, ethnicity became a mobilizing force in the competition for economic and political power.[11]

1 Gillian Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," *Journal of African History* 58, no. 3 (2017).
2 Henning Tamm and Claire Lauterbach, "Dynamics of conflict and forced migration in the Democratic Republic of Congo" (Oxford: Refugee Studies Centre, Oxford Department of International Development, 2010), p. 3.
3 Koen Vlassenroot, "Chapter One: Reading the Congolese Crisis," in *Conflict and Social Transformation in Eastern DR Congo*, ed. Koen Vlassenroot and Timothy Raeymaekers (Ghent: Academia Press, 2004), pp. 40–41.
4 Niamh Gaynor, "The limits to community-based conflict resolution in North-East Congo," *Community Development Journal* (2015), p. 4.
5 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 476.
6 Ibid.
7 Vlassenroot, "Chapter One: Reading the Congolese Crisis," p. 41.
8 Ibid. pp. 42–44.
9 Stephen Jackson, "Sons of Which Soil? The Language and Politics of Autochthony in Eastern D.R. Congo," *African Studies Review* 49, no. 2 (2007), p. 487.
10 Stephen Jackson and Peter Geschiere, "Autochthony and the Crisis of Citizenship: Democratization, Decentralization, and the Politics of Belonging," *African Studies Review* 49, no. 2 (2006), p. 102.
11 Vlassenroot, "Chapter One: Reading the Congolese Crisis," p. 42.

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2. Importance of the notions of 'autochthony' and identity

The notion of autochthony, which is related to migration and colonialism,[12] is used to refer to the so-called natural relationship between people and the soil, hence also territory. It is also directly related to ideas of national citizenship and has been used as a way to include or exclude people from certain rights,[13] especially against Banyarwanda or Kinyarwanda speakers (in this case Hutu and Tutsi). Jackson notes that two dimensions of citizenship are being denied to them: on the one hand local rights and obligations between the individual and customary authority, which has implications for land allocation, and on the other hand the ethically vital and lived sense of belonging and the existential security for the individual within society as a whole.[14]

The question of identity and autochthony, concerning mostly Kinyarwanda speakers has been politicized and started in the end of the 19th century, more specifically in 1885 with the Berlin Conference, also better known as the Scramble for Africa. It is important to note that they are not a homogenous group since they arrived during different times for different reasons. These periods can be divided into four and are important in politics for whether or not they are eligible to be seen autochthonous and hence have Congolese nationality. The first group are Hutu and Tutsi who already lived in Kivu before the colonization. The second group are the immigrants who served, from 1937 on, as a labor force for the colonial economy. Then there are Tutsi refugees coming to DRC between 1959 and 1963 because of the then ongoing events in Rwanda. The last group are the refugees as a result of the Rwandan genocide in 1994. Currently the law says that those individuals who belong to ethnic groups residing on Congolese territory before 1960 (Congolese independence) should be considered Congolese citizens.[15] But this law leaves still a lot of room for interpretation of 'people' and 'territory' since the colonial administration did not acknowledge official organizations among the Kinyarwanda speakers, thereby saying that they did not exist.[16,17] The denial of ethnic citizenship remains a potent source of conflict, argues Jackson.[18] The too-strict equation of identities and territories thus was not without consequences. It resulted in seeing people from a 'different soil' as nonbelonging, foreign, alien and nonauthentic.[19] Even in the DRC, there is a division among the Tutsi population. Some Tutsi people, who call themselves *Banyamulenge* (people of Mulenge), want to stress that they were in the DRC before 1960 and distance themselves in this way from more recent migrated Tutsi.[20] Nowadays, it can be claimed that Kinyarwanda speakers daily live with the decisions made by the colonial administration a century ago.

In some cases, autochthony is also linked with the Hamitic hypothesis.[21] It is the hypothesis that the Bantu people, including Nande, Hunde, Hutu, etc., were the autochthonous population in Central Africa. Nilotic tribes, including Tutsi, Hima, etc., were pictured as invaders from the Horn of Africa and were allochthons. Although this theory has no theoretical evidence, it still finds its way into today's discourse.[22] The idea of a greater Rwanda is another idea that plays an important role and is crucial to understand current dynamics. This includes the premises that, first, the territory of Rwanda was bigger before the colonization and included parts of the Kivus, and second, that by the placement of artificial borders by the European colonialists, the Banyarwanda population was split.[23] These thoughts are still very present today and not only have an impact on the way the Congolese look at the involvement of Rwanda in the conflict but are also seen in tensions occurring in the communities towards the Kinyarwanda-speaking population.[24] It

12 Jackson and Geschiere, "Autochthony and the Crisis of Citizenship: Democratization, Decentralization, and the Politics of Belonging," p. 97.
13 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 469.
14 Jackson, "Sons of Which Soil? The Language and Politics of Autochthony in Eastern D.R. Congo," p. 481.
15 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 475.
16 Ibid. p. 477.
17 Judith Verweijen and Koen Vlassenroot, "Armed mobilisation and the nexus of territory, identity, and authority: the contested territorial aspirations of the Banyamulenge in eastern DR Congo," *Journal of Contemporary African Studies* 33, no. 2 (2015), p. 195.
18 Jackson, "Sons of Which Soil? The Language and Politics of Autochthony in Eastern D.R. Congo," p. 494.
19 Jackson and Geschiere, "Autochthony and the Crisis of Citizenship: Democratization, Decentralization, and the Politics of Belonging," pp. 98–99.
20 Jackson, "Sons of Which Soil? The Language and Politics of Autochthony in Eastern D.R. Congo," p. 484.
21 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 469.
22 Jackson and Geschiere, "Autochthony and the Crisis of Citizenship: Democratization, Decentralization, and the Politics of Belonging," p. 107.
23 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 470.
24 Ibid. p. 471.

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has been used by different parties to justify their violence against each other, as will be explained later. So, it can be said that the past and its representations have been manipulated to serve political needs.[25]

3. Deeper insight into the current conflict

3.1. Three dynamics of the conflict

Vlassenroot identifies three dynamics of the conflicts: 'Three local dynamics can be distinguished. The first relates to the nature of the Zairian state. Because of the patrimonial nature of this state (which points at the fact that political power gave access to economic resources), power was exercised through the exploitation of informal networks of patronage. The second dynamic relates to the local mechanisms of land access and control. Because these mechanisms were based on traditional structures of land distribution, most non-indigenous communities were excluded from equal land acquisition. The last dynamic of conflict concerns the insecure access to citizenship for the Banyarwanda leading to permanent insecurity for them.'[26]

3.2. Effects of refugees, the Rwandan genocide and the two Congo Wars

The social and political crisis from the reign of Mobutu was exacerbated by the arrival of more than one million Burundian and Rwandan refugees. The presence of a significant number of highly politicized and militarized refugees had an impact on the local political competition and struggle.[27] The identification of the Banyamulenge with Rwandan Tutsi was reinforced by the recruitment of Banyamulenge youths by the Rwandan Patriotic Front.[28] Attacks on local Tutsi Banyarwanda as well as autochthonous ethnic groups in North Kivu were one of the effects. These attacks were used by the Rwandan regime as a perfect excuse to intervene in or invade the eastern provinces of the DRC.[29] Under Kabila's regime, the newly created Forces Armées Congolaise were too fragmented to handle the situation. It set in motion two sorts of dynamics: first, a total fragmentation of the political and military landscape, militarization of the society, and the formation of new rural militias; and secondly, a new meaning emerged for mechanisms of protection, authority and the access to wealth.[30]

What followed was the First Congo War in 1996–1997. It was heavily dominated by Rwandan Tutsi, but also by Banyamulenge and Congolese Tutsi. This only reinforced the identification of 'Tutsi' as 'from Rwanda'.[31] The nationality problem was, without doubt, a trigger for the first and second DRC wars, in which Congolese Tutsi, particularly, played a central role. Neither side was able to claim full victory, so they joined with regional allies and resorted to vicious warfare via localized militias.[32] Along with the nationality problem, the number of armed actors involved grew during the second DRC war (1998–2003). The first reason was the growing division within the RCD (Rassemblement Congolais pour la Démocratie) rebel movement into different factions. The second reason was the entrance of new actors and the formation of new coalitions. Besides the growing resistance by civil society and church leaders, the RCD rebellion resulted in the formation of rural militias, known as Mayi-Mayi.[33] It can be said that invasions from different countries, such as Rwanda and Uganda, destabilized eastern DRC by linking local conflicts to the broader regional conflict dynamics.[34]

25 Ibid. p. 487.
26 Vlassenroot, "Chapter One: Reading the Congolese Crisis," p. 42.
27 Ibid. pp. 46–48.
28 Verweijen and Vlassenroot, "Armed mobilisation and the nexus of territory, identity, and authority: the contested territorial aspirations of the Banyamulenge in eastern DR Congo," p. 199.
29 Vlassenroot, "Chapter One: Reading the Congolese Crisis," pp. 48–49.
30 Ibid. pp. 49–50.
31 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 482.
32 Jackson and Geschiere, "Autochthony and the Crisis of Citizenship: Democratization, Decentralization, and the Politics of Belonging," p. 106.
33 Vlassenroot, "Chapter One: Reading the Congolese Crisis," p. 51.
34 Tamm and Lauterbach, "Dynamics of conflict and forced migration in the Democratic Republic of Congo." p. 7.

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4. The main rebel groups and their impact in north eastern DRC

The Congo Research Group reports that there are currently over 130 armed groups operating in North and South Kivu provinces.[35] According to Thakur, the motivations of these armed groups and militias can be understood at three mutually constitutive and reinforcing levels. The first is an emphasis on personal enrichment and criminal economic-related activities (controlling mining areas, arms trafficking, illegal tax collection and so on). At the second level, many militias are also motivated by the prospect of providing security to their communities, reinforced by a dangerous ethnicized configuration. The use of ethnicity and protection as motivation enables armed groups to get local sympathy and has proven to be an effective strategy for recruiting, training and retaining young people as combatants. The third level involves taking advantage of the post-transition political climate and resisting the demilitarization process. There is a low level of impunity, thereby making it easier for armed groups to flourish.[36]

The Mayi-Mayi have reconstructed their identity on the basis of their strong claim to be 'authentic' Congolese and are generally anti-Kinyarwanda, anti-Tutsi and anti-Rwanda.[37] They claimed to defend specific communities and their lands while using a discourse of self-defense and autochthony.[38] The Forces Démocratiques de Libération de Rwanda (FDLR) are the most significant foreign militia in North and South Kivu. They were formed in 2000 and comprise ex-FAR (Forces Armées Rwandaises) and people belonging to Interahamwe that fled to the eastern DRC during the Rwandan genocide in 1994. Their discourse is radically pro-Hutu. In 2007 a new militia, Front pour la liberation du Nord Kivu (FLNK), emerged. This group is a collective of Mayi-Mayi and FDLR deserters and they share a common anti-Tutsi ideology.

To counter the anti-Tutsi sentiment of previous groups, another Tutsi armed group has arisen with Laurent Nkundabatware in North Kivu. He wants to defend the Kinyarwandan Tutsi population against the FDLR and other anti-Tutsi organizations[39] and used victimhood discourses, very real Tutsi grievances, to underpin and to legitimize his rebellion.[40] In 2006, Laurent Nkundabatware was part of the formation of CNDP (Congrès national pour la défense du peuple). Several times the CNDP had the opportunity to be integrated into the Forces Armées de la Republique Démocratique du Congo (FARDC) but it never worked out. On 23 March 2009, there was a political agreement between the Congolese government and CNDP. This agreement allowed CNDP rebels to be integrated into the government troops, the FARDC. The integration of the CNDP led to a lot of frustration amongst other members of the army and a few years later the Kabila regime tried to minimize the power of CNDP. Some members of the FARDC who were part of the CNDP before the integration left the army and fought against Kabila. From this day on, they were an independent rebel group called M23 operating in North Kivu.[41,42] Mathys says that they were framed as an extension of Rwandan military, political and economic interests.[43] In 2013, the M23 rebels were defeated by the FARDC.[44]

Currently the epicenter of the violence is Beni and Rutshuru territory. 31% of all the killings of civilians took place in Beni. This was mostly driven by fights between the Congolese security forces and the Allied Democratic Forces (ADF), a Ugandan armed group, and the clashes between the Mayi-Mayi and the army. Rutshuru territory, where several Congolese and Rwandan armed groups operate, had the highest number of kidnappings.[45]

Many years of violence and suffering has had a disruptive effect on economic survival mechanisms, caused distressed relations between different communities and led to a generalized crisis of authority.[46] As Verweijen and Vlassenroot put it so powerfully, 'the links between armed mobilization and the nexus of territory, identity, and authority

35 CRG, "Congo, Forgotten, The Numbers Behind Africa's Longest Humanitarian Crisis," (Center on International Cooperation, New York University, 2019). p. 3.
36 Monica Thakur, "Demilitarising militias in the Kivus (eastern Democratic Republic of Congo)," *African Security Review* 17, no. 1 (2008), pp. 60–61.
37 Ibid. pp. 57–58.
38 Verweijen and Vlassenroot, "Armed mobilisation and the nexus of territory, identity, and authority: the contested territorial aspirations of the Banyamulenge in eastern DR Congo," p. 200.
39 Thakur, "Demilitarising militias in the Kivus (eastern Democratic Republic of Congo)," pp. 58–59.
40 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 486.
41 Koen Vlassenroot, "Het conflict in Oost-Congo verklaard," *MO** 2013.
42 Kris Berwouts, "Kivu: een lappendeken van gewapende groepen," *MO** 2013.
43 Mathys, "Bringing History Back in: Past, Present and Conflict in Rwanda and the Eastern Democratic Republic of Congo," p. 483.
44 Christoph Vogel and Jason K. Stearns, "Kivu's Intractable Security Conundrum, Revisited," *African Affairs* 117, no. 469 (2018), p. 696.
45 CRG, "Congo, Forgotten: The Numbers Behind Africa's Longest Humanitarian Crisis," p. 7.
46 Vlassenroot, "Chapter One: Reading the Congolese Crisis," pp. 53–56.

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are both contingent and reciprocal, as violent conflict also impacts the meanings and boundaries of identities, authority structures and territory'.[47] The enemy is most of the time pictured as Rwanda and in this way also as Hutu and Tutsi living in the DRC. Actions against Tutsi in the DRC sprout from fear that goes back to the Hamitic hypothesis and the idea of Great Rwanda.

5. Ebola virus outbreak as a political weapon: Elections 2018

Running up to the elections, held on 30 December 2018, the tensions rose higher in the DRC. This violence drove the community further away from the response efforts that were made by the aid organization in order to limit the Ebola virus outbreak. On top of that Beni and Butembo, both big cities in the north-eastern DRC, were suspended from the presidential vote. This only fueled the already existing rumors that Ebola virus either was a political strategy to disenfranchise voters or that the Ebola virus outbreak response given was only a business that benefited the rich and powerful.[48] The National Independent Electoral Commission (CENI) said that the outbreak of Ebola virus in parts of North Kivu made it too unsafe to open places where people could vote. In total 1.2 million Congolese were unable to choose a president. No one can confirm if the Congolese government used the Ebola virus outbreak as an excuse to exclude an area that was in favor of Martin Fayulu, one of the candidates. The support he had was thanks to, on the one hand, Mbusa Nyamwisi, who was popular among the Nande ethnic group, and on the other hand, Kabila's failure to stem violence in the north0eastern DRC.[49]

Right after the elections, the community resistance and the armed conflicts escalated dramatically. Attacks on health facilities and treatment centers were common and the concern was that armed groups were exploiting the Ebola virus outbreak for broader military or political ambitions. Some Ebola virus disease treatment centers were closed and the fear of more attacks reduced the likelihood of new patients coming for treatment. Because of the turbulent state of the region, aid organizations were forced to surround themselves with people who were able to endure and react to a possible attack. This militarization of the response combined with distrust in the communities caused further violence, ending in a vicious circle.[50]

47 Verweijen and Vlassenroot, "Armed mobilisation and the nexus of territory, identity, and authority: the contested territorial aspirations of the Banyamulenge in eastern DR Congo," p. 191.
48 Vinh-Kim Nguyen, "An Epidemic of Suspicion – Ebola and Violence in the DRC," *The New England Journal of Medicine* 380, no. 14 (2019), p. 379.
49 Pierre Englebert, "Aspirations and Realities in Africa: The DRC's Electoral Sideshow," *Journal of Democracy* 30, no. 3 (2019), pp. 129–130.
50 Nguyen, "An Epidemic of Suspicion – Ebola and Violence in the DRC," pp. 379–381.

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Supplement VI: Informed Consent Form

Interview consent form

Research Project Title: **Ebola Virus Disease Outbreak in a War-torn Region: Eastern province of DRC**
Research Team: **Jef Baelen, Karolien Coolen, Benoit Deforche, Hanne-Lise Frateur, Joachim Langeraet, Imogen Van Oystaeyen, Tony Wawina**.
Research Participant's Name: ……

Thank you for agreeing to be interviewed as part of the above research project. This research project is part of the Honours Programme Transdisciplinary Insights at KU Leuven. The goal of this research project is to analyze and, if possible, propose a solution to a so-called 'challenge', starting from a transdisciplinary perspective. Our challenge focuses on the Ebola virus outbreak in North Kivu, a region currently affected by conflict. The conflict makes efficient vaccination and treatment extremely difficult. In order to understand the situation on the ground, we are collecting data from multiple actors including personal experiences, NGOs, IGOs, official governments and academia.
Ethical procedures for academic research require that interviewees explicitly agree to being interviewed and to how information contained in their interview will be used. This consent form is necessary for us to ensure that you understand the purpose of your involvement and agree to the conditions of your participation. Following is an **information sheet** which we strongly advise you to read. After doing so, we ask you to sign this form to certify that you approve the following:

– The interview will be recorded and a transcript may possibly be produced;
– If you would like, a copy of the transcript will be sent and you have the opportunity to correct any factual errors;
– The transcript of the interview will be analyzed by the Research Team (mentioned above);
– Access to the interview transcript will be limited to the Research Team and additional academic researchers who function as coaches to this team;
– Any summary, interview content, or quotations from the interview that are made available through academic publication or other academic outlets will be anonymized and special care will be taken to ensure that other information in the interview which could identify yourself is not revealed. All or part of the content of your interview may be used in academic papers, feedback events and in an archive of the project as noted above. However, in the case of verbatim (word-by-word) citations we need your explicit permission;
– Any variation of the conditions above will only occur with your further explicit approval.

By signing this form, I agree that:

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time;
2. The transcribed interview or extracts from it may be used as described above;
3. I have read the information sheet;
4. I don't expect to receive any benefit or payment for my participation;
5. I can request a copy of the transcript of my interview and make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality;
6. I have been able to ask any questions I might have, and I understand that I am free to contact the research team with any questions I may have in the future.

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Contact information: if you have any further questions or concerns about this research project, please contact:

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_____

Participant's Name

_____ _____

Participant's Signature **Date**

_____ _____

Researcher's Signature **Date**

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Supplement VII: Trust

In order for humanitarian intervention and outbreak control to be effective, there is a need to understand the local culture as this impacts how people think and feel. Culture is both 'in the mind' (Geertz, 1973) and a 'provider of settings' (Whiting, 1988), it has both mental and public representations (Shore, 1996), it has cognitive constructs to establish knowledge frameworks, and it consists of public artefacts (Sperber, 1996). In the control of a disease outbreak, culture matters to how a community thinks by placing, for example, foods and illness into social space and categories of meaning. Besides creating categories of meaning, culture also influences people's understanding of the world. In the case of Ebola, it influences the type of medical care people would like to receive, feel comfortable with and deem appropriate. For many people in North Kivu, a traditional healer located within the village will be trusted over an isolation ward run by WHO physicians in yellow suits. Emotions and how people feel in certain situations will determine their behavior and openness towards (foreign) humanitarian intervention. Again, an understanding of cultural practices is of vital importance as culture patterns an emotional reality (Hewlett, 2008, 71). As Ebola virus outbreaks have occurred in the DRC for many decades, the Congolese people have accumulated a fair amount of cultural knowledge about how to deal with and control the disease. Accurately understanding and working with this indigenous knowledge will improve any efforts of humanitarian intervention and outbreak control.

It was only during the 2000–2001 Ebola virus outbreak in Northern Uganda that the WHO invited anthropologist to gather indigenous knowledge and participate in control efforts. During the 2003 Ebola virus outbreak in Congo, anthropologists were invited by the WHO from the get-go to analyze how local people view, explain and respond to Ebola, but also to make sure treatment centers were modified to the beliefs, practices and concerns of the local community (Hewlett, 2008, 35). It was during this time that the first policy changes in the strategies of Ebola virus outbreak response teams were made. Despite the more than 35 years of experience with Ebola virus in West Africa, little effort had been made by the public health department to invest in social mobilization and health education campaigns which could influence the spread of Ebola virus (Hewlett & Amola, 2003; Roes et al., 2017). Since 2003, much more effort was put into health education and communication with the local community; previously the establishment of an isolation unit was the primary goal, but it failed to be effective due to a lack of trust from the community as they feared and consequentially avoided the units (Hewlett, 2008, 44). The importance of education and communication becomes very obvious following the logic of the health belief model. This proposes that behavior change will only occur when individuals understand the risk to their health and know what actions to take in order to protect themselves or their families (O'Malley, Forrest & Mandelblatt, 2002; Roes et al., 2017). The involvement of medical anthropologists truly made intervention teams interdisciplinary, with intel from both the medical field and social sciences. However, the research and respect for the local culture and knowledge cannot fully erase mistrust originating from a shared colonial and postcolonial past between many Western humanitarian health care organizations and NGOs and the local community. Barry S. Hewlett, following fieldwork in Congo during the 2003 outbreak, concluded that the existing assumptions of local people that whites come to exploit and make a profit resulted in the interpretation that the Ebola virus outbreak is something created by Euro-Americans to restrict locals' activities in order to get more access to resources (Hewlett, 2008, 36–39). This mistrust influences the way local communities experience foreign health care workers and treatment centers. An Ebola virus outbreak should therefore be approached by foreign health care organizations with the greatest caution and sensitivity to local culture and practices.

The situation in North Kivu is even more complicated given the presence of conflict. Therefore, the current political and security situation have made effective outbreak control, health education and communication with local communities even more difficult than in the past. Conflict, and population displacement that goes with it, are well-known factors which facilitate disease transmission and inhibit humanitarian response efforts. On top of that the public health care system in the DRC still needs some improvement (Garret, 2003, 14). One of the reasons the Ebola virus spread so rapidly, and the outbreak was so difficult to control, during the 1995 Kikwit outbreak was the non-existence of basic, essential elements of public health: 'Ebola spread because of an inevitable outcome of disgraceful disconcern for health of the people, anyone associated with Ebola was likely to have experienced stigmatization. Many healthcare workers had to deal with a fearful public, absent public health and medical resources and were

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often viewed as agents of death' (Garret, 2000; Hewlett, 2008). On a political level, the 2016 national elections were put off until December 2018, which sparked violent protest throughout the country and was condemned by the international community (UN, 2018). The United Nations issued a declaration stating: 'armed groups in Eastern DRC have launched repeated attacks on positions of the Congolese Army, with a severe impact on the civilian population. The North Kivu province is one of the countries' most displacement affected regions' (UNHCR, 2018). The ineffective political and health care system has made treatment and outbreak control very difficult. The local community has problems trusting its own politicians and health care system. The overall complex situation in the DRC has resulted in the presence of many global humanitarian actors and NGOs in the region. Humanitarian actors, such as the WHO and NGOs like the Red Cross and Médecins Sans Frontières, have been involved in the Ebola virus outbreaks since the early 1970s. However, the violent working conditions have caused organizations to withdraw from North Kivu and gave Ebola virus free rein to spread widely (Médecins Sans Frontières (MSF) International, 2019). The different NGOs and health organizations work around different recurring issues and concerns. A first concern and topic for medical anthropologists to analyze is burial procedures: how do local people bury their dead and did any of the rituals contribute to Ebola virus transmission? A second issue is the compliance of the restriction of the consumption of game meat. Finally, there is the question of the role of traditional healers in the transmission of Ebola. Healers are part of the local primary health care system; therefore it should be researched whether or not they can be incorporated into control efforts (WHO, 1997; Hewlett, 2008).

In order to deal with mistrust, miscommunication and the recurring issues and concerns, many NGOs and health care workers are applying a community-based prevention/intervention approach in order to control the Ebola virus outbreak and include indigenous knowledge. Specifically for the Ebola virus outbreak in North Kivu, the WHO in cooperation with UNICEF and the International Federation of Red Cross and Red Crescent Societies developed a 'Risk Communication and Community Engagement Preparedness and Readiness Framework' in order to prepare future health workers for conditions in the field. It provides basic background information with a central focus on the socioeconomic and cultural aspects gathered via evidence-based research (WHO, 2018). However, in many instances, especially when it comes to prevention, general measures are still the standard even if they will not be well received by local community. In order for prevention to be the most effective, health care workers should listen to and specify prevention for each individual community. By incorporating local culture and beliefs, not for just North Kivu, but for every village and community specifically, health care workers will find it easier to build a beneficial and productive trust relationship.

In the case of the DRC, humanitarian actors have to first get permission from the Congolese government to operate in the region. This is the first hurdle in the building of a trust relationship with the local community. Following political instability and regional conflict, Congolese people in North Kivu have insufficient faith and belief in the government. This could lead to them not trusting humanitarian NGOs as they could interpret them as working with the government instead of being independent actors in the field (Del Valle, H.; Healy, S. 2013). As mentioned before, outbreak control is strongly linked with effective communication and cooperation between all the actors involved (Diallo and Thuillier 2005). The concept of trust and building a trust relationship in humanitarian aid is new (Diallo and Thuillier 2005). Each actor and stakeholder involved has its own expectations, assumptions and goals about the relationship. From the perspective of the health workers, a successful trust relationship is established when local communities act according to the health workers' expectations or when the local communities follow advice given about outbreak prevention. However, a successful trust relationship from the perspective of the local community is not as easy to define (Diallo and Thuillier 2005). Trust between individuals is affect-based (emotional) or knowledge-based (the result of a cognitive process) and can be both. Affect-based trust can be understood as 'trust at first sight', which is almost impossible to achieve in the case of an Ebola virus outbreak (McAllister, 1995; Jones, 1998; Williams, 2001; Diallo & Thuillier, 2005). Knowledge-based trust emerges through communication in which each actor implicitly reveals to the other his/her values, expertise, integrity, consistency, loyalty, sense of justice and others (Victor and Cullen, 1988; Butler, 1991; Butler, 1994; Hosmer, 1995; Lewicki & Bunker, 1996; Diallo & Thuillier, 2005). Health care workers should treat the local community as more than patients. Working together and informing the local community about the current development in the treatment of Ebola virus disease will tackle miscommunication and anxiety.

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Fostering Transdisciplinary Collaboration Through Transdisciplinary Literature Reviews: Investigating the Accessibility of mHealth Technologies

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Abstract

Transdisciplinary research aims to investigate complex problems by integrating knowledge from multiple disciplines through knowledge co-creation. Initiating and planning transdisciplinary research requires a thorough review of the literature within many disciplines, demanding that researchers conciliate meanings of concepts from different disciplines, define the boundaries of each discipline within the topic and identify synergies between disciplines. Thus, conducting a transdisciplinary literature review can pose a challenge to researchers, and little guidance is available on how to approach this challenge in a systematic way. To address this, we develop a protocol for transdisciplinary literature reviews, extending the heuristics proposed by Leavy (2011). We describe how researchers can determine the relevant bodies of knowledge for the issue investigated, how they can locate and summarise relevant literature from all relevant disciplines, how they can determine the scope of each discipline within the project and how they can visualise the interaction between disciplines in regards to the topic researched. We also suggest methods for researchers to create new interactions between disciplines and propose new conceptual frameworks on the basis of the literature synthesis performed in the transdisciplinary literature review. To demonstrate how our framework can be employed to review literature on complex issues while integrating knowledge from multiple disciplines, we use the issue of accessibility of mHealth technologies as a case study and apply our guidelines to conduct a transdisciplinary literature review on the topic. We integrate findings from the social sciences, ethics, economics, law, psychology, medicine and engineering, among other disciplines to examine the accessibility of mHealth and propose promising areas for future transdisciplinary projects.

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The findings from this case study suggest the proposed transdisciplinary review guidelines can be used as a sole research methodology for initial transdisciplinary research projects, as well as an auxiliary tool for larger transdisciplinary projects.

Key words

mHealth, transdisciplinarity, hackathon

Introduction

Mobile health technologies (mHealth) have the potential to revolutionise healthcare. By providing a patient-centred approach to healthcare, mHealth technologies can empower patients and improve health outcomes, especially in people with chronic health problems (Roess, 2017). As with other health technologies, access to mHealth can vary depending on the country in which a person lives (Chan et al., 2017), their socioeconomic status (Camacho-Rivera et al., 2019), their age (Hoque & Sorwar, 2017) and their cognitive (Arnhold et al., 2014) and physical abilities (Yu et al., 2017). There are many layers to the issue of accessibility in mHealth and these issues cannot be addressed by technical expertise alone. Thus, a transdisciplinary perspective is necessary to integrate all aspects of this issue and arrive at sustainable solutions that could help mitigate the lack of accessibility in mHealth.

Methodology

To tackle the issues associated with mHealth, we initially planned to organise a transdisciplinary hackathon. In this event, transdisciplinary teams would be presented with complex issues related to mHealth and asked to formulate transdisciplinary research projects that could address such issues. However, due to the COVID-19 lockdown, we were unable to organise such an event. Thus, we decided to narrow down our scope and tackle the challenge of mHealth technologies and their accessibility through a literature review.

We decided on conducting a transdisciplinary literature review because it is important to develop a thorough understanding of the issue investigated before solutions can be proposed to address that issue. Literature reviews are the first step in conducting a research project and if conducted within a transdisciplinary framework, they can provide a comprehensive description of the problem and identify promising areas for further investigation (Montuori, 2013). For this purpose, we adapted Leavy's (2011) framework to conduct a transdisciplinary literature review surrounding the accessibility of mHealth technologies. We delineated our problem and determined the actors involved in the issue using an actor constellation exercise (Pohl, 2014). By using the PESTLE framework (Yüksel, 2012), we explored which disciplinary bodies of knowledge would be relevant for the issue of mHealth accessibility. Following, we searched Web of Knowledge for relevant articles, book chapters, conference proceedings and other scholarly publications pertaining to our topic of interest. We found 186 articles, which were in their majority categorised within the disciplines of life and biomedical sciences and technology. A large proportion of retrieved articles were concerned only with the usability or feasibility of a specific device or mHealth technology.

After this search, we have summarised our findings in a concept map (Figure 1).

At the centre of our map, in dark blue, we find our research question: "What influences accessibility to mHealth technologies?" In light blue, the four main factors can be found. Other influencing variables can be found in grey. For example, accessibility to mHealth technologies depends on the access to infrastructure, which is determined by the level of development of the country, as well as the centrality of the specific area within this country.

It is important to note that the only limitation addressed by a proposed solution is the issue of usability. Researchers have suggested they can increase accessibility by employing user-centred designs, which should increase usability of these technologies.

Results and discussion

Through our literature review, we found that mHealth accessibility is most significantly affected by the usability of the device or application, how much infrastructure the users have access to, the cost of the device and the level of health literacy the user has. However, these main factors are affected by other variables: for example, the level of infrastructure depends on the economic development of a country, as well as the centrality of the area in question within a country. We also found that most of the factors contributing to lack of accessibility were not the target of applied research that focused on solutions to this issue, with the exception of

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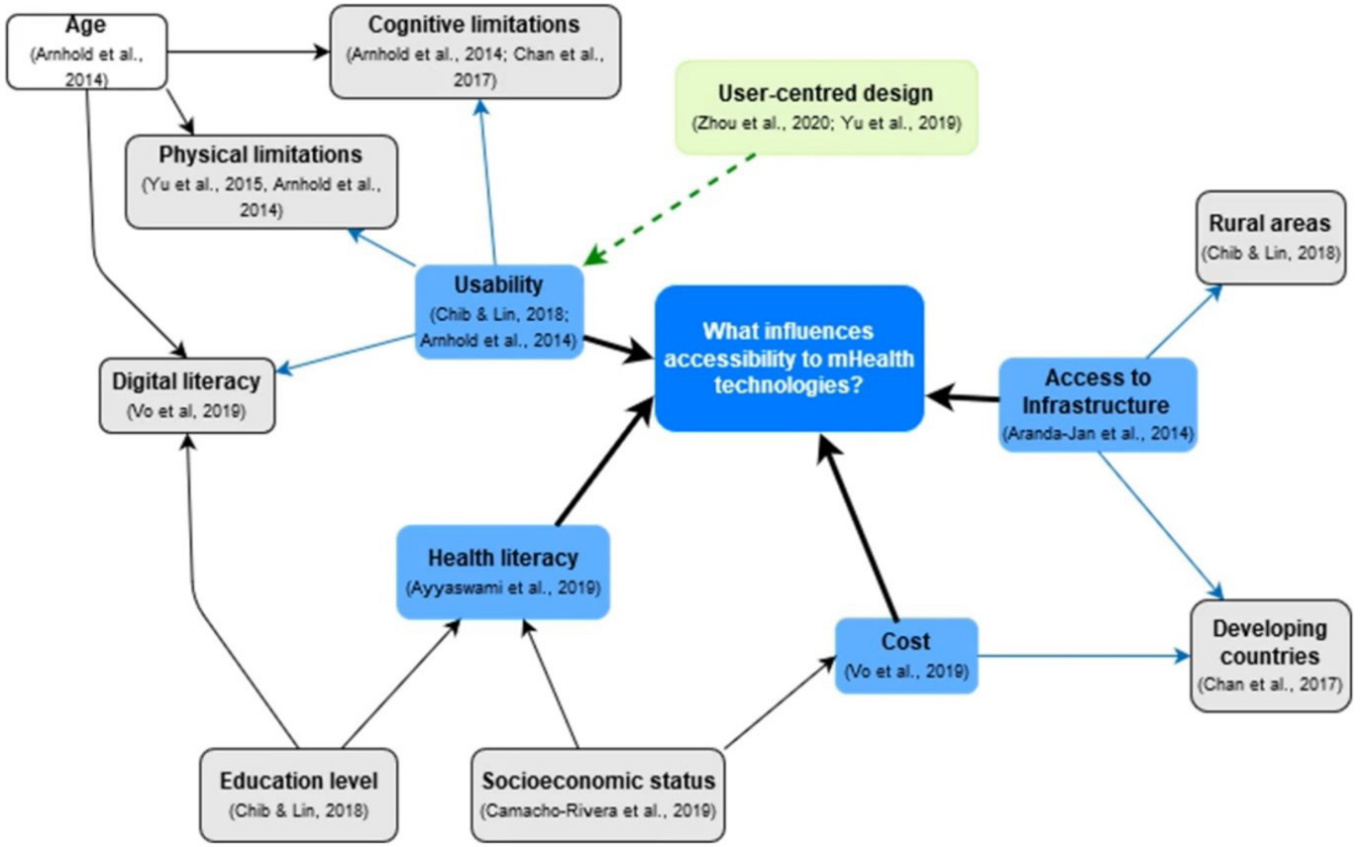

Figure 1. Concept map of the findings

usability. In fact, researchers have suggested that they can increase the accessibility of mHealth technologies by employing user-centred design and increasing the usability of these devices.

Conclusion

In summary, the accessibility of mHealth technologies is a multidimensional problem that has been scarcely explored in the literature. While current research has explored this issue from a technical perspective, a transdisciplinary perspective that explores the human, social and legal perspectives of this issue is needed to provide a holistic understanding and enable the creation of sustainable solutions to increase the accessibility of mHealth. While the literature review enabled us to gain an interdisciplinary perspective on the topic, we propose that a hackathon would be a promising approach to diversify perspectives. A hackathon will help us gain a truly transdisciplinary view, hopefully working towards a further understanding and addressing the issue of accessibility in mHealth.

List of supplementary material

Supplement 1: Original challenge document
Supplement 2: Video presentation

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Supplement 1: Original challenge document

BANK OF TRANSDISCIPLINARY CHALLENGES

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Dear,
Welcome to the Bank of Transdisciplinary Challenges!
This is an initiative where people concerned about the future translate their concern into a scientific challenge. The challenge typically revolves around a specific society, environment, and/or business problem or opportunity that you want to be addressed by a transdisciplinary research team.
Are you concerned about a specific theme or topic for the future?
We invite you to be part of this initiative by filling out this form and sharing your challenge with our academic team and other stakeholders.
We will inform you if your challenge is taken up by our research team, and of any further activities.
Hope to hear from you soon.
The Bank of Transdisciplinary Challenges.

SECTION 2 OF 5 – Before informing us about your challenge, we would like to know a bit more about you.

First Name: Jurgen
Last Name: Vercauteren
E-mail Address: jurgen.vercauteren@kuleuven.be
Affiliation: KU Leuven

- ☒ Academia as a Researcher
- ☐ Academia as a Student
- ☐ Government
- ☐ Industry
- ☐ Local Organization
- ☐ Non-profit Organization
- ☐ Society
- ☐ Other:

If you are affiliated to an organization, please fill in its name here:
You can also include some contact details of your organization.
Would you like to receive updates about this initiative?
YES

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SECTION 3 OF 5 – ABOUT YOUR CHALLENGE

Title of the Challenge
TRANSDISCIPLINARITY AND HACKATHONS

Key words (at least 7 key words)
Transdisciplinary research, hackathons, data for good, health

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.

The research question is based on the theme “How will technology contribute to diagnosis and predicting diseases” from the Flemish Science Agenda 2018.
Recent developments in diagnostics, such as the detection of cancer in the blood on the basis of the NIP test or small but fast and efficient mobile pocket laboratories (for example the Idylla mini lab of Biocartis), influence the future of our healthcare. On the other hand, the development of portable sensors such as heart rate monitors, apps on smartphones and watches that can set up an ECG (for example on the iWatch or iPhone approved by the FDA) or continuously measure blood sugar, is advancing personalised medicine. The possibilities with regard to 3D printing of bones and cartilage (tissue engineering) also contribute to this. Artificial intelligence can go one step further: making decisions about therapies can be left to machines and robots. Finally, all these new applications generate an enormous amount of data, which in turn can be used to sharpen these techniques. But can all people handle this sophisticated progress? How do we ensure the quality of all these new technologies? How far can we go ethically with this? Will this remain affordable for everyone? Can data be hacked or the privacy of the patient violated? These and other questions and concerns could be addressed in the hackathon.

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?

To come up with some practical recommendations for policy makers, for healthcare professionals and even for industry concerning the implications of the fast-evolving development and application of new technologies in disease diagnostics and treatment.

Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?
Please be aware that our transdisciplinary research teams accept only challenges that have to be dealt with from different points of view.

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.

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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:_____

Can we contact you for getting further details of your challenge? YES

Do you accept the terms and conditions for the proposition of this challenge? (See below) YES
Terms and Conditions
1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people and planet base on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.
2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame
3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge
4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.
5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.
6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the "Transdisciplinary Insights Course" based on the Honors program regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access

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"Transdisciplinary Insights e-Journal". Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the "Transdisciplinary Insights e-Journal" or at a "Transdisciplinary Insights Course"-related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the "Transdisciplinary Insights e-Journal" to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters' names and/or logos will be acknowledged by the "Transdisciplinary Insights e-Journal"
8. "Transdisciplinary Insights Course" reserves the right to change or update these T&Cs from time to time without prior notice to you.
Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: jorgericardo.novablanco@kuleuven.be

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
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?
Pharma (Janssen, Roche, Abbott, …) and representatives of the Flemish government.
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

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

If you have questions about some parts of the process, please ask them here:

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Supplement 2: Video presentation

The results of this work were presented at the symposium KU Leuven Facing the Future (https://rega.kuleuven.be/cev/Symposium/facing-the-future). The link to the short video presented at this symposium, summarising this complex challenge, can be found here: https://kuleuven.mediaspace.kaltura.com/media/Mobile+Health_Symposium+May+2020/1_tralnbtx.

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Tackling the Challenge of Inclusive Cities from an Urban Food Perspective

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Abstract

This paper focuses on food as a case study to understand issues of inclusivity in cities. More specifically, we focus on the process of food production, distribution, consumption, and sharing in the city of Leuven. Most urban spaces encompass material and discursive practices that influence differing rights and abilities to engage in the urban food chain. In this study, we initially used constellation mapping to identify relevant actors and conducted a follow-up field study to generate an in-depth understanding of the mechanisms and processes of inclusion and exclusion linked to the urban food chain in the city of Leuven. We collected data from multiple stakeholders using interviews and field observations. Iterative analysis was conducted using a within and cross-case approach. Based on our findings, we propose three solutions to stimulate inclusivity through the concept of food: closing the knowledge gap, removing social stigma from the distribution process and optimising the supply chain. These are influenced by the idea that we enter the food chain not only as consumers and distributors, but also as social beings invited into the food chain and working towards inclusivity through our own personal acts of solidarity.

Key words

Food, inclusivity, urban, interdisciplinary

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1. Background

In October 2019, a new challenge on 'Inclusive Cities' was launched by a member of the research group Social, Methodological and Theoretical Innovation / Kreative from the faculty of Social Sciences, KU Leuven (Supplement 1). As a transdisciplinary collaboration of students and professors, we were invited to study how economic and social objectives can be reconciled in developing sustainable urban communities or contexts. During a one-day boot camp session, the group of students and coaches assigned to the challenge decided on 'food distribution, consumption and sharing' as their topic focus. Food is a basic physiological need. In contemporary urban cities, one of the core facets of building resilient and 'hunger-proof' communities is achieving food security and managing sustainable food systems (Barthel & Isendahl, 2013; Koc, MacRae, Mougeot, & Welsh, 1999; Morgan & Sonnino, 2010). In light of rapid urbanisation and adaptation of neoliberal market strategies, some scholars have already flagged differential opportunities and barriers that exist in the production, distribution, and consumption of food (Alkon & McCullen, 2011; Slocum, 2007). The complex issue of food inclusivity – who has access to food, how, and when – needs to be addressed in more detail. In this study, we bring in a spatial perspective to map processes and mechanisms in urban food systems. This perspective fundamentally assumes that challenges to food inclusivity in production, distribution, and consumption are deeply entwined with spaces and places in the community (Mares & Alkon, 2011).We will unpack spatial thinking using a systemic and inductive approach to identify the relevant actors and trace how community food initiatives and practices unfold in different sites in the city. Situated in Leuven, Belgium, this study aims to contribute insights in building food resilient, secure, and sustainable communities by advancing more communal, inclusive, and hybrid urban foodscapes. Furthermore, these urban foodscapes are re-envisioned not just to reconcile the economic and social dimensions of food systems, but offer a transformative outlook (e.g. cyclical food maps that disturb notions of giving and receiving) and strengthen a participatory orientation to food citizenship (e.g. challenging a purely top-down macro-economic approach to food security and waste reduction).

The challenge was framed in the context of the Sustainable Development Goals (SDGs), as requested by the organisers of the transdisciplinary honours programme. The SDGs programme, published by the United Nations in 2015, serves as a model to achieve a better and more sustainable future for all citizens of the world through 17 categories. Goal 11, in line with our challenge, supports creation of cities and human settlements that are inclusive, safe, resilient and sustainable. In a time when individualism is rising in Western countries and their inhabitants feel lonely despite living in densely populated areas, cities have become the clear epitome of this development but, in substance, represent its solution (Snell, 2017). Community and a notion of identity are based on reciprocity, giving and receiving, recognising and being recognised. Food serves as a way to connect, as it lends itself to extending beyond transactional relations to social relations. The ways we interact with food – growing, buying, cooking, serving, sharing, eating and wasting – constitute events through which we can have social interactions between humans, our relationship with animals and the bioecological system as a whole, constituting a social metabolism (de Molina & Toledo, 2014).

While we evaluated SDG 11 as our key target, we spotted opportunities to link SDG 11 with SDGs 10 and 12. Reducing inequality, the target of SDG 10, might be seen through the lenses of community building and sustaining. Food serves as a way to connect, but also disrupts a human-centred logic in food distribution, as it lends itself to extending beyond transactional relations to social relations. The goal to build sustainable cities and communities, as implied in SDG 12, goes in line with the involvement of members of towns and communities in the process of food growth, purchase, cooking, serving, sharing and eventually also wasting. By looking into the various factors that contribute to the willingness to give as well as the ways in which people can give, we hope to be able to better understand how giving can contribute to the inclusivity of a city. Our long-term aspiration is to empower and promote the social, economic, cultural, legal and political inclusion of all.

1.1. Problem Statement

Food inclusivity and security in cities constitute a recognised worldwide wicked problem (Candel, 2016; Nelson & Stroink, 2014). A wicked problem is characterised as dynamic, open, complex, and unsolvable (Wexler, 2009). As such, addressing the 'wickedness' of such a problem necessitates taking an innovative,

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multidisciplinary and multi-sectoral approach (Mares & Alkon, 2011). Focusing on food as a case study for inclusivity allows for exploration of space and place where different groups are included and excluded. Challenges are marked with deep-seated economic, social, political, and cultural exclusions that restrict certain people from fully participating in the food system (DuPuis, Harrison, & Goodman, 2011; Hinrichs, 2003; Skinner, 2008; Moragues-Faus & Morgan, 2015; Zukin, 2008). For example, while organic food is preferable for the environmentalist, it is often not affordable for people with lower incomes. Food is also a wicked problem as globally the mechanisms used to 'produce, distribute, and consume food have led to social structures that at times deny people their right to food' (Badion, 2019, p. 40). It is not a local issue that can be easily isolated. With imports and exports, current food chains which are linear in nature make heavy demands on agriculture, environment, industry and innovation and do not return nutrients to soils. Such tensions between different stakeholders at various points in the food system are unavoidable and may seem unsolvable. Coming up with partial solutions that promote inclusivity regarding food requires a long-term transdisciplinary investment. In this light, this study contributes modest insights to understanding the wicked problem of food inclusivity in urban cities and to providing possible ways of reframing its solutions.

The argument we propose in tackling this problem is that a circular economy can yield benefits to the economy of the city, human health and the environment as well as helping to achieve pre-defined Sustainable Development Goals. A circular economy of food creates a cycle that aims for waste not to exist at all and instead be the input of other trophic and supply chains (Ghisellini, Cialani, & Ulgiati, 2016). Some of the waste products of food can provide additional value before wasting happens by generating new food products in various ways (giving the food and sharing a meal). Cities can work towards a redistribution of edible food by means of food sharing in the consumption stage. Also, the potential waste level can be reduced at the distribution stage. By better matching supply with fluctuating demand for different food types, discounting soon-to-expire products and using overripe produce for in-store food outlets, food retailers can reduce their waste. At the stage of food growth, cities can supply food that is not only grown in an eco-friendly manner, but also locally and best fitting to local conditions, thereby building resilience.

1.2. Objectives and Research Questions

Our approach to defining the goal of our study and research questions remained open and evolving and the result of an iterative, reflexive, and inductive mode of inquiry. Several questions were raised during an initial exploration of the problem of food consumption, distribution and waste. For example, how do particular welfare structures include and exclude people in Leuven through food? How is information distributed? Via which communication channels? What role could technology play in linking, bridging, and transforming exclusions, marginalisations, and disconnections? What are the economic, legal, political, and cultural systems that drive and inhibit the redistribution of food to those in greater need? What supply chains and channels are available that enable greater food access and consumption? How do existing food practices restore or damage communal relationships? In what ways can artful design and upcycling-related thinking remap urban foodscapes, rebuild a cohesive yet diverse community life, and instil a sense of safety and community belongingness? None of these questions initially stood out as more important than the other. Neither did we intend to provide an easy and one-size-fits-all answer to each of these questions. Over time, new questions emerged during team meetings or field visits (e.g. how do practices of food sharing and food waste link to marginalisation of groups and how can we transform these practices?). In the process of collecting and analysing data and writing storylines, we came to understand that tackling issues surrounding food moves beyond its physiological dimension. This insight has further shaped our inquiry process clustered around a central research question: *How can economic and social objectives be reconciled in developing sustainable food communities?*

To frame our thoughts, we found inspiration in the classic work of Marcel Mauss (1966, 2002), entitled *The Gift*, wherein he posited models of exchange in social life. In Carrier's (1991) review of Mauss' (1966) concept of 'gift', he clarifies that gift giving, by contrast to a commodity exchange, 'generates and regenerates the [social] relationship between the giver and the recipient' (p. 125). We build on the social-connective-affiliative aspect of Mauss' (1966, 2002) practice of gift giving

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by situating social relations in the spatial processes embedded in city life. For Lefebvre (1994), production of (urban) space is contingent on materially differentiated social relations of people (i.e. marginalised groups have difficulty accessing certain places and spaces in the city). From a spatial perspective, the issue of food inclusivity foregrounds the central premise of unequal rights to the city, that is, which groups possess the rights, while denying the rights of others, to produce, distribute, access, consume, share or waste food. We learned to recognise the socially rooted character of giving, as well as the material-spatial inequalities inherent in urban spaces. The core objective of our study is therefore to challenge both the liberal sensibilities of Mauss' (1966, 2002) practice of gift giving as well as Lefebvre's (1994) rather static and hierarchical view of social relationships. To achieve the Sustainable Development Goal (SDG 11) of creating inclusive, safe, and resilient cities and human settlements, we offer a re-imagination of urban foodscapes that subscribes to a flattened perspective of people, places, and objects. It does justice to the idea of urban foodscapes that enable intercultural exchanges, sense of belongingness, and citizenship (Duruz, Luckman, & Bishop, 2011).

2. Defining Relevant Knowledge Frameworks

The identification of other relevant knowledge frameworks was informed by a collective thinking process enriched through reflections on our personal experiences, disciplinal knowledge and theories on food chains, and subsequent fieldwork. We chose Maslow's (1943) hierarchy of psychological needs as an additional starting point to frame our research inquiry. First, we theoretically challenged Maslow's (1943) needs perspective and brought it in line with the idea of common goods as a regulatory principle in defining our specific targets (see target knowledge, section 2.1). Second, we expanded Maslow's (1943) needs perspective vis-à-vis different system levels derived from our collective inquiry process (see system knowledge, section 2.2). Third, we further investigated how to best transform existing practices linked to food chains in order to achieve greater inclusivity in urban spaces and places, hereby taking into account the social-connective-affiliative nexus promoted by Mauss (1966, 2002) (see transformative knowledge, section 2.3).

2.1. Target Knowledge

To begin with, Maslow's (1943) hierarchy of needs (Figure 1a classifies human needs into five categories or levels: physiological, safety and security, belongingness, esteem, and self-actualisation. A basic assumption of his perspective is that people in general strive for the goal of attaining a sense of 'integrated wholeness' or the realisation of their full potential as a human being. A necessary condition to achieve this goal is the need to satisfy lower needs (e.g. food as an example falling under the physiological level) before being able to satisfy higher needs (e.g. esteem, self-actualisation). Some findings already show that satisfying basic needs is positively correlated with a person's psychological health (Lester, 2013). However, in Maslow's (1943) theory these needs are not discrete or separate categories. He states clearly that what people do is typically 'multi-motivated', even giving the example '[e]ating may be partially for the sake of filling the stomach, and partially for the sake of comfort and amelioration of other needs' (Maslow 1943, p. 390). Furthermore, in social relationships, the position of who is in need and who is giving is also interchangeable, based on the theory from Mauss (Carrier, 1991). This suggests that the direction of the consumption and distribution component may switch orientation, which is why we decided to work with lines instead of arrows in the central part of Figure 1b. We propose to visualise the complex configuration of needs in a more flattened relationship, and connected in a variety of ways.

2.2. Systems Knowledge

In Figure 1, we propose that the issue of food represents not only a basic physiological need but multiple motivations, needs and relationships between them. These components are strongly interdependent with the system level: social, economic, environmental, cultural, legal and political. Access to food and ingredients is directly connected with food production systems, the seasonality of the ingredients and complex import–export networks. On a larger scale, this could pose an issue to food security at a time when the effects of climate change are putting food production at risk due to erratic weather patterns, including changes in temperature, drought and excess precipitation. On a local scale, the inability to produce some crops due to drought or other effects has direct economic, social and

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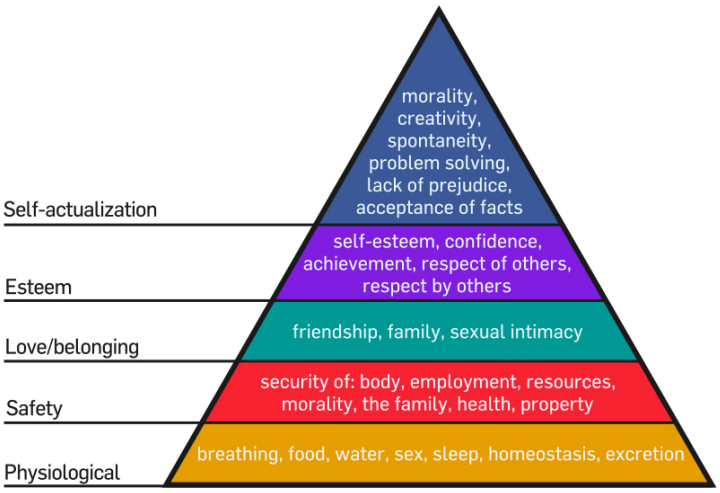

Figure 1a. Maslow's hierarchy of needs
Source: https://en.wikipedia.org/wiki/File:Maslow%27s_Hierarchy_of_Needs.svg (Creative Commons attribution).

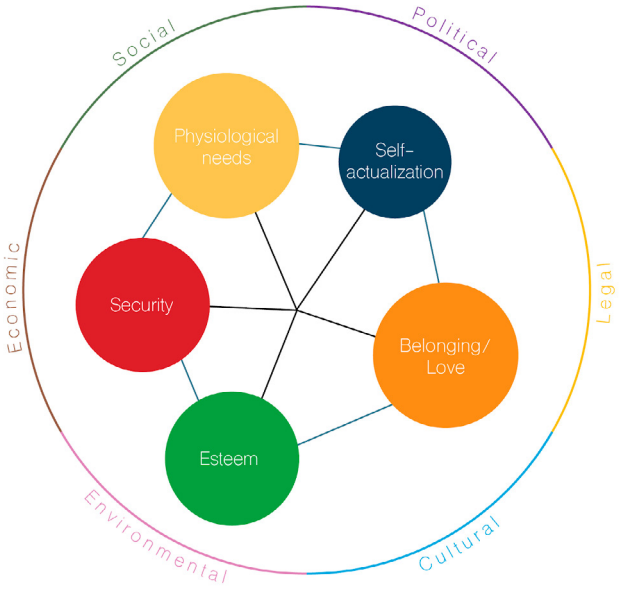

Figure 1b. From a hierarchical towards a flattened needs perspective

cultural consequences. In economic terms, it affects the cost and hence access to food. In social and cultural terms, it affects access to specific staples that constitute the basis of what a society consumes on a daily basis and for traditional holidays. Different situations in these systems can spark or connect with needs in an endless variety of combinations, which is why we included the systems as the outer ring in Figure 1b.

Food may be seen as meeting a physiological need – a basic need for survival. Without food, there will be no security nor safety. Also, taking the time to prepare food connects with personal safety. Cooking requires space and time, most notably in the presence of others (familiar or unfamiliar). Preparing food in a specific way is a learned process that has historically been passed from person to person in informal ways through families or in formal training (Ochs & Shohet, 2006; Vieira & Cervato-Mancuso, 2015). Therefore, when a person prepares a meal that is pleasing to the senses (a creative activity of self-actualisation), they are connecting with the basic physiological needs (food and security) as well as psychological needs for esteem and belonging to a group. This is illustrated by a typical Belgian family meal: *stoofvlees* (beef stew). Many families have a special twist on this typical meal, and sharing the specific preparations moves an individual into a deeper level of belonging within the family. But *stoofvlees* is a meal to be shared, and so there is another kind of belonging in eating together. During cultural or religious holidays, preparing and sharing meals takes on an additional level of meaning for individuals and for groups of people. Religious holidays with traditional meals, such as Ramadan, Passover, or Christmas, highlight the interaction between individual needs with communities and with systems. For example, Christmas dinner is a *social* event, and it also has impacts on the economy. It is *social* in both a present and a historic sense as people connect the foods associated with Christmas to their memories showing that *cultural* factors are also at play. In a similar way, a Seder at Passover or an Iftar during Ramadan functions as a meal that pulls together both personal needs (physical, esteem, belonging, self-actualisation) and systems (economic, social, cultural). Acquiring the food used for religious celebrations interacts with economic, environmental, social, cultural, and political systems.

Because food meets multiple needs, it is useful to evaluate different organisations as they relate to the system. For example, it is possible that food banks may be used as a targeted means of inclusion or exclusion through systems. Through placement and upkeep of the facility, the foods which are on offer, and the manner in which foods are selected, all present opportunities to choose inclusion or exclusion. An inclusive city might have a great number of various foods because of the different nationalities, races, genders or other social groups that live in it. However, production, access, and consumption of food among these groups are often unequal, at which point *political* systems may become evident.

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Moreover, food is a crucial measurement of wealth, an aspect of the economic systems of a city. For example, the Engel coefficient is applied to measure the economic development of a family or even a region. The higher the coefficient is, the poorer a family or a region would be. As they spend almost all of their income on food, there is nothing left for them to buy other commodities.

Engel coefficient = expenditure on food / total income

Engel's law indicates that if a family has a low income, the proportion of spending on food would be large. Citizens would expand their other consumption only when they have obtained enough food to survive (Yang, 1998). Therefore, in a city struggling to cross the poverty line, spaces for creative forms of exchange and reciprocal forms of giving and taking should be created to prevent situations in which residents live hungry. It puts them in a situation in which they are unable to realise basic needs and live a full life.

Food connects people when sharing a meal, and the social systems within a city influence the habits, spaces, and places where sharing occurs. When we talk about food, it is also necessary to mention events which, by their nature, use the concept of dining together to connect cultures, generations, old settlers and newcomers. This was experienced by one of our group members, recalling a joint picnic of one of the Brussels communes on the occasion of a car-free day. People brought their food and shared with each other, exchanged recipes and met their neighbours. While the city, a political system, took the initiative to organise the event that brought together different groups, it was the people who took part, in the social system, who contributed greatly to community bonding using food sharing. Thus, food could help participants to meet new people and obtain skills in an alternative kind of exchange.

An integrated approach is needed to create value streams bringing together the economic with the social perspective. To develop such an approach, it is important for stakeholders to behave in a more 'food-conscious' way. Food sharing is an important way to create a circular or cyclic economy which has practices of locally grown products, activities of eating together and redistributing foods within a city. Although food sharing initiatives are gaining importance in some cities – from community gardens to restaurants and cafeterias using about-to-expire food to create meals, etc. – the cumulative impact of these urban food initiatives towards the inclusivity of diverse people in a city has to be further understood.

The context of food initiatives in a city must be analysed to develop better practices in terms of equality, resilience, safety and inclusivity.

Food is vital for people's physiological needs, and it is the most basic need. Belasco (1999) said, 'Food is the first of the essentials of life, our biggest industry, our greatest export, our most frequently indulged pleasure, and also the object of considerable concern and dread'. It can be both pleasure and dread because food, as a basic need of human beings, is neither a purely economic issue nor a simple social issue. Since food is necessary for living, accessing food is a form of inclusivity.

2.3. Transformation Knowledge

After developing an understanding of the relations and goals of the systems, additional effort is needed to transform urban foodscapes that foster food inclusivity, enhance efficiency in food systems, and ensure environmental sustainability. The transformation made in this regard should consider various forms of innovation, such as technological, social, organisational, or managerial, among others. This innovation should allow actors to better organise and coordinate their communal food activities and practices that address deeper and more complex causes of social exclusions, system inefficiency, and food wastage.

Various stakeholders that fall at any point in the urban food system may need to rethink existing policies, practices, and norms that enable or obstruct food inclusivity. Other scholars and practitioners have already adopted a holistic and sustainability approach to improve the local food economy (Reynolds, 2009). In this regard, technical and inter-sectoral expertise as well as greater community engagement need to be bolstered. For example, one can revisit existing public and private partnerships in developing innovative financial (e.g. incentivising local producers) and social policies and programmes that promote greater access and support for local food businesses. Additionally, there is a need to ensure that small-scale farmers, food processors, distributors and the like are not left out and efforts should be made to assist them to fully participate in the local food economy (i.e. exploring the efficacy of the farm-to-table concept in order to cut out intermediaries or third parties).

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3. Methodology

We tackled our challenge via a combined approach of mapping exercises and field visits. We started the mapping of relevant initiatives and actors we were familiar with through residency or study life in Leuven during a boot camp module organised at the start of the transdisciplinary honours programme. Our first assignment was the development of a constellation map that showed the connections between initiatives in relation to food production, consumption and distribution, which we later extended with food sharing, food regulation, food preparation and food recovery initiatives. Relations between initiatives were reconsidered as the fieldwork progressed.

The fieldwork component should be situated in a broader case study design approach, involving a series of visits, either by individual members or by the whole team, of a selection of initiatives (each of them considered 'a case') on the constellation map (see Figure 3 for a full overview of initiatives identified). We selected seven actors that we explored in more detail: municipal government; Carrefour; Hal 5 hosting Het Perron and Korst; 't Lampeke; Enchanté; and Too Good To Go. We based this selection on a maximum variation sampling strategy, taking into account profit and non-profit initiatives, policy and community or social welfare organisations, and formally versus informally organised structures (including a short community garden initiative visited in the context of our contact at 't Lampeke). Visits to initiatives typically lasted between 45 minutes and two hours. We used a combined data collection approach of interviews, observation and geomapping. During observation time we took pictures of things and people in context, which we later reflected upon and integrated with the storylines generated through the interviews. In the context of this study, the pictures are used to give a sense of place to the reader and illustrate some of the ideas encountered during the interviews, rather than to serve as an additional collection technique from a methodological triangulation perspective. The following questions guided our interviews:

1. What is your target group?
2. Who do you reach/not reach/want to reach?
3. How are you reaching them?
4. What reasons do you see for people engaging/not engaging?
5. How do you set criteria for participants? What considerations? Who decides?
6. Who are you cooperating with? Partners?
7. How did you decide on the place? What does this place mean for you?
8. What is the structure of your organisation?
9. What do you achieve/want to achieve?

Each person interviewed or photographed was approached with an informed consent sheet, in which we explained the honours programme as well as the particular goals of our study and how the findings would be used (Supplement 2). Only transcripts and images for which we received written or oral consent were used in this study. In total, we were able to interview five people from four different organisations and conducted observational exercises in two settings, including Hal 5 (Korst and Social Grocers) and the community centre and community garden from the social welfare organisation 't Lampeke (see Figure 2) within the timeframe of the honours programme. We also studied the practices of Too Good To Go and Enchanté via web-based information and physical flyers distributed.

We analysed fieldwork data using a combination of a cross-case and within-case approach. We mapped each initiative against pre-set parameters including inclusion, exclusion, and mechanisms influencing inclusion or exclusion, each according to the food activities on the constellation map. The food activities are the following: food regulation, food production, food distribution, food preparation, food consumption, food sharing, and food recovery. From here, we developed a matrix that enabled us to cross-compare the different practices and detect interesting general trends and patterns between them (Table 1). In addition, we studied

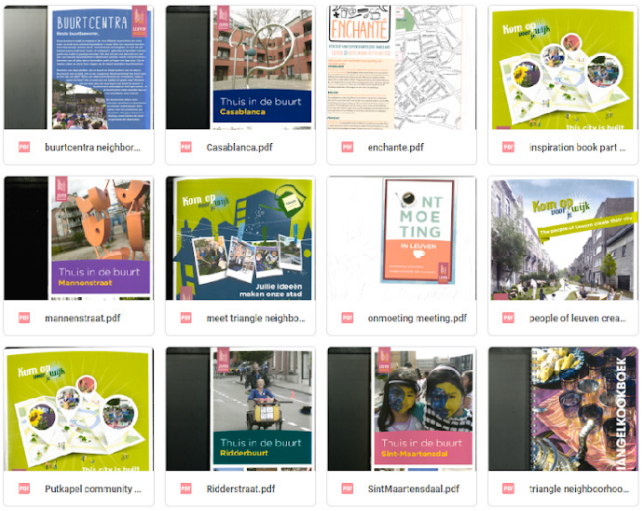

Figure 2. Overview of welfare initiatives in the city of Leuven

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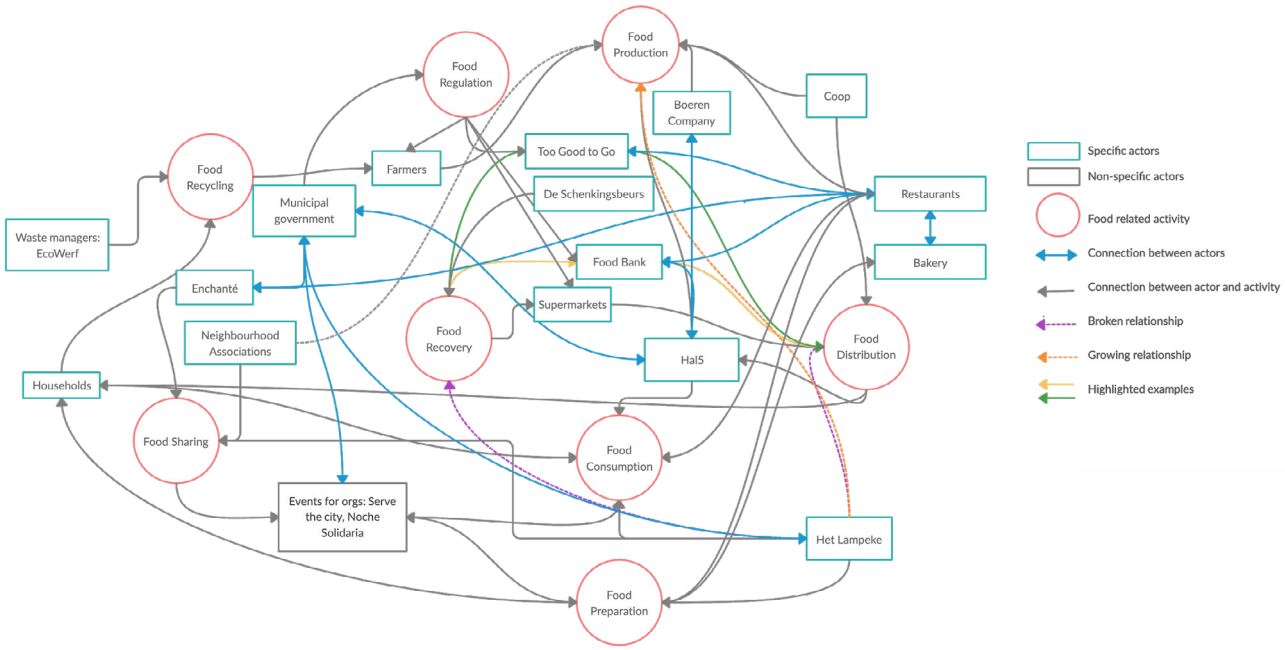

Figure 3. Constellation map: food inclusivity map of Leuven
Note: Rectangles represent actors, turquoise borders represent specific actors with clear leadership, and grey borders non-specific actors (only events in this case). Circles represent activities. Arrows going from an actor to an activity represent the fact that this activity is performed by the actor. Arrows going from an activity to an actor represent the fact that the result of this activity is used by/benefits the actor. Bidirectional arrows represent the overlap. Blue arrows connect bidirectional relationships between actors. Dashed arrows represent weak relationships. Purple arrows represent a flawed relationship, while orange represents an improving one. Two cycles for representation are shown in green and yellow connecting food recovery and food distribution by two very distinct actors, Too Good To Go and the food bank respectively.

a selection of these cases in more depth, by providing a detailed image of descriptive characteristics of the case, as well as how the practice worked in relation to the research questions we were interested in.

4. Findings

4.1. Constellation Map

In Figure 3, we portray the constellation map with the activities we identified via brainstorming sessions and field visits in red circles and the actors in turquoise rectangles. Events are a separate type of actor since they are not necessarily a continuous organisation with a representative (nor necessarily the main focus of the organisation), hence the colour differentiation (turquoise vs grey). The direction of the arrows shows the relationship between the actors and the activities. An arrow going from an actor to an activity means that this activity is performed by the actor, while an arrow going from an activity to an actor means that this activity is generally done for the actor (the product of this activity is used by the actor). The bidirectional arrows show the overlap. The direct relationships between actors are shown in blue bidirectional arrows. Dashed arrows show a weak relationship. Purple arrows show a flawed relationship and orange arrows show improving ones. The latter type of arrows are used to show an example with ’t Lampeke, where some activities are flawed at the moment, such as food distribution and recovery, while others are growing, such as the food production portion with their garden.

Currently the constellation map shows the circularity of food production and consumption, exploring the actors involved and conspicuously showing the side participation of activities, such as food regulation, which is performed by the municipal/other governmental actors unto different organisations involved in production and distribution of food. Furthermore, the smaller cycle of food recovery and food distribution created by two very different actors (food bank and Too Good To Go) was highlighted by adding different colours (green and yellow) to the graph. This differs from the type of recovery that De Schenkingsbeurs does, as they redistribute to

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organisations rather than people directly. Food sharing still must be adequately operationalised in order to be able to connect it to different actors. At the moment, events where a meal was physically shared in the context of sharing dishes or information were included. However, in terms of inclusivity and interaction, sharing was also considered in terms of reducing the burden of the costs (affordability) or recognising the actual costs incurred in local, organic production (such as fair/direct trade). The process of food production and consumption can always be considered in terms of sharing when there are interactions as well.

4.2. Cross-Case Analysis

What we learned from our cross-case analysis (Table 1) is that each case study focused on a few of the food activities; very few included all seven. Although it was part of our constellation map, very few conversations about inclusivity around food led to discussion on food regulations. The closest was a conversation at 't Lampeke about political funding for social care projects. Food distribution was a major part of conversations with the Social Grocers, Carrefour, 't Lampeke, Korst, and the municipal government. These groups work together to provide healthy food choices and variety within a space that brings communities together. The conversation on food distribution crosses over into the conversation on food recovery as distribution points become potential sources for food recovery. In our cases, supermarkets and other food vendors are generally eager to donate usable but unsellable products. However, they do not put their own staff hours towards the donations, shifting that burden onto the receiving organisation. This is where Too Good To Go fills an administrative gap between restaurants, grocers and individual consumers.

The preparation, consumption, and sharing of food is evident in another grouping of interrelated inclusion mechanisms. Leuven has several active neighbourhood groups that host parties and food sharing events throughout the year. In neighbourhoods with a larger percentage of social housing, these are augmented by community centres. Several of these centres offer budget-friendly meals, which the municipality has named '*Ontmoeting*'. This connotes encounter, connection, understanding, and access. Community building opportunities and values are supported in food initiatives from each of the seven actors in a variety of ways. Despite the willingness of the political system, alongside social and economic partners, there remain barriers within the economic and social systems to more robust inclusivity.

Generally speaking, the government agencies, consisting of the municipal government and community centres, enjoy a high reputation in an inclusive food system containing all seven food activities in pursuit of promoting more social inclusivity and fairness. At the same time, social powers, some food supplies, supermarkets, and even the public have a strong willingness to donate to or advocate for an inclusivity-friendly system. However, there are some inevitable limits in practice. Some commercial food shops or supermarkets need to prioritise commercial profit maximisation and high-grade food brands. Therefore, they can only decrease the price of certain basic foods or offer specific coupons for the target group in limited areas due to the absence of connecting mechanisms, regulatory mechanisms or other encouraging mechanisms. Specific contents are shown in Table 1.

4.3. Within-Case Analysis

In what follows we present our within-case analysis of Hal 5: Korst, Hal 5: Social Grocers, Carrefour, and 't Lampeke, which provides a more detailed, supportive narrative. The narrative combines the interpretive voice of our team members with raw study data in the form of citations from the interviews.

Field Visit to Hal 5

At Hal 5 we conducted interviews with the employees of the two organisations that reside in Hal 5, namely Korst Bakery and Het Perron. We discussed how they contribute to an inclusive city around the concept of food by understanding their customer segment, product variety, their idea of shopping and the physical space. Hal 5 is an old railway hall that houses initiatives and organisations that focus on food, community building and sustainable business. Hal 5 was initiated as a project aimed at adding value to the place, neighbourhood and Leuven. Once you step inside, you can grab something to eat or go to the bar where there is the possibility to meet new people. The stalls and tables are organised around an intimate space at the head of the long hall. Shops are located across the hall, which creates a spacious atmosphere that invites people to enter and discover their products.

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Table 1. Case content overview

Stakeholders	Process: Inclusion/ Exclusion/ Mechanism	Food Regulation	Food Production	Food Distribution	Food Preparation	Food Consumption	Food Sharing	Food Recovery
Municipal Government	Inclusion	did not discuss	Community gardens Neighbourhood beer	(Opportunities) Social Grocers Social Restaurants	Social restaurants Community centers	Neighbourhood parties Lunch at ZorgCentrum Social restaurants	Neighbour-hood parties Neighbourhood cookbook World party	Grocery store donations to Social Grocers
	Exclusion	did not discuss	Lack of accessible space within every neighbourhood	Events such as Kermis (Fair) Christmas market, Food truck party Hapje Tapje	Time Experience Familiarity with Belgian foods	Cost	Community willingness Cost	Requires staff and transport
	Mechanism	did not discuss	Donations of land Community initiative	Member cards Subsidies Donations (Enchanté) Cooperative grants	Volunteer organisations Social care sector	Social care sector Community initiatives	Collaboration with Enchanté	Staff who collect donations
Carrefour	Inclusion					Adapting prod-ucts and sales to their surrounding customer base Price range serving all social groups	Food sharing	Goods that are about to expire redistributed within the network of social initiatives in Leuven Reduction of prices Use of the app Too Good To Go
	Exclusion					Adaptation is only based on profit maximisation		
	Mechanism					Profit maximisation		Collaboration with fair of Donations Green Office, Hal 5 Too Good To Go
Hal 5: Social Grocers (food bank and solidarity shop)	Inclusion	Only people with a 'social pass' can get the discount (Social Grocers)		Allows clients to choose items as they would in a shop Social Grocers receives free delivery from Carrefour	Coffee and soup available for customers Large community table			Primary source of foods from donations from Carrefour, food bank
	Exclusion			Fewer shoppers without subsidy participate (Social Grocers)		Many shoppers did not stay to drink coffee		
	Mechanism	Municipality checks eligibility for discount pass			Space and food available	Space and food available	Space and food available	

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Table 1. Case content overview (continued)

Stakeholders	Process: Inclusion/ Exclusion/ Mechanism	Food Regulation	Food Production	Food Distribution	Food Preparation	Food Consumption	Food Sharing	Food Recovery
Hal 5: Korst (bakery)	Inclusion		Focus on sourdough. grain from farmers, company (farms around Leuven); 150 kg a week. All ingredients biological Four people working at time	Various restaurants (Land aan overkant, Bar Stan, Surely, Foodhub, Wikke)		Everyone who likes sourdough bread and values the quality 80% are regular customers		
	Exclusion					People not valuing quality of bread or those who cannot afford the higher quality		
	Mechanism					Korst values quality over quantity, believing that higher-quality bread is competitive over lower-quality bread from supermarket		
't Lampeke (community centre)	Inclusion	Receive subsidies from local, regional governments	Standard Flemish food Vegetarian diet	Drop-off point for bio boxes Used to supervise Social Grocers once per week	Volunteers from groups, individuals, community	Offer food with low price	Food brings people together with emotions (opinions, religious, preference like vegetarian)	Companies contact to provide donations (Delhaize, Bulk, etc.)
	Exclusion	Subsidies only used for first aids	Donation from Delhaize (lack of labour to handle it)	Lack of interest from broader community	Need basic skills	Only the people living in the neighbourhood	Need to cover minimum cost	Requires staff and transport
	Mechanism	Coordination with local target groups and national representative groups	Donation (get materials at lower price)	Relies on voluntary participation Advertising to recruit volunteers	Relies on voluntary participation Advertising to recruit volunteers	Serve standard Flemish food Offer vegetarian diet periodically Most of the visitors come for cheap meat	People come and keep coming for a certain period Some drop and some stay, meanwhile some new people join in	Staff who collect donations
Enchanté (food sharing)	Inclusion					Plenty of donations	Willingness to donate	
	Exclusion					Asking for the coupon/assessing need of client	Hesitation to receive without contribution	
	Mechanism					Paper coupons on a display board, some in front of/some behind register		
Too Good To Go (food recovery)	Inclusion							Access to usable but unsaleable food at a lower cost
	Exclusion					Geared to individual transport to locations		
	Mechanism					Need smartphone to access		

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Korst is a boutique bakery working with the principle of 'from the field to the store'. They bake sourdough bread which is very popular and also cakes and pastries. They emphasise the fact that they only bake with biologically responsible ingredients. They supply local grain from agricultural cooperatives from Leuven and distribute bread to various stores and restaurants nearby. Knowledge and quality are taken as basic principles when it comes to baking. This is the reason why the daily production volume remains limited in the small shop, not to compromise certain product quality. At first sight, the price of one loaf of bread is remarkably high, which creates an image of Korst as a seemingly elitist bakery. As noted by the pastry chef of Korst, Patricio, the majority of customers are indeed from middle and upper-middle class and they tend to visit the bakery regularly. The customer segment is highly specific and demographically distinguished. This bakery has a genuine characteristic of selling bread as a niche product and hence the price does not fluctuate very much with demand. The relatively high price is considered a reason for some people not to engage in the act of shopping at this bakery. Reducing the price can only be achieved if the higher-cost organic ingredients are replaced. However, being ecological friendly is a concept that they refuse to give up for the sake of reducing prices and eventually attracting new customers from different segments. Instead, they aim to create awareness among customers by informing them about the food and its production processes. Patricio said, 'For example, sometimes people find it [the bread] expensive at first. Then they take a bite and hear the story of it which is all food related. You must try yourself. Being aware of that, you can get people interested in buying your products and make better decisions about what to eat.' They aim to overcome the social prejudice towards the bakery by creating awareness and attracting more people to the store through interacting. When it comes to the bakery's space, it resembles a shop where the kitchen is visible through the glass walls of the store. Having visible walls in a way creates transparency regarding the baking process and the ingredients used and seems to facilitate the conversation of creating awareness.

After visiting the exclusive shop Korst Bakery, we met the manager of Het Perron, a shop that sells food and fast-moving consumer products. The place is termed a solidarity neighbourhood as it imposes a two-tier price system, with a lower social price (up to 40% discount) for people with a limited income and competitive market price for solidarity customers. The store is financially supported by the Flemish Government, the Province of Flemish Brabant, the City of Leuven, the OCMW Leuven and Carrefour. The place offers shopping for people from diverse cultures and ethnicities who are in financial difficulties, from Moroccan to Chinese and also refugees. OCMW shares a database of people (around 700 customers) with Het Perron who can benefit from social prices by assessing their income and other financial and social status. Sophie, the manager of Het Perron, mentions that not all of the customers in the database visit the store because of the fear of being acknowledged as financially disadvantaged. She quoted that fear as, 'Oh my god, I live in poverty and I have to go to a special shop. For some people it's difficult to make that step, but we try when they come here often to talk to them and tell them it's okay. It's not always easy. We still need more people to come to the shop.'

Carrefour, one of the largest suppliers, provides soon-to-expire meat and fish products free of charge or for a price of only 10 cents in the store. Sophie emphasised that it is very significant for people with low income to have these products for 10 cents. When she showed us the refrigerator where those products are kept, the price tags were visible to customers who do not speak the language or may be illiterate and thus unable understand product descriptions, as can be seen in Figure 4 below.

Hal 5 was a choice of location for the solidarity neighbourhood. Before they moved to Hal 5, Het Perron was providing services in a little shop where they had on average 70 customers in a three-hour time slot. After they moved to Hal 5, people were afraid of acknowledging they face poverty by shopping there, as Hal 5 attracts a lot of middle- and higher-income clients for other business available under the same roof. Ideally, the shop should be open to everybody. People's fear of entering seemed to lessen over time. Sophie addressed this situation by giving an example: 'There was a woman who got divorced, and she had one income. It was difficult for her to come to the shop with needs and she didn't even have enough means. But now she comes every week, she buys vegetables. She's very happy now, she made a big leap. From having everything to nothing. Refugees are another story, they don't speak the language and it's different for them. But also for them it's sometimes difficult, but they have less fear than people that had everything and then had nothing all of a sudden. We're here for everybody, some people come here to talk a little bit, sit and have a coffee.'

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Figure 4. Refrigerators in Het Perron

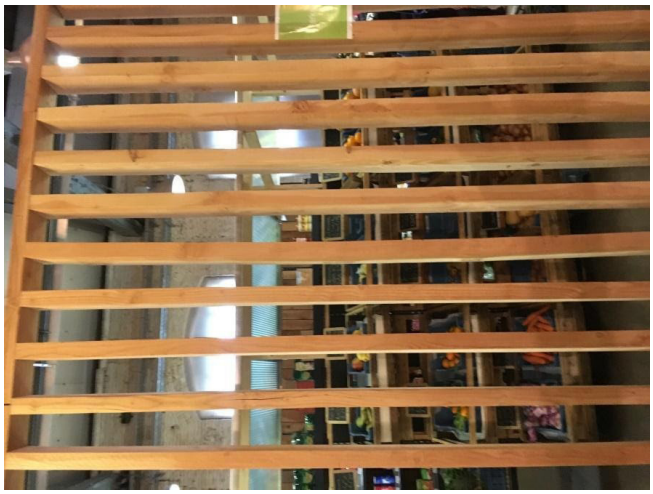

Figure 5. The fence instead of a solid wall near the entrance of Het Perron

Figure 6. The entrance of Het Perron

Het Perron seemed to remove physical barriers in the public space. It was possible to see inside the store through a wooden fence instead of a solid wall (see Figure 5). By allowing both those inside and those outside to see into the store, the fencing helps reduce the sense of separation. It also fits with the general aesthetic feeling throughout Hal 5 that encourages openness. That public/private architectural interface also reflects the complex relationship between systems evident in the Social Grocers: social, political, and economic. There were two doors – an entrance and an exit – which were clearly marked. This helped to maximise the flow through the store just as in other grocery stores. The entrance door was wide open, and made use of the space to post information (see Figure 6). Just inside the wide open doors, the entrance space was large and welcoming. With the greetings from volunteers or staff, customers feel invited into the shop.

At Het Perron, shopping cards, which are used as a means of receiving the discount, are provided to each customer. Regular customers are also given with a card so that they do not have to be identified in order to get the discount. First of all, these cards are not stigmatising

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Figure 7. The inside view of Het Perron

Figure 8. The front of 't Lampeke

as they are shown directly at the counter. Secondly, it is inclusive in that it welcomes people with various financial statuses, rather than attempting to impose a single pricing system for the products. The shopping set-up allows patrons to select their own products and produce rather than receiving a pre-made packet (see Figure 7).

As more people from different social backgrounds tend to visit the place, the notion of social stigma will be lessened. However, in order to achieve that, more regular customers should be attracted to the store. Sophie voiced the idea of people engaging in a relationship, as '[i]t would be nice someday to go to the food court and see them buy another cup of coffee'. Nevertheless, it is worth noting that free coupons for the bar and restaurant area of Hal 5 do not seem to be in high demand, as lots of free lunch and drink coupons were still available on the board, as shown in Figure 5. It seems that social stigma is not only a concern for people experiencing financial difficulties but also for people with a stable income, who are afraid to be involved in the act of getting a free coffee that requires no payment.

As a conclusion, Hal 5 is an important mediator not only between people and socially responsible businesses but also among the people that it reaches. However, the perception of social segregation will remain, as places such as Korst Bakery that serves a customer segment which consists mainly/mostly of medium- to high-income people. The interaction among people will be much more difficult to establish and the inclusion of people in Hal 5 may be hindered. Thus, at Hal 5, social integration and solidarity needs to be addressed and sustained as more people from heterogeneous demographic groups visit and interact in the space.

Field Visit to 't Lampeke

There is a large window at the front of the community centre that looks into a group of sofas facing each other (Figure 8). Behind them, a long row of tables covered in brightly coloured cloths stand ready for community members. Upon entering, a sideboard with hot coffee and warm water for tea greets you, along with the smell and rhythmical sound of chopping vegetables that invite you further in. There are people enjoying coffee on the sofas and ladies sitting together at the end of one of the tables. The 't Lampeke community centre clearly manifests its vision as an extended living room, combining

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Figure 9. Inside ’t Lampeke

food preparation, consumption and sharing with social activities. Sven, from the community centre, explained, ‘we are open for the whole community and the whole neighbourhood.’ This is an intentionally broadly inclusive statement.

The target group is the neighbourhood and the goal is to provide a space to bring people together. Part of a larger project, ’t Lampeke has been in the community for 50 years, and the house is one of the growing branches that focus on different stages of life. Still, they mainly see elderly and single people. People come to ’t Lampeke by looking through the window, being invited through other projects, or after reading the welcome letter new neighbours receive. Anyone who comes into the house can sign up for a healthy meal that features fresh foods. To keep things simple, everyone pays the same price for lunch – 2 euros. That price is intentionally kept low so that people on fixed incomes can participate. People that come might have special requirements related to food. Nowadays, most meals are vegetarian for health purposes, sustainability and religious reasons. However, the number of visitors went down when vegetarian plates were introduced as the standard, as people wanted meat to substitute for the

Figure 10. ’t Lampeke seating

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lack of meat at home. For many, buying meat was not an option. 't Lampeke often uses Halal food as it is of good quality and yet cheaper than the standard so it provides a good option. It is important, Sven noted, for people to have a way 'to contribute and also to own it.' Participation extends beyond menu preferences into the kitchen where volunteers prep (Figure 9) or clean up, and are rewarded with a free meal. 't Lampeke sometimes allows people to pay for their meals later if they do not have the money, as it is better to be able to work with them and have them return. Participation also extends into the sitting room (Figure 10) where group activities or casual conversations continue over coffee or an activity. Difficult or personal conversations can continue in the garden that is situated about 200 metres from the main building, on a walk through the neighbourhood, or upstairs in the offices. This space is meant to invite the community into generous participation. However, not everybody comes to the community centre. The large window can be welcoming to some, or present a challenge to others who would prefer privacy or want to avoid the stigma of being labelled as being in poverty.

Privacy is a concern, and not only because of the window. People like 'that it's little and cosy', but, Sven went on to explain, there is limited space for private or sensitive conversations. Some of these sensitive conversations are sparked by eating a meal together; others centre around food. The process of including vegetarian options led to several conversations over months. These were emotional conversations because people felt an ownership of the house as well as the pressure of eating a fresh meal, feeding their children, changing social views, religious convictions, healthy foods, animal rights, and costs, and some are even learning the process of discussing differing opinions. This highlights the complexity of inclusivity in a city where people have diverse experiences with and expectations of cultural, economic, social, and environmental systems. Each of these systems participates in the conversation of community meals by proxy through the individuals, and in the reality of the operations. At times, these systems are supportive of inclusivity. When the systems hinder inclusivity, the community house pulls together community conversation and advocates for change at a local or national level.

Locally, 't Lampeke is connected to the city and through the city to other community centres and social organisations. Until recently, this included a weekly interaction with Het Perron until they moved to Hal 5. Staffing the grocery once a week created and reinforced connections to local individuals and families receiving grocery support. It had built a two-way bridge between individuals, families and the community centre. Connections could be reinforced through other municipal inclusivity initiatives such as Uitpass, biking lessons, and Enchanté. Often those who may benefit from these programmes are reluctant to use them, until a volunteer or worker from the community centre accompanies them the first few times.

However, the workers at 't Lampeke are already creating and organising activities, planning and preparing community meals, and supporting several more difficult cases each month. It takes 25 volunteers to run the house with meals and programming. This leaves little time to introduce people to municipal initiatives. There is also the reality of a shrinking budget for social connections but continued funding for food support. This leaves 't Lampeke in a difficult position regarding food recovery opportunities. Several businesses from small independent food stores, co-ops, and large supermarket chains have called and offered to donate their near-expiration and surplus food. However, collecting donations requires transportation, and staff hours to collect and load the donations, as well as to unload, label and store donations properly. At this point, it is simpler to buy food than to organise staff or volunteers to participate in collection schemes that require six-days-a-week participation.

The municipal, political and economic systems offer both support and limitations for the work of the 't Lampeke community centre. As priorities shift in these systems, so does funding. In the past, they had received funding for first aid food packages from an investment bank. However, the bank chose to focus its philanthropy on providing food packets not fresh food and that funding was lost. One option is to extend the current community garden project in order to grow food specifically for the community centre. However, the extended living room is too far from where the garden is situated and where many of their target clients live. At the moment geographical proximity is suboptimal. The approach of the community centre is to view food as a social commodity, not just a physiological one. This contributes to the desire to create an atmosphere that is welcoming and open where nutritious, fresh foods are prepared and shared. Viewing food solely as a basic physical necessity rather than as being connected to social

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and cultural systems works against policies that allow food to be employed as a tool for community building. Still, there are opportunities to address the mismatch between the availability of food through donations or initiatives such as Enchanté and community centres in the city.

Interview at Carrefour

Our fieldwork continued in the local branch of the Carrefour retail chain. During an interview with a manager of the store, which is located not far from the city ring road, we focused mainly on the issue of waste management and sustainability. Despite the fact that the store is – due to its location – positioned for student grocery shopping, the aisles are filled mainly by working people, seniors and families with children on the weekends. We can therefore say that store's customers come from different social backgrounds and income categories.

Discussing Carrefour's target group, we could not avoid the topic of inclusivity. As the store manager said in an interview: 'Our store is not only a place to buy food, but also to interact with other people. Here, you can find different kinds of food for different kinds of people under one roof. None of that is exclusively for one social or cultural group.' And despite the fact that Carrefour market, like any other retail chain, is profit-oriented and price therefore rises with the quality of the product, we can see that management is really trying to live up to its words.

Waste management may serve as an example of the efforts of the store. To prevent extensive food waste, several measures, depending on the nature of the product and its packaging, have been taken. If the product is packaged in plastic or paper and the warranty period is approaching, its price may be reduced by up to half. Such a reduction makes it more affordable for a wide range of customers and increases the likelihood of its sale. Dry products in packages are often picked up by local organisations, which then – on the condition of immediate consumption – use the products according to their focus. This branch of Carrefour market cooperates with the Green Office of KU Leuven, and a community initiative, De Schenkingsbeurs, that focuses on collecting goods that are about to expire and their further redistribution within the network of social initiatives in the City of Leuven, like social services and grocery stores. At the moment, however, neither is a long-term cooperation and the consumption of food whose expiration date is approaching is usually unpredictable. Unfortunately, uncollected food usually ends up in the trash, as do fruits, vegetables and meat products that no longer look 'good'.

Interview with the City of Leuven

Considering the nature of our research, we decided to conduct an interview with the city representatives as well. One of the first things we learnt from them was that 'Leuven is a city for everybody' and thus also access to healthy food should also be for everyone, regardless of income. Therefore, the city, together with its partners, organises several initiatives that aim to achieve this. Together with partners such as community centres, social restaurants, OCMW or Hal 5, they try not to provide charity to low-income people, but rather to subsidise what they need, according to their own choice. Therefore, they support projects such as the previously mentioned Social Grocers, Het Perron, in Hal 5, which is a grocery or social grocer with two different prices for one product.

One of the problems the city faces is how to contact the target group. The City of Leuven works with an integrated network of people where everyone knows everyone. In theory it means that social workers can direct clients to social restaurants or to cafes which participate in the Enchanté initiative. At the same time, every once in a while, the City of Leuven sends out a letter to people with low incomes about existing projects and initiatives. However, a written letter, as the simplest form of mass access to the target group, has several shortcomings: not everyone receives the letter, and not everyone opens it, reads it and understands it.

Another challenge is the lack of inclusivity in projects and events that are not directly organised by the city or those that bring together several actors. Whether it is the farmers' market, the traditional winter market or the fair, food prices are usually too high and socially disadvantaged people are therefore unlikely to take part in such events. While the city cannot influence the prices of the sellers at the market, it almost always does so when organising its own events. An example of an event organised by the city is the family picnic in the City Park. In this case, the city has an agreement with the bar owner which allows visitors to participate even if they do not buy anything from him and instead consume their own food.

We also learned about many projects and initiatives that are started directly by the city's residents. These

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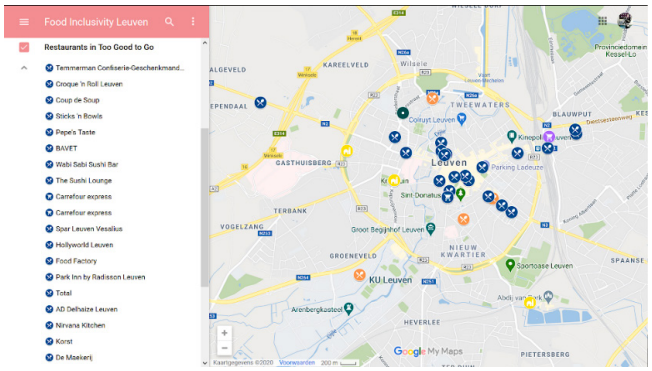

Figure 11. Map of food inclusivity in the City of Leuven
Source: https://www.google.com/maps/d/edit?mid=1K-7KJjLE6ZwkVQJK9ifccGglODwrD6pmk&usp=sharing.

bottom-up projects enjoy great support from the city, which helps in their organisation by either providing logistics or a financial contribution. These are, for example, the so-called '*buurtfeestjes*' (neighbourhood parties), in which the city usually provides the organisers with chairs and tables or ensures that the street is closed to cars. In return, the city is able to influence the level of inclusiveness during these events by, for example, making them free for kids under a certain age. Another example is also support for the Public Iftar, an event organised jointly by city mosques that brings together not only different social but also religious and cultural groups. Another neighbourhood project, which started with the installation of a bench as a place to gather, has turned into a local recipe collection. This collection contains favourite recipes from all the inhabitants of the neighbourhood, complete with stories behind their choice. A recipe book then serves not only as a reason to initiate conversations between neighbours, but also as a welcoming gesture for new inhabitants of the quarter.

Mapping exercise Too Good To Go

Too Good To Go is an application providing a platform for selling surplus food. Traders, such as restaurants, bakeries, and supermarkets, are able to reduce their wastes and gain potential customers simultaneously. Consumers get a 'magic bag' from traders with discounted prices by placing orders on the app. The content of the bag varies according to the surplus of the day.

Food waste produces abundant methane, which accounts for 8% of global greenhouse gas emissions. Meanwhile, freshwater resources are also wasted along with the food waste. In Belgium, 3.5 million tons of food

Figure 12. Enchanté notice board in a restaurant at Hal 5, with vouchers

are thrown away every year, which means each resident has wasted an average of 345 kg of food. Too Good To Go Belgium has saved 1,084,307 meals since it was launched on 1 March 2018 (Falsetti, 2019). Ghent, Antwerp and Leuven were amongst the first Belgian cities that launched the system. In Leuven the Too Good To Go initiative started initially with approximately 20 distributors offering magic boxes. The number of participating distributors has been growing ever since.

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Figure 13. Enchanté, distribution of participating locations

Mapping exercise Enchanté

Enchanté refers to a network of shops that offer small services to those in need. They all adopt the logic that a small gesture can make a big difference in the life of people in need. As such, they contribute to the mission of turning Leuven City into 'an affectionate place where everyone feels at home and wanted' (Enchanté Leuven). Whether it is to recharge a battery, fill up a bottle of water, read a book on a terrace without the need to consume something, heat up a baby meal in the microwave, or leave your backpack behind while strolling through the city, these shops invite you in with a sticker on their window. One of the services caught our attention – the postponed coffee initiative. Sympathetic customers sometimes pay extra to support the consumption of a coffee for someone else. The trader can give this consumption away at a later time to those who need it. There are vouchers with the name of the customer that donated on them available at the bar for someone else to pick up (Figure 12).

Enchanté service centres are distributed evenly across Leuven City, as shown in Figure 13, which is very helpful to surrounding residents. However, there are inevitable shortcomings related to stigma. For example, if one wrote down his wish for physical gifts or food, this person could feel embarrassed if an address or phone number was provided, as the casual passer-by could categorise the person as 'in need' or 'poor in resources'. In addition, there could be disappointment if no one replies. In addition, vouchers might not easily be picked up in public by regular customers either as they would not like to be associated with someone who cannot afford to buy his/her own coffee.

5. Discussion

Our inquiry process was meant to increase understanding about how economic and social objectives could be reconciled in developing sustainable food communities. We could have taken up the challenge to revise the societal model that gives rise to inequalities in relation to food worldwide. Our aspiration would then be to change 'the system' and what we would have available to do. If food is supposed to connect people, if each one of us enters the food chain not only as a consumer or a person in need, but also as a social and cultural being, would it not be more appropriate at this point to think about solutions that are within our own reach and that we can actively imagine ourselves doing or acting upon? It is within this modest logic of responding to each other that we presented a couple of strategies to consider in a video presentation at the end of our project (Supplement 3).

Solution 1: Closing the knowledge gap

Based on the observations in Het Perron and 't Lampeke, they serve a variety of cultures of origin, and language can be a barrier in spaces where food sharing is meant to be inclusive. Hence written and oral communication in different languages should be made available to engage people more in the stakeholders' activities.

Solution 2: Removing social stigma

Within Enchanté, there are many vouchers that have not been used. The perception of being seen as 'needy' if offered the voucher or being uncomfortable to self-identify as needy by asking for the voucher might underlie the hesitation to ask. The same problem was mentioned by the coordinator of 't Lampeke. People do not always enter the building because of the fear of being perceived as poor or in need by others. We suggest two ideas to create a reciprocal encounter by which the social stigma problem can be avoided. The first is to make the vouchers less visible so the transaction becomes implicit. Instead of asking for them, people would discover the vouchers hidden in public places. We also suggest the idea that upon redeeming a voucher, participants would get a 'receipt' that encourages them to continue to act either by purchasing a voucher for someone else, volunteering to hide a voucher, working in a community centre, or other opportunities. Hence, by engaging in the moment, recipients become a contributing part of

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the network, potentially leveraging the experience into an ongoing cycle.

Solution 3: Optimising the supply chain

Lastly, a significant misconnection mentioned by the stakeholders falls between those who want to donate food surplus (restaurants, supermarkets) and Het Perron and community centres. Neither group has the staffing or transport vehicles necessary to facilitate the process of receiving and then transporting the food. We recommend supporting the transportation of food donations either through existing food delivery bike services in return for a small fee, or a network of volunteers, a 'Giveroo' service. This would be coordinated with an app or a centralised database of the potential transporters that can share their resources and availability by pursuing a non-profit-seeking approach. By assigning volunteers to a pick up, not only does the performance of the supply chain improve but new social networks are also built while serving the community together.

Working collaboratively on a challenge that fits no one's expertise in particular is challenging in itself and inevitably leads to a couple of limitations in the study process. While we developed our line of inquiry, there was the growing insight that the connections we drew during our first initial mapping of actors and activities during the boot camp suggested a narrow focus on a limited set of activities for each identified actor in the constellation map. For example, supermarkets were easily linked to food distribution in relation to households and city initiatives through food banks. However, it was only later in the project that we realised that there were many possible connections that did not see the light because of pragmatic and other reasons preventing the actors from establishing a structural relationship. This is evidenced for example in the case of 't Lampeke, which that indicated that they would welcome food leftovers from supermarkets, and had been approached, but could not find a way to structurally embed the act of collecting the food in their daily activities. The fieldwork visits and interviews brought more clarity about how different agents on the map were related to each other. In addition, it provided clarity about connectors that were not in place, were suboptimal or could potentially be created with the right mechanisms in place. We compiled the interview guide and most visits were done as a group. Discussions on site were fed by the insights developed from the contact persons we engaged with on site, but also from our respective fields of interest. It is in these moments of informal chatting and sharing of food that we found the group members in their most attentive phase during the transdisciplinary honours programme.

The transdisciplinary nature of the research programme enabled the team to harvest valuable lessons beyond its initial goals and expectations. *We had much to learn.* In grappling with the 'wickedness' of food inclusivity in urban cities, the findings and insights derived are deemed to be partial and contextualised. While remaining cognizant of the plans, goals, and strategies crafted in the beginning, the team's decisions, for the most part, were guided by the opportunities that emerged in the process of inquiry. Although co-creation of knowledge is ideal, the role of the stakeholders was limited to being key informants in the data collection phase. For various reasons (e.g. different work schedules of each group member, interruptions due to COVID-19 in the latter phase), active and sustained stakeholder involvement was very challenging to implement. The team was also keen to apply theories in practice as well as to distil richer insights from the multiple interactions amongst stakeholders (e.g. bought food from them, shared tables with some) and members of the team (e.g. shared food with each other). Furthermore, the food sites included in this project are non-exhaustive given the various food establishments found in Leuven, Belgium. The constellation map created alongside the stories collected may also act as springboard to contribute to further work on tackling urban food systems and how issues related to inclusions/exclusions and their mechanisms are addressed. In addition, future research should study the relevance of these organisations in the food chain by inventorying how many people are actually reached by them and what their specific profiles are. Here, percentages of people supported by food and/or social assistance programmes and benefitting from school feeding programmes, the number of community-based food assets in the city and the presence of food-related policies and targets with a focus on vulnerable populations would be worthwhile to consider, as would the frequency of food system-learning and skill development in food and nutrition literacy (Milan Urban Food Policy Pact, 2018).

6. Conclusion

Humans' relationship to food and the whole system of who owns food, has access to it and controls the

mechanisms through which it is produced, consumed and distributed is what we would call a wicked problem that requires a major political and economic shift in order to answer our collective desire to strive for inclusivity worldwide. On the other hand, food sustainability contains essential concepts of inclusivity on a local city level, including social justice, fair labour, trade, farming, organic food production, waste and the concept of 'natural' (Morawicki & Díaz González, 2018; Jones & Cox, 2011). Our most important conclusion is that inclusivity is met where levels of trust, reciprocity and acts of solidarity have been built. What we learned from looking across the cases is that there was a lot of goodwill to connect citizens and organisations with different strengths and different needs, but in the practical operationalisation, things often did not work out in the best possible way. The mechanisms of inclusion and exclusion that we encountered during our research and the impact of these mechanisms could not be defined in clear input and stable outcome measures, even within the group of vulnerable populations. Some people chose to exclude themselves from food support, even though they would be considered eligible for it. We found that fear of social stigma played a major role in here. For similar reasons, middle-class casual passers-by who were encouraged to use an Enchanté voucher responded that they did not want to be perceived as a person in need by the public and refused to engage. Also, we noticed that the social actors were strongly entangled with the economical actors on the constellation map, as opposed to how they were represented in guidance documents such as the City Region Food System Indicator Framework (Carey & Dubbeling, 2017). Raising awareness about mechanisms of exclusion and best practices towards inclusivity would be a first necessary step in which the city council could take up an important role. We further propose closing the knowledge gap and informing people about valuable food options, eliminating the element of stigma from the food distribution process, and optimising the supply chain as a starting point in the move towards inclusive cities. The small pieces of the puzzles our team proposed from thinking across disciplines (Supplement 4) might not be meaningful enough to initiate change on a macro scale or create a new hypothesis. However, when we blend them with other insights and observations that new generations of students will be making, they could form the foundation for a future organisation or perhaps a new habit of mind and behaviour towards food inclusivity.

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List of supplements

Supplement 1: Original challenge document
Supplement 2: Informed Consent
Supplement 3: Video presentation
Supplement 4: Biographies of the authors

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Supplement 1: Original challenge document

Name of the Challenge: Inclusive environments

Challenge submitter: Prof. Karin Hannes

Affiliations: KU Leuven, Faculty of Social Sciences

Key words
Could you indicate at least 20 key words about your challenge?

Change, inclusivity, cities, interaction, public space, time–space, dimensions, mobility, communication, infrastructure, complexity, relationships, responsible city, race, gender, social, laws and policies, biodiversity, social equity, justice, policy makers, living ecosystem, urban narratives, health and wellbeing, transdisciplinary perspective, gentrification, spatial dimensions, sociomaterial

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.

In recent years, the city has been influenced by increasing globalisation, flexibility, rapid technological developments, a highly diverse and competitive market and accordingly changing social and health-related conditions. These transition processes are evidenced by on the one hand a change in 'urban infrastructures', and on the other hand a change in the 'social-behavioural interaction patterns'. Nowadays, cities are considered the economic heart of a particular area. On a local basis, they are strongly exposed to cultural imports, but at the same time they are influenced by a growing internationalisation and digitalisation movement that seems to compress time–space dimensions and geographically stretches out our social relationships or even disconnects them from physical places or other species with whom we share our environment.

Many aspects that were traditionally part of the public domain – such as mobility or communication infrastructure – shifted to the private domain or entered a virtual type of space, resulting in progressively more complex relations with governance and regulation. A 'differentiated mobility' of people is noticed, between those who 'control' the complex flows and movement in the modern time–space compressed urban areas (the jetsetters) and those who might become 'imprisoned' by it. This suggests that issues such as race, gender, social status, connectivity and other human characteristics might hinder people's mobility in a particular space or – on the other hand – make them feel 'out of place' and impact on their wellbeing and health. By extension, urban planning mechanisms, laws and policies that shape the material conditions of our cities also have an ecological impact and directly influence biodiversity.

How can we reconcile economic and social objectives in developing sustainable urban communities or contexts?
How can we promote inclusivity and social justice in an urban development climate that is essentially market driven? Can we think about sustainable cities, not only in terms of doing less damage, but actually in terms of repairing and restoring relations that might already have been damaged? How should we relate to place and space in times where the concept community is less and less related to a coherent and homogeneous entity linked to a geographical bounded area, but rather tied together by a distinct mixture of wider and more local social relationships that keep us 'in place'? How should we relate to others and the many other species with which we share our environment? What role could art and design play in inviting dialogue about the future of our cities or in disrupting or challenging movement patterns? Does it enable us to 'invite people in'? In sum, what does the responsible, inclusive city of tomorrow look like and which narratives or voices do we need to put forward for policy makers to consider?

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?

Potential objectives related to this challenge are:
(1) redefining our notion of space from a bio-psycho-socio-material perspective;
(2) imagining the design of cities from an other-than-human and living ecosystem perspective;
(3) inventory current flows in our cities and how to influence them;
(4) balancing smart growth processes against gentrification processes and geographical place's history;
(5) rethinking participation processes for urban development;
(6) studying spatial dimensions of health and wellbeing;
(7) thinking into existence net-positive architecture, design and art interventions that generate more than they consume;
(8) studying urban development into context (what determines who is in/out, has power/is powerless?); etc.

Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?
Please be aware that our transdisciplinary research teams accept only challenges that have to be dealt with from different points of view.

Because of the complexity of the urban condition and the entanglement of physical-material, ecological and social-behavioural characteristics of urban place, researchers in the humanities should pair up with architects, designers and geographers, as well as biologists and those involved in studying the effect of spatial, racial or other types of stigma on the health and wellbeing of different urban populations. It is anticipated that making sense of the increasingly complex interrelations between bio-psycho-social conditions and the material-environmental characteristics of local urban places in a globalising context can only be done from a transdisciplinary perspective.

Could you indicate from which disciplines you want a researcher to address this challenge, you need to pick at least one of each group listed below?

Humanities and Social Sciences Group
- ✓ Arts
  Canon Law
- ✓ Economics and Business
- ✓ Law
- ✓ Philosophy
- ✓ Psychology and Educational Sciences
- ✓ Social Sciences
  Theology and Religious Studies
- ✓ Criminology, gender studies
- ✓ Other:

Science, Engineering and Technology Group
- ✓ Architecture
  Bioscience Engineering
  Engineering Science
- ✓ Engineering Technology
- ✓ Sciences
- ✓ Other:

Biology and biodiversity
- ✓ Biomedical Sciences Group
- ✓ Kinesiology and Rehabilitation Sciences
- ✓ Medicine
  Pharmaceutical Sciences
- ✓ Other:

Possible partners, experts and/or other stakeholders to involve in this challenge
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?

How would you like to support the 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:

Potential supporters and stakeholders in this challenge:

University: Jessica Schoffelen. KU Leuven Faculty of Social Sciences, LUCA School of Arts, Social Spaces research group?
Government: City of Leuven?
Industry
Other organisations:
Leuven Mindgate?
Nieuwstedelijk Theatre Company?
Buurtwerking 't Lampeke, local high school STROOM?
https://www.leuven.be/vaartkom

Do you accept the terms and conditions for the proposition of this challenge? (See below)
- ✓ Accept
  Do not Accept

Terms and Conditions.
1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people and planet base on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.
2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame
3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge

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4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.
5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.
6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the "Transdisciplinary Insights Course" based on the Honors program regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access "Transdisciplinary Insights e-Journal". Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the "Transdisciplinary Insights e-Journal" or at a "Transdisciplinary Insights Course"-related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the "Transdisciplinary Insights e-Journal" to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters' names and/or logos will be acknowledged by the "Transdisciplinary Insights e-Journal"
8. "Transdisciplinary Insights Course" reserves the right to change or update these T&Cs from time to time without prior notice to you.
Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: tdi@kuleuven.be

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Supplement 2: Informed Consent (Hannes & Wang, 2020)

Community and a notion of identity are based on reciprocity, giving and receiving, recognising and being recognised. Food serves as a way to connect, as it lends itself to extending beyond transactional relations to social relations. The ways we interact with food – growing, buying, cooking, serving, sharing, eating and wasting – constitute events through which we can encounter the other.
How can we use food as a concept to analyse the way in which place and space facilitate or hinder behaviour which makes a city more inclusive for its inhabitants?

Could anything bad happen from this study? We hope not, but there are a few risks:

- There is a risk that the questions make me uncomfortable, or I may have negative feelings about this project.

What are the good things that could come out of this study?

- You will learn about others' perspectives on inclusivity and reciprocity.
- You will have the opportunity to learn about community-building initiatives.
- At the end of the study, the results will be shared in a publication. You may ask to receive a notification via email.

How will you protect my privacy?

- If you do not want your name mentioned in the study, we will change your name on our records so that you cannot be identified. We will store the research records safely on our computer, in a place that only the researchers can access. We will not share any of your personal information without your permission.

Will the sessions be audio taped?

- In order for us to understand and record your ideas accurately, all sessions will be audio taped. If you do not wish the session to be audio taped, notes will be taken.

Your rights as a study participant:
Everything you do in the study is voluntary. You can leave the study at any time you want. Your decision to leave the study will not affect your relationship with me. You do not have to answer any questions you don't want to. All data and materials collected in relation to you will be destroyed if you ask for it. If you have any questions or concerns about your rights as a study participant, you can contact Prof. Karin Hannes: karin.hannes@kuleuven.be.
The Institute for the Future – KU Leuven, and the Honours Programme Transdisciplinary Insights support this initiative. More info: www.institute-for-the-future.be

Inclusive Cities project: How can we use food as a concept to analyse the way in which place and space facilitate or hinder behaviour which makes a city more inclusive for its inhabitants?
I understand the purpose of this research.
I understand that I will be asked to share information about my community.
I understand the risks and benefits of being involved in this project.
I understand that my voice will be taped during the interview to facilitate analysis, that the tape will be kept private and confidential.
I agree to be audio taped.
I understand that my role in this study is voluntary. I can refuse to answer questions, and I am free to stop participating in this study at any time, although I understand that my participation is vital for the success of this research project.
I feel informed about the research and have had a chance to ask questions. I understand that I may ask questions at any time during the project.
In signing this form, I agree to participate in the research project.

Print Name **Sign Here** **Date**

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Consent for taking and using my picture and interview

I consent to be photographed as part of the Inclusive Cities project.

I know that means my picture might be published to show the results of the study. For instance, my picture may be used in a dissertation, in book chapters, on a website, in journals, as a conference presentation, at a photo exhibition, at a meeting, in all other scientific channels or other not-for-profit public events related to this study.

Print name **Sign here** **Date**

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Supplement 3: Video presentation

Video presented at the symposium KU Leuven Facing the Future (https://rega.kuleuven.be/cev/Symposium/facing-the-future available on: https://kuleuven.mediaspace.kaltura.com/media/Inclusivity+from+an+urban+food_Symposium+-May+2020/1_ddty6rd5

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Supplement 4: Biographies of the authors

Ellen Anthoni is an FWO-funded PhD researcher in the SoMeTHin'K (Social, Methodological & Theoretical Innovation / Kreative) research group at KU Leuven. She is a (pr)academic, partly inside and partly outside of academia. She has experience in the private sector as a trend researcher, youth expert, future fantasiser and art director and is on a mission to build better futures, based on insights in and together with the next generation. Her PhD is about 'the potential of participatory futuring and futures storytelling for change' in which she researches how to shape an urban culture in which citizens take up an active role in sustainable development processes by co-creating and spreading stories of preferable futures through the city.

Amy Casteel is a PhD researcher at the Faculty of Theology and Religious Studies, KU Leuven. She is a member of the Research Unit on Pastoral and Empirical Theology. Previous work among internationally mobile youth and families led to encounters between her systematic theological training and the lived practices of individuals, sparking an academic interest in the intersections of religion, migration, and adolescent development. Amy has focused on making theology practical in life situations through identifying and processing hidden losses as well as celebrating hidden treasures with families and individuals with a migration background. Having lived in five countries at various life stages, her research interests consider various aspects of migration in relation to theology as well as adolescent spiritual development.

Yaren Erol is a degree student of the Master's in Business Engineering at KU Leuven. She completed her Bachelor's in Industrial Engineering at Middle East Technical University (METU) in Ankara, Turkey. She learned about the fundamental forces that are expected to shape industrial engineering in the near future and decided to take action regarding urban sustainability within a framework of engineering and industrial economics. In the Master's programme of Business Engineering, she selected the major of Global Value Chains, New Technologies and Industries enriched with the Corporate Sustainability in order to develop a more socially inspired viewpoint in relation to the global sustainability agenda. Yaren wants to pursue a career in data science. In 2016, Yaren was the Coordinator of the TEDxMETUAnkara Communication directorate.

Kateřina Kubesová is a Sinologist, political scientist and a recent graduate from KU Leuven. Kateřina studied at universities in both Europe and China and is interested in environmental sustainability and urban planning. In her free time, she likes to play tennis and visit art galleries and museums. Kateřina comes from the Czech Republic but currently lives in Brussels with her family.

Joren Ossewaerde is a student from the Netherlands and has been studying in Leuven for two years now. He already graduated from University College Roosevelt in the Netherlands with a Bachelor of Arts and decided to go and study philosophy. This year, he graduates with a thesis about Kierkegaard and euthanasia and will start an educational Master's. His aim is to become a teacher of philosophy at a high school as he really enjoys passing on knowledge and seeing others grow as a result.

Xiaokun Sun is a PhD researcher at the Faculty of Construction and Technology, Bruges Campus, KU Leuven. After obtaining her Master's degree at the University of Southern California with a Graduate Certificate in Architecture and Urbanism and her Bachelor of Engineering in Urban Planning at Beijing Forestry University in China, she worked as an urban planner and landscape architect in China and the US for over seven years. She was engaged in the study of greyfield and brownfield redevelopment and green infrastructure construction, having participated in a lot of post-industrial cities revitalisation planning, encompassing industrial development, urban environment remediation and social life revival. Previous work experience sparked her transdisciplinary interests in urban mining as the principal sustainable method in dealing with construction and demolition waste in urban sustainable development in the context of a circular economy, especially in post-industrial cities.

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Melanie Valencia is an Andean, originally from Ambato, Ecuador. She obtained her Master's in Public Health at Columbia University and her BS in environmental chemistry at Wagner College and is currently pursuing a PhD in circular economy from both economics and material perspectives in the Research Centre for Economics and Corporate Sustainability, Brussels Campus at KU Leuven. Her research focuses on the social determinants of a circular economy and she has been working at the intersection of environmental engineering, climate change and social innovation in Ghana and Ecuador. She was named an MIT Innovator Under 35 in 2016 for her work at CarboCycle, a biotech start-up transforming organic waste into a palm oil substitute. She was one of Project Drawdown's research fellows to estimate the impact of scaling existing solutions to mitigate climate change.

Ningyu Yang was born and raised in China. After graduating with a Bachelor's degree in Business Administration in 2009, she started to pursue her first Master's degree in Management Science at VUB in Brussels in 2010. After graduation, she went back to China and became an editor at a news agency. In 2019, Ningyu went back to Belgium to become a student again and has obtained another Master's degree in Business Economics at KU Leuven in 2020. She is now pursuing a Master's degree in Actuarial and Financial Engineering at KU Leuven. Ningyu attended many extracurricular activities at university. She was a member of the council of the Chinese Students and Scholars Association in Brussels and organised several spring festival galas and seminars in Brussels.

Qingchun Wang recently graduated as a PhD researcher from KU Leuven. She received a scholarship from the China Scholarship Council to conduct research in a Belgian research institute and was long affiliated to the SoMeTHin'K research group of the Faculty of Social Sciences. Her research interest is in the development and application of qualitative research methods. She specialises in visual research methods of a participative nature, more specific photo-elicitation and photovoice projects. She has a keen interest in acculturation processes of international students.

Nico Canoy is Associate Professor at Ateneo de Manilla University in the Department of Psychology. His research work broadly involves thinking with and doing critical theory applied to intersecting areas of health, genders and sexualities, and intimate social relations. Nico has been a visiting fellow at KU Leuven in the context of the Global Minds Programme and co-coached this group of students on the challenge of inclusive environments.

Karin Hannes is Associate Professor at the Faculty of Social Sciences, KU Leuven, and coordinator of the Social, Methodological and Theoretical Innovation research group. The group pushes towards the development of methods and models for positive change in society. Prof. Hannes tests, evaluates, implements, and improves existing methods, techniques, models or d.a.t.a sets generated in fields such as urban development, the public arts, the design and technology sector, community-based research practice and the global sustainable development area. Where necessary, she develops her own innovative methodological approach to respond to emerging social challenges. Her perspective is multimodal in nature, combining numerical, textual, sensory and/or arts-based research d.a.t.a to study complex social phenomena. She works from an inclusive, academic activism perspective.

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TRANSDISCIPLINARY INSIGHTS
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Youngsters' Sustainable Food Choices in the Supermarket

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Abstract

As climate change is gaining recognition and its impacts manifest, the role of the individual is increasingly being investigated. More specifically, the impact consumption has on both the environment and actors throughout the food chain is crucial in this role. Considering the small share sustainable consumption currently has in overall shopping, bridging the gap between unsustainable and sustainable choices will be paramount in addressing the increasing threat climate change and unjust development pose to our society. The attitude–behavior gap is a phenomenon further complicating the issue. It points out that although a person may have an understanding and desire to act upon knowledge that certain products are more sustainable than others, he does not actually act upon that knowledge when shopping. The limited research regarding the attitude–behavior gap, especially for young people, hinders retailers from creating a shopping environment that encourages sustainable shopping. To address this problem, the authors aimed at understanding consumption behavior in a supermarket environment, with special focus on food choices by students. More specifically, we addressed the following question: "How can we overcome the attitude–behavior

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gap for pro-sustainable attitudes in supermarkets?" Our survey-based research amongst 248 students could provide insights for effective interventions – such as education, social programming or in-store modifications – to ensure more sustainable mindsets while grocery shopping. We found that students are not consistently making sustainable choices, despite most having a general understanding of sustainability. Women tend to choose sustainable food more often than men, even though price and quality also had a substantial influence, together with health. We also found that students may consider or even believe in the importance of sustainability and being eco-conscious consumers without actually taking the necessary steps, showing an attitude–behavior gap. Enacting widespread sustainable development will require many small-scale paradigm shifts, such as a local supermarket incorporating more local and seasonal products or fighting food waste. However, climate change mitigation and environmental justice can only be realized by a widespread cooperation of these initiatives.

Key words

Sustainability, attitude–behavior gap, consumer behavior, students, supermarket

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List of supplements

Supplement 1: Original challenge document
Supplement 2: Video presentation

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Supplement 1: Original challenge document

BANK OF TRANSDISCIPLINARY CHALLENGES

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Dear,
Welcome to the Bank of Transdisciplinary Challenges!
This is an initiative where people concerned about the future translate their concern into a scientific challenge. The challenge typically revolves around a specific society, environment, and/or business problem or opportunity that you want to be addressed by a transdisciplinary research team.
Are you concerned about a specific theme or topic for the future?
We invite you to be part of this initiative by filling out this form and sharing your challenge with our academic team and other stakeholders.
We will inform you if your challenge is taken up by our research team, and of any further activities. Hope to hear from you soon.
The Bank of Transdisciplinary Challenges.

SECTION 2 OF 5 Before informing us about your challenge, we would like to know a bit more about you.

Two organizations will take the lead: Vormingplus Oost-Brabant and Rikolto. Here follows a short description:

1.
First Name: Katrien Last Name: Zuallaert
E-mail Address: Katrien.zuallaert@vormingplusob.be
Affiliation:

- ☐ Academia as a Researcher
- ☐ Academia as a Student
- ☐ Government
- ☐ Industry
- ☐ Local Organization
- ☒ Non-profit Organization
- ☐ Society
- ☐ Other:

If you are affiliated to an organization, please fill in its name here:
Vormingplus Oost-Brabant, Paul Van Ostaijenlaan 24, 3001 Heverlee

As one of the 13 regional social-cultural organizations in Flanders we organize educational activities (courses, workshops, excursions, readings, projects, etc.) for adults in their free time. Our main focus lies on sustainability, diversity and public space. Our starting point is to raise awareness and engage people in these wicked issues by approaching the issues as matters of concern.
Whether we like it or not, the world is changing and the old solutions no longer provide us with the answers we need. We strongly believe that change does not bring only uncertainty and fear, but also opportunities. To find new solution

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it is imperative that people connect with each other, that they depict new possibilities and re-invent solutions. Every crisis holds a possible new answer. New models can be built.
Our target market is the citizens of the 30 communities of our region, the district of Louvain. Every citizen is welcome to join our activities, young and older people, academically trained and illiterate, urban citizens and countryside dwellers.

2.
First Name: Liesbeth
Last Name: Van Meulder
E-mail Address: liesbeth.vanmeulder@rikolto.org
Affiliation:

- ☐ Academia as a Researcher
- ☐ Academia as a Student
- ☐ Government
- ☐ Industry
- ☐ Local Organization
- ☒ Non-profit Organization
- ☐ Society
- ☐ Other:

Rikolto, Blijde Inkomsstraat 50, 3000 Leuven

Rikolto is seeking to change the recipe of our food system. Rikolto is an international NGO with more than 40 years' experience in partnering with farmers' organizations and food chain stakeholders across Africa, Asia, Europe and Latin America. Rikolto runs programs in 14 countries worldwide through seven regional offices, among which Belgium. We build bridges of trust and trade between the food industry, governments, research institutions, banks and farmers' organizations around this one central question: "What will we eat tomorrow?" and how will we achieve this – together. We plant and harvest new solutions, making the food system more transparent, so consumers are able to make a sustainable choice.

Would you like to receive updates about this initiative?
YES/NO

SECTION 3 OF 5 – ABOUT YOUR CHALLENGE

ABOUT YOUR CHALLENGE

Title of the Challenge
PRICELESS

Key words (at least 10 words)
Sustainability, consumer behavior, supermarkets, food system, system change, social experiment, alternative business model, products

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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.

There are many niche initiatives that promote alternative food distribution models to enhance sustainable consumption. These impact only a small number of consumers. How can we upscale these interesting examples? How can we influence mainstream actors?
In Belgium we know that the majority of consumers do their grocery shopping in supermarkets. Moreover, supermarkets have a strong position in the food chain: once they draw "the sustainability card", they can influence other chain actors.
→ Supermarkets can leverage sustainable consumption, but how?
What Rikolto has experienced in working with retailers during the last years: they are making efforts to become more sustainable, but not enough, and the efforts are not integrated in their business. Not only is the experience of shopping itself arguably downgraded, but products are ever cheaper and more standardized, in the interest of competition. A mentality shift or change towards a more sustainable business model can be pushed when consumers use their power and give a strong signal. In surveys, citizen-consumers say they *want* to make sustainable choices, but they don't act accordingly. This is called the "attitude–behavior gap": consumers have pro-sustainable attitudes, but they don't translate this during their consumption, because of different constraints: too expensive, too difficult to find, not enough time.
→ How can we overcome this attitude–behavior gap? How can consumers give a strong signal to retailers?
Moving different actors in a more sustainable direction requires multi-stakeholder dialogue and chain-wide collaboration.
→ How can we take up the challenges described in a way that all actors are involved?

Our experiment:
In 2019–2020 Vormingplus Oost-Brabant and Rikolto will develop an educational (action) model that shows the complexity of the sustainability issue for consumers. The idea is to (temporarily) open a new supermarket: "Priceless". Consumers can buy products in the store, but instead of showing the price of the products we give other information (e.g. distance travelled, ecological footprint, amount of water needed, farmer price, seasonality, health index, etc.).
In order to make this experiment as realistic and solid as possible, we want to develop this pop-up store in co-creation with supermarkets, researchers and consumers. Our goal is to try to question the current rules. As a result we want the issue to become a matter of public debate. Therefore we need to collect experiences, visuals and data during the project.
It is key to share and discuss these lessons learned within a steering committee, where the three types of stakeholders are represented. Students of TDI can contribute by research to achieve this by answering following research questions:
– How can citizens stimulate supermarkets to make more sustainable choices?
– Can retailers guide consumers towards more sustainable choices, and what would they need to do? For this we need more insight into consumer behavior.
– Is there a role for other actors from the food system?
– How can we create a multi-stakeholder setting?

The research will be an essential part of the project. Below we describe the preliminary project plan that will be executed by Rikolto and Vormingplus – and which will probably change throughout the implementation process.

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PHASE 1: Collecting partners (April–September 2019)

ACE bank (inspiration)
How did they approach the opening of the bank?
Which tips can they give us?

Inez Lauwagie (coordination)
Rona Kennedy (director)

Supermarkets
Exploratory conversations with (ex)managers, umbrella organizations, ...
Get a view on the aspects of the project they can be involved

Research
Ongoing research on this topics at KUL?
Describe role of TDI

Citizens
Original project call 'take part in our action research'
Collecting 10 participants from the region

Exploratory: conversations with stakeholders

PHASE 2: Preparation processes for the store (September 2019–April 2020)

Communication
Mysterious communication
Opening job offers for manager
Send teasers
Organizing group visits to the store (e.g. classes, neighbors, ...)

Supermarkets
Mapping thresholds to pay attention to sustainability
Exchange views with citizens
Explore possibilities of products and layout of the store

Research
Define challenges with researchers in preparation and execution (e.g. substantiate criteria, social experiment, observation, ...)

Citizens
10 citizens get together 6 times
Action research: own shopping behavior, dreaming about the ideal supermarket, take a look at alternatives, talk to experts, visit supermarket behind the scenes, ...)

Exchange between supermarkets, researchers and citizens

PHASE 3: Priceless (April–June 2020 // September 2020)

Communication
Contacting press for opening store
Attract groups for visits (education?)
Organizing key moment to reveal the goal of Priceless

Supermarkets
Board of advisors

Research
Detailed plan of the approach of the different criteria in the store
Social experiment: How can we measure the effect that the store has on the clients?
Is it meaningful to capture experiences of the people working in the store?

Citizens
Involve citizens to run the store: group that did the action research, students, actors, researchers, ...

The store 'Priceless' opens its doors to the public

PHASE 4: Aftercare (end of 2020)

Communication
Delivering the output in a thoughtful way to the different stakeholders and spreading it throughout different communication channels

Supermarkets
Output: What was the effect of the different criteria on the consuming behavior?
Rikolto includes the results of this experiment in their dialogue with the retail sector with the aim of encouraging supermarkets to facilitate sustainable choices for customers and giving sustainability a central place in their stores

Research
Output: data on sustainability of products
Output: results of social experiment

Citizens
Output: Visualized reactions of visitors
Output: Diary images behind the scenes

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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?

We would like supermarkets to be encouraged to guide consumers towards sustainable choices. That is why we think following objectives might be the focus of preliminary research:
– Gain insight into consumer behavior through realistic experiments. The evidence-based learnings that come out of these experiments can be used to encourage retailers towards making more sustainable choices in their supermarkets.
– Creating scenarios for future stores in which supermarkets, consumers and research all contribute.
– Testing concrete concepts and tools (marketing, business model, etc.) in a setting of a store.

Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?
Please be aware that our transdisciplinary research teams accept only challenges that have to be dealt with from different points of view.

The incredible variety of food on our plates is not to be taken for granted. How can we feed the world in 2050 in a sustainable and healthy way, taking into account the ever-growing world population in a changing climate? We will need a strong, inclusive and stable food sector that can provide affordable food for all, today and tomorrow, and offer value to all actors in the chain. Business as usual will not lead to this sustainable outcome. Our challenge implies a system transformation: we need new rules for our food “game”, new principles for inclusive business models, involving all actors in the market and society.
If we want every actor (consumers, retailers, producers, citizens, governments, etc.) to contribute to this new sustainable food system, we will need transdisciplinary research to support this transition: getting the insights and developing the tools to get ready to meet this challenge!

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:

How can retailers/society overcome the attitude–behavior gap? Citizens would like to consume in a more sustainable way, have positive attitudes towards more environment-friendly products, fair trade, etc. but when they end up in a supermarket, hungry, stressed, thinking of their finances, being influenced by all kinds of advertising, etc., sustainability is the least of their concerns. This is what in literature is called the “attitude–behavior gap”. A consumer is not a rational actor: we don’t always do what we want, because of different reasons (lack of offer, price sensitivity, social normal, lack of information and transparency, emotions, etc.).

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There are many researchers from different domains (sociology, economy, philosophy, psychology, etc.) studying (ethical or sustainable) consumption behavior. Often this is being done in surveys, small pilots or online-experiment settings, where the risk of social bias is large. Our pop-up store is an experiment as well, but will not be positioned as one. Consumers coming to our shop will not know they are participating in an experiment, which makes the research outcomes more trustworthy and raises the chances that conclusions might be adapted or applied in real-life stores.
We ask researchers to think with us on how to set up this experiment, and determine what product aspects/information (besides price of course) can be used to measure consumption behavior, what indicators, etc. Besides this we need researchers to reflect on the question "how can we sensitize consumers, how can we lead them towards a more sustainable consumption? Is it ethically ok if you nudge them or is this not in line with consumer freedom?" Lastly, we can also think about "how will you encourage another eating culture", one where we revalue our food, the environment and the ones that have produced it. Can we de-commodify our food and can this have an impact on our choices in the supermarkets, on the way we eat, on the prices we want to pay?

Domain of Science, Engineering and Technology:

- ☐ Architecture
- ☒ Bioscience Engineering
- ☒ Engineering Science
- ☐ Engineering Technology
- ☐ Sciences
- ☐ Other:

How can we set up an attractive pop-up store? How will we nudge consumers? How will we measure consumer behavior in an innovative way (e.g. using eye tracking technologies)? How will we define the sustainability of the products on our shelves, knowing that there is no 100% transparency in most of the supply chains. And how will we communicate the sustainability aspect to consumers? Should we only use labeled products or should we develop ourselves a sustainability index, knowing that "sustainability" is not a black and white story?
For these questions we need creative people with a scientific background or technical skills: architecture students, (bioscience) engineers.

Domain of Biomedicine:

- ☐ Kinesiology and Rehabilitation Sciences
- ☐ Medicine
- ☐ Pharmaceutical Sciences
- ☒ Other:

Can sustainable food be unhealthy? We don't think so. A sustainable and inclusive food system should give all people worldwide access to sufficient, healthy food. We know that obesity and malnutrition often are two sides of the same coin. How can this health aspect be included in our experiment?

Can we contact you for getting further details of your challenge? **YES**/NO

Do you accept the terms and conditions for the proposition of this challenge? (See below) **YES**/NO

Terms and Conditions
1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people

and planet base on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.
2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame
3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge
4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.
5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.
6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the "Transdisciplinary Insights Course" based on the Honors program regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access "Transdisciplinary Insights e-Journal". Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the "Transdisciplinary Insights e-Journal" or at a "Transdisciplinary Insights Course" -related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the "Transdisciplinary Insights e-Journal" to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters' names and/or logos will be acknowledged by the "Transdisciplinary Insights e-Journal"
8. "Transdisciplinary Insights Course" reserves the right to change or update these T&Cs from time to time without prior notice to you.
Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: jorgericardo.novablanco@kuleuven.be

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
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?

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

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

If you have questions about some parts of the process, please ask them here:

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Supplement 2: Video presentation

Video presented at the Symposium “KU Leuven facing the Future” webinar (https://rega.kuleuven.be/cev/Symposium/facing-the-future), 7 May 2020, 14h15–14h45 Sustainable choices in the supermarket: available on https://kuleuven.mediaspace.kaltura.com/media/SustainableChoices_Vid_Final/1_19q7j05j

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TRANSDISCIPLINARY INSIGHTS
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Training Non-Directiveness? A Transdisciplinary Survey of Medical Students' Perspective Towards Prenatal Counseling and Down Syndrome

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Abstract

The non-invasive prenatal test (NIPT) is a highly sensitive blood analysis tool that allows for the early detection of multiple chromosomal abnormalities, including Down syndrome. Prenatal testing in general and a positive test outcome in particular leave pregnant parents facing difficult ethical decisions and life-changing dilemmas. The language used by medical practitioners in this context has the potential to exert a strong influence on parents in their decision-making process. During counseling, health care professionals (HCPs) are expected to encourage parents to make an informed yet autonomous decision, which hinges on maximally unbiased, clear and consistent communication from the HCP. It is still unclear whether medical students are aware of this importance of unbiased communication, how they perceive the role of HCPs in the prenatal counseling process, and what perspectives they have regarding the disabilities screened for. Our research project aims to address this gap, presenting the results of a transdisciplinary survey completed by 245 medical students at KU Leuven. In particular, the survey investigates:

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(1) the students' view on the ideal prenatal counseling process; (2) their knowledge of NIPT and Down syndrome (the most prevalent disability NIPT screens for); and (3) their general attitudes towards disabilities. Results reveal that more than 50% of medical students do not feel prepared for genetic counseling. The survey further shows a lack of knowledge and some clearly negative attitudes towards life with disability; 20% of medical students agree that a life with Down syndrome should be avoided. Overall, results indicate fairly heterogeneous distribution of knowledge and fairly diverse attitudes of the students, suggesting revisions in the current curriculum might be needed to increase the homogeneity towards counseling and disabilities in the medical student population.

Keywords

Down syndrome, NIPT, KU Leuven, medicine, genetic counseling

Background

1. Introducing NIPT

The journey between the conception and birth of a child is one characterized by questions and insecurities. As a case in point, pregnant parents have various options regarding prenatal testing of their unborn child. In Belgium, a non-invasive combination test was long considered the gold standard, complemented by an invasive amniocentesis or chorionic villus sampling in case the combination test turned out positive. Since 2013 a new test has been rapidly gaining ground: the Non-Invasive Prenatal Test (NIPT). NIPT isolates free fetal DNA in maternal blood collected through a non-invasive blood sample. NIPT is meant to screen for chromosomal abnormalities like the non-viable trisomies 13 and 18 and the viable and more prevalent trisomy 21, better known as Down syndrome (DS).[1] The NIPT test has a sensitivity and specificity between 94.4% and 100% for the chromosomal abnormalities stated above.[2] Since NIPT thus by itself does not reach the desired 100% security to diagnose chromosomal abnormalities, in case of a positive NIPT additional invasive tests will still be performed. The NIPT can be performed from week 12 of the pregnancy onwards; by then enough fetal DNA can be detected in the blood of the mother. In Belgium, the government has tried to make NIPT as widely available as possible by capping its cost at €8.68 for all women who have health insurance in Belgium, whereas the laboratory cost would otherwise be €263.25. The government pushed the reimbursement through in July 2017 and thereby made Belgium the first country in which NIPT is accessible at this scale (Cernat et al. 2019).[3]

2. Ethical concerns

Since NIPT only requires drawing blood from the pregnant woman and does not pose a risk to the fetus, its implementation has revolutionized prenatal screening (Gammon et al. 2016).[4] Nevertheless, the test is accompanied by serious ethical concerns, which have not been sufficiently addressed. A first concern is the mere availability of NIPT: parents-to-be might be left with the impression that they are socially obliged to take the option of prenatal screening, even if they personally would rather not. Medical professionals can exert influence on this choice to proceed to prenatal testing by their language and attitude towards the matter, due to the parents' view on their expertise and authority on the subject. They might (unconsciously) make parents feel that not having prenatal screening might seem irrational or socially "not done". In Belgium, communication on NIPT by health care professionals has not always been a positive experience for all pregnant parents, even though the professionals themselves do not deem their approach to be problematic (see Barilla et al. 2019,

1 "Clinical implementation of NIPT – technical and biological challenges" (Brady et al. 2016), "Current use of noninvasive prenatal testing in Europe, Australia and the USA: A graphical presentation" (Gadsbøll et al. 2020).

2 Numbers from an updated meta-analysis (Gil et al. 2017).

3 "Facilitating informed choice about non-invasive prenatal testing (NIPT): a systematic review and qualitative meta-synthesis of women's experiences" (Cernat et al. 2019).

4 "'I think we've got too many tests!': Prenatal providers' reflections on ethical and clinical challenges in the practice integration of cell-free DNA screening" (Gammon et al. 2016).

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Crombag et al. 2020).[5] Up to 30–40% of women in Belgium are insufficiently informed about NIPT.[6]

The case of a positive NIPT constitutes a second concern, in which the abovementioned ethical dilemmas are even more profound. Given a positive test result, the main question will be whether to continue or to terminate the pregnancy. The latter is legally possible in Belgium, even after the normally applicable period of 12 weeks under the Law on Abortion. Down syndrome can be seen as a fetal condition that is not curable, one of the two exceptions provided for in the law,[7] making termination legally possible until the final days of pregnancy.[8] This stresses the importance of communication by health care professionals: their role is to inform and guide parents to make these life-changing decisions in a way that will minimize the emotional conflict or regret of the parents afterwards.

Counseling by health care professionals that is as unbiased, clear and consistent as possible is thus essential to reach this informed and sustainable decision-making. By counseling, we understand providing information and guidance to parents confronted with life-changing decisions. By sustainable decision-making, we understand the process that leads to a choice by the parents that can stand the test of time and which tries to minimize their emotional conflict or regrets afterwards.[9] Several studies, however, show that there is a tendency towards directive counseling, especially in case of a positive NIPT test (mainly see Crombag et al. 2020).[10]

3. From medical trainee to health care professional

This paper reports on the continuation of the TDI Honours Programme on NIPT and Down syndrome. The 2017–2018 project[11] focused on mapping out the stakeholders and issues involved with NIPT. The 2018–2019 year built on this, organizing a round table with these stakeholders to gauge opinions on the relevant information enabling informed decision-making and stimulating reflection on the part of health professionals and expectant parents.[12] This year (2019–2020), our team has built on these two earlier projects, further scrutinizing the perspective of health care professionals on informed decision-making.

Crombag et al. (2020) showed that there was a firm medical bias in how current doctors counsel NIPT. The medical aspect of the matter is the primary angle from which counseling is approached, the emotional and social elements playing less of a role. We theorized about where this rather technical and medical view stems from, which led us to an earlier stage in their career: as a medical trainee. During their medical training students are educated in genetics, medical conditions of genetic disabilities and communication skills, creating the foundation for genetic counseling in their later career.

In the research project described in the remainder of this paper, a transdisciplinary survey was created targeting medical students at KU Leuven. The survey aims to investigate the perspective of medical students on prenatal screening and disabilities, particularly as concerns: (1) the students' view on the ideal prenatal

5 This was described in a former publication in the framework of this project: "Stimulating Sustainable Decisions in Prenatal Screening" (Barilla et al. 2019). Albeit not representative for the entire Belgian population, the interviews conducted by the team presented several negative experiences with regard to the communication on NIPT. Parents stated that there was not enough information provided, or that it was not comfortable to refuse or that no option to refuse was presented at all. See also: "Receiving the news of Down syndrome in the Era of Prenatal Testing" (Crombag et al. 2020).

6 "A discrepancy between the knowledge about what Down syndrome entails (44.74%) and the knowledge about prenatal testing (65.15%)" (Buyle 2018: 11). Buyle found that age, literacy, socioeconomic situation and the provision of information brochures were factors that influenced women's attitude and knowledge towards prenatal tests and Down syndrome (2018): see "Stimulating Sustainable Decisions in Prenatal Screening" (Barilla et al. 2019: 3).

7 Wet van 15 oktober 2018 betreffende de vrijwillige zwangerschapsafbreking, tot opheffing van de artikelen 350 en 351 van het Strafwetboek, tot wijziging van de artikelen 352 en 383 van hetzelfde Wetboek en tot wijziging van diverse bepalingen, *BS* 29 oktober 2018.

8 The Belgian Law on Abortion prescribes that such a decision can only be taken after a positive advice of two doctors. In case those doctors or other parties concerned do find difficulties in taking a decision, there is the option of asking advice from the ethical commission. This ethical commission is an institution that every hospital in Belgium needs to have by law, as of 27 March 1995. See: Koninklijk besluit van 12 augustus 1994 tot wijziging van het koninklijk besluit van 23 oktober 1964 tot bepaling van de normen die door de ziekenhuizen en hun diensten moeten worden nageleefd, *BS* 27 september 1994.

9 In the literature, this is also called "effectiveness of choices", "positive decisional outcome" or "meaningful decision-making" see: "Stimulating Sustainable Decisions in Prenatal Screening" (Barilla et al. 2019: 2).

10 "Receiving the news of Down syndrome in the Era of Prenatal Testing" (Crombag et al. 2020).

11 "Down to Counsel: Towards a Transdisciplinary Toolbox for Non-directive Counseling in Prenatal Screening for Down Syndrome" (Costan et al. 2018).

12 "Stimulating Sustainable Decisions in Prenatal Screening" (Barilla et al. 2019).

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counseling process; (2) the students' knowledge of NIPT and Down syndrome (the most prevalent disability NIPT screens for); and (3) the students' general attitudes towards disabilities.

Research questions

The general aim of our research was to see whether the medical bias reported for doctors when counseling is already visible in their medical training and to hence identify potential opportunities for the medical training program. Based on the use of a causal loop diagram (see Supplement 1) input from literature, academic and societal stakeholders (cf. infra: method), the group formulated research questions that led to a set of hypotheses, which in turn could be tested through the survey created. In particular, we want to address the following research questions:

1) How do KU Leuven students feel communication of NIPT and its results should be approached?
This first and main research question addresses the perception of prenatal counseling by medical students, who as future doctors might be responsible for counseling later in their career. As will be explained in the method section, we used two scenarios to address this research question, thereby adopting a blank-slate approach. Therefore, we did not formulate a hypothesis and really wanted to see students' uninfluenced and intuitive view on how prenatal counseling, focused on NIPT, should take place.

2) Do KU Leuven medical students have adequate knowledge of NIPT and Down syndrome?
We wanted to see whether KU Leuven medical students have an adequate knowledge of NIPT and Down syndrome. As stated above, a medical bias was found when health care professionals provide prenatal counseling (Crombag et al. 2020). By adequate knowledge, we thus do not mean mere medical knowledge about NIPT or Down syndrome, but also knowledge of non-medical aspects, such as societal, educational, psychological, financial or emotional aspects. This concept of adequate knowledge was partly founded on the input we got from the – mainly societal – stakeholders that have been included in the development of this transdisciplinary project since 2017. We hypothesize that medical students would have better knowledge about NIPT than about Down syndrome, since knowledge about NIPT is more related to the medical aspect, as opposed to the life with disability aspect represented by Down syndrome.

3) What are the attitudes of KU Leuven medical students towards people with disabilities and towards prenatal counseling?
We wanted to assess the attitudes KU Leuven medical students could potentially have towards people with disabilities. The questions aimed at investigating the level of equality students feel with people with disabilities, in terms of abilities and quality of life. We hypothesized that the results on these questions might show a degree of heterogeneity. We also included questions on whether students consider a neutral way of counseling to be possible and expedient, to acquire results on their attitudes on counseling on NIPT as well. We considered asking these questions to be useful since students' attitudes might exert an influence on their opinion on how counseling should be done in general and especially on how they would do it themselves.

4) Does the sociodemographic background of KU Leuven medical students have an influence on their attitude and/or knowledge, thereby influencing their ability to provide counsel in a non-biased way?
The last questions targeted the sociodemographic background of KU Leuven medical students. We asked them about their age, gender, phase of training (Bachelor's/Master's) and whether they knew someone with Down syndrome. Since we were only going to send the survey out to KU Leuven medical students, we initially hypothesized that the results would show no clear effect of age, gender or phase in training. Nevertheless, taking the general aim of our research into account, we included these sociodemographic questions to see whether students' sociodemographic background could have any possible effects on their knowledge of and attitude towards NIPT and life with disabilities. An additional hypothesis is therefore that people who know someone with Down syndrome will probably have better knowledge of and a different attitude towards Down syndrome than those who do not know someone with Down syndrome.

Method

For our research project we decided to construct a transdisciplinary survey, based on three types of input:

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input from (i) a literature study; (ii) academic and societal stakeholders; and (iii) a semi-structured interview with a pair of students. We chose to build a survey for our project, since we considered this medium the most appropriate way to reach out to the medical students and gather as many answers as possible and to hence arrive at a bird's eye perspective on medical students' knowledge of and attitude towards prenatal screening and disability. This decision was backed by our stakeholders.[13] The approach to the survey was transdisciplinary, since we aimed to co-create knowledge among different stakeholders, all of whom brought their own experience into the project (Dehens et al. 2017).[14] The survey itself was intended to ask KU Leuven medical students questions about three aspects: their view on how communication on NIPT and its results should be approached (RQ1), their knowledge, whether adequate or not, on NIPT and Down syndrome (RQ2) and their attitudes towards people with disabilities and prenatal counseling (RQ3). Additionally, in order to answer RQ4, the survey included questions on the sociodemographic background of the respondent. In the remainder of this section, we first describe the input that delivered the building blocks for our survey. In a second part, the creation of the survey itself will be dealt with, followed by a description of our sample and finally a brief explanation of the types of analysis we conducted on our results.

1. Input

The first source of input, the literature study, consisted mainly of studies reporting results from surveys on people's attitudes towards people with disabilities, to gain an insight into the different scales and instruments used to measure those attitudes. The other part of the literature study was about NIPT itself, what it screens for and the way pregnant women experience the existence, availability of and communication about NIPT and its results.

Second, we consulted both societal and academic stakeholders in designing the survey structure and formulating specific questions. We also built on insights derived through stakeholder contact in the first two years of this project (see Costan et al. 2018, Barilla et al. 2019). As for our own contacts with societal stakeholders, we consulted Fara vzw, a Belgian organization specialized in prenatal counseling.[15] During an interview conducted on 11 February 2020, they provided us with advice regarding the content and type of questions and how we could ask them in our survey. Fara vzw also encouraged us to make use of a focus group to consult on themes students themselves feel are important in the debate on NIPT and prenatal counseling. Additionally, e-mails were sent out to the other societal stakeholders that have been part of the project since 2017, including a pediatrician (for the perspective of a health care professional specializing in children), Down Syndrome Flanders (for the societal perspective on Down syndrome) and the management of VBOV (which is the professional organization of Flemish midwives). The responses were rather limited; either we received no answer at all, or people only offered limited new information compared to their previous input or gave general answers to the question about what they would want to ask future doctors concerning counseling practices. We therefore mainly based ourselves on the input gained from Fara vzw as to societal stakeholders.

In addition to the societal stakeholders, we consulted academic stakeholders from various disciplines. We interviewed Professor L. De Catte (gynecology, KU Leuven/UZ Leuven), who provided us mainly with information about the medical aspects. Apart from Professor De Catte, we asked C. Van Audenhove, Professor at the department of social health care, who teaches classes in psychology in the medical training program and is director of LUCAS (KU Leuven/LUCAS) and Professor E. Claes, working at the Centre for Political Science Research (KU Leuven, Faculty of Social Sciences) for methodological input on how to construct the survey.

The last source of input was the semi-structured interview with a pair of third-year Bachelor's students from the medical program. We initially invited four of them for a meeting, but due to practical impediments two students cancelled at the last minute. Nevertheless, the two other students provided us with valuable information about the relevance of the questions we already

13 See also: "Evaluation of nursing and medical students' attitudes towards people with disabilities" (Sahin et al. 2010).

14 "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" (Dehens et al. 2017).

15 Fara guides expectant parents through three main questions when it comes to prenatal counseling, namely: whether to take prenatal screening or not, whether to take diagnostic tests or not and what to do if there is something wrong. Their carry out four values in the field of prenatal counseling: understanding, trust, accessibility and commitment.

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had in mind for the survey. We presented them with those questions we had designed to try to answer our research questions. We informed ourselves about their attitude towards NIPT and Down syndrome and their knowledge on those two subjects by presenting them a scenario about counseling. Depending on their answers to our prepared questions, we asked additional questions to go further and deeper into a specific issue. We did this in order to gain better insight into how our questions might be interpreted by students, which sometimes could be different than originally intended. This way we could test our questions before sending them out to the whole group of KU Leuven medical students. They further helped us with determining an academic background and showed a willingness to share their personal opinions.

2. Survey components

The final survey, constructed with the online tool QuestionPro, consisted of four main blocks: a first block that concerned general and sociodemographic information, which was in its turn split into two parts; the general questions were included at the start of the survey, and the sociodemographic questions were kept for last. The second block consisted of two scenarios, aimed at uncovering the uninfluenced view of students on counseling on prenatal screening. The third and fourth blocks of the survey dealt with knowledge about NIPT and Down syndrome and attitudes towards prenatal counseling and people with disabilities respectively. Those questions on attitudes towards people with disabilities were formulated as questions on attitude towards Down syndrome, since this is the most prevalent disability NIPT screens for. We only used a validated questionnaire[16] for those questions in block four and designed the questions for the other blocks ourselves, a choice we will justify for each block of questions.

In general, we designed the survey in such a way as to avoid directiveness. Therefore, the scenarios came directly after the general questions, since here we were looking for students' uninfluenced and intuitive view on prenatal counseling, focused on NIPT. The blank-slate approach we had in mind would not be achieved to the fullest if we had put other questions before the scenarios, since students might have been influenced by the mere reading of the knowledge or attitude questions. Below, we describe the content of the different blocks of the survey, a PDF version of which can be found in Supplement 2.

As mentioned, the first set of questions was aimed at obtaining general information from the students with questions about their age, gender and what phase of their medical training they were currently in. Another question asked about what type of furtherance they had in mind for their medical education, so as to know more about their field of medical interest (which might result in some of them knowing more about prenatal screening, NIPT or Down syndrome than others).

The second block consisted of the two scenarios (see Supplement 2) aimed at answering the first research question on students' view on how NIPT and its results should be approached (RQ1). The use of scenarios in the survey created the opportunity to analyze a survey-respondent's bias instead of assessing the knowledge required for counseling. The first one described a woman of 29 years old, Laura, who was in the sixth week of her first pregnancy and for whom it was her first consultation. The students were asked to briefly explain their perspective on counseling on prenatal screening and what they consider to be important in this process. The question was an open-answer type of question, divided into three parts: who should provide counseling, when and how should this be done? The second scenario dealt with the situation in which Laura came back to hear the result of her NIPT, which turned out to be positive for Down syndrome. Students were asked the same open-answer questions as with the first scenario. Even though open-answer questions are rather difficult to work with, we were of the opinion that this would be the best and most direct way to gain an insight into how KU Leuven medical students feel communication on NIPT and Down syndrome should be approached. One of our academic stakeholders, Professor E. Claes, supported this view.

The third block of the survey concerned the knowledge of students about NIPT and Down syndrome, thereby trying to find an answer to the second research question about adequate knowledge (RQ2). Each topic had separate questions dedicated to it. Since the knowledge sought after in this research question is *adequate* knowledge, the questions can be distinguished as "medical"

16 "Wa ne mongool, een experimenteel onderzoek naar offensive advertising 'for the better good'" (Nowicki 2018: 50 and accompanying supplement 8, 13–14), which edited the questions into Dutch from "Classical and modern prejudice: Attitudes toward people with intellectual disabilities" (Akrima et al. 2006: 605–17).

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and "non-medical". By "medical" questions we mean questions that test the knowledge on medical aspects of NIPT and Down syndrome. The non-medical questions on the other hand aim at non-medical aspects, e.g. societal, financial, psychological, educational or emotional aspects. As explained under the second research question, we consider adequate knowledge to contain both types of knowledge, medical and non-medical.

The format of the questions ranged from multiple-choice questions to questions equipped with a sliding scale. Since we intended to send the survey to medical students ranging from first year Bachelor's to Master's students, we were aware of the risk that some of the questions could be rather difficult for some of the students. Therefore, we inserted an "I don't know" option as a possible answer in these knowledge questions.[17]

The fourth block of questions asked students about their attitudes towards counseling and towards people with disabilities, with a focus on people with Down syndrome. These questions aim at providing an answer to the third research question (RQ3). We measured students' attitude towards people with Down syndrome using a validated questionnaire. They had to answer 12 questions, using a 7-point Likert scale, ranging from "totally disagree" to "totally agree".[18]

The last set of sociodemographic questions were part of the first block of questions together with the general questions at the beginning of the survey. They were needed to address the last research question (RQ4). We asked the students whether they knew people with Down syndrome and if so, what place in their lives those people had.

3. Respondents

As mentioned earlier, the survey was sent to all KU Leuven Bachelor's and Master's medical students (9410 students in total) between 7 and 14 April 2020. A total of 245 students (2.6%) completed the survey.[19] The sample showed a fairly homogeneous distribution across phases in training, with 81 Bachelor's students and 163 Master's students. One student, who was already in a further phase of medical training, was excluded from our analysis when comparing answers in function of phase of training, since considering him as a distinct category would lead to irrelevant results. Our sample includes 55 male students and 190 female students. To further grasp the particular background of our respondents, we asked them whether they knew people with Down syndrome in their near environment, a question 34 students answered positively, 206 negatively (5 not providing an answer).

4. Analyses

For each block of questions dedicated to one of the research questions above, we analyzed the results of the survey as follows: for the first research question (RQ1) for which we used the two scenarios, we conducted a qualitative thematic analysis. Results for the questions devoted to the second and third research questions (RQ2+3) were analyzed using descriptive statistics, basic quantifications and cross tabulations with regard to the other blocks of questions. For the fourth research question (RQ4) concerning the sociodemographic situation (gender, knowing people with Down syndrome, Bachelor's or Master's students) we looked for its possible effects on each of the former questions. Here we used inferential statistics (Chi^2, t-test, ANOVA) where relevant and appropriate. In the following description of the results, these possible effects will only be mentioned in so far as they showed relevant differences.

Results

1. Scenarios

In the first scenario question, which described a first consult with a 29-year-old, six weeks pregnant woman, students were asked to briefly describe by whom, when and how they thought counseling on NIPT should take place. Their answers were subject to a qualitative thematic analysis, of which the results of the answers to *who* should counsel*, when* this should happen and *how* will each be explained in the following paragraphs. Table 1 summarizes the results:

A total of 73.06% of the students answered that they consider a gynecologist as the one who should counsel, while 36.73% preferred a general practitioner. Those

17 Due to the program we used, the questions with a slider bar, which also had an "I don't know" option, needed to be two questions for technical reasons. In this way, students could choose the "I don't know" option and answer with the slider bar in the same question. We therefore decided that for the analysis of the results, the answer of those students on the slider bar would not be taken into account.

18 Nowicki 2018: 50 and supplement 8, 13–14, which edited the questions into Dutch from "Classical and modern prejudice: Attitudes toward people with intellectual disabilities" (Akrima et al. 2006: 605–17).

19 The survey was sent out during the Covid-19 pandemic, which might have had an influence on the number of respondents.

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Table 1. Results of scenarios 1 and 2

Scenario 1	Most freq. answer	N	%	2nd most freq. answer	N	%	3rd most freq. answer	N	%
By whom	gynecologist	179	73.06	general practitioner	90	36.73	doctor	17	6.94
When	6-12 weeks	131	53.47	first consultation	67	27.35	other	20	8.16
How	giving info	212	86.53	explaining NIPT	30	12.24	NA	NA	NA
Medium	brochure	16	6.53	website	3	1.22	referral	3	1.22
Content	practicals of NIPT	105	42.86	pro/cons/risk NIPT	82	33.47	NIPT is not obligatory	58	23.67

Scenario 2	Most freq. answer	N	%	2nd most freq. answer	N	%	3rd most freq. answer	N	%
By whom	gynecologist	197	80.41	guiding doctor	105	42.86	clinical geneticist	30	12.24
When	as soon as possible	211	86.12	NA	NA	NA	NA	NA	NA
How	giving info	211	86.12	explaining result	198	80.82	explaining options	129	52.65

two percentages show an overlap, since 19.59% of the students indicated both a gynecologist and general practitioner. Master's students tended to choose a gynecologist more (n=135, or 82.32%) than a general practitioner (n=59, or 35.98%) when compared to Bachelor's students (gynecologist: n=44, or 54.32% and general practitioner: n=31, or 38.27%). Only 2.45% of the students in our sample were of the opinion that a midwife instead of a doctor should provide counseling. Women named gynecologists more often than men did: 75.26% (n=143) of the women mentioned gynecologists, as opposed to 65.45% (n=36) of the men.

On the question *when* prenatal counselling on the NIPT should ideally take place, students provided different answers, the vast majority of which (n=230, or 93.88%) can be located in the range between six to 12 weeks, viz. when the first consult is typically planned. Where some students provided a specific point in this six to 12-week period (example A), others referred to a period within the range (example B). The more abstract answers to the question were also interpreted as part of the six to 12-week period (example C).

Examples of when students think counseling should take place:

A) "Na 8 weken" (=At 8 weeks) or "Tijdens het eerste consult" (=During the first consult)
B) "Tussen 6–8 weken" (=Between 6 and 8 weeks)
C) "Zo vroeg mogelijk" (=As early as possible)
D) "Voor de NIPT" (=Before the NIPT)

The answer "before NIPT" (example D) was also considered to fall within six and 12 weeks, since NIPT is only possible from week 10 of the pregnancy. This could hint at an ethical consideration in the answer: by saying counseling should be done before NIPT is taken, students might consider this counseling to be necessary before proceeding to testing. This was however not made explicit by students in their answers.

As concerns *how* counseling on NIPT should be done, 86% of the students (n=212) mentioned they would provide general information on NIPT (example E) while 12% (n=30) would explain only the way NIPT works. Only one student would immediately refer the expectant parents to "Centrum voor menselijke erfelijkheid UZ Leuven" (Centre for Human Genetics UZ Leuven), without giving information. Many students did not specify the exact way in which they would provide information but highlighted specific topics they would address such as the method used for NIPT (42.86%, n=105, example F), explaining the advantages and disadvantages of NIPT (33.47%, n=82, example G), the fact that NIPT is not a compulsory test (23.67%, n=58, example H), discussing the possible outcome of the test and the accompanying options (19.68%, n=49 example I). Only 3.67% mentioned the financial aspect of taking a NIPT (n=9, example J).

Examples of specific topics students would include when counseling in scenario 1:

E) "Informatief" (=Informing)
F) "Uitleg dat niet invasief is. Opsporing van mogelijke chromosomale afwijkingen. Bloedafname." (=Explanation about NIPT not being invasive. Detection of possible chromosomal abnormalities. Blood sample.)
G) "Neutraal enkel aanbrengen dat die bestaat en wat de voor en nadelen zijn." (=Mentioning in a neutral way that NIPT exists and what its advantages and disadvantages are.)

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H) "Bedoeling van de NIPT test, gevolgen van een positieve NIPT test, risico's verbonden aan een NIPT test, kans op vals positief resultaat. Nadruk dat niet verplicht is, maar eigen keus." (=Aim of NIPT, consequences of a positive NIPT, risks attached to a NIPT, chances of false positives. Emphasis on fact that it is not obligatory, but a choice.)
I) "Waarom getest wordt, welke bevindingen er kunnen zijn, vals negatief en positief, implicaties van de bevindingen en bespreken wat patiënt hier mee zou doen." (=Why test is done, which findings can be made, falsely positive or negative, discussing of the implications of findings and what patient would do with those findings.)
J) "Algemene uitleg over de opties van de test, wat er getest kan worden, terugbetaling…" (=General information on possibilities of the test, what is tested for, reimbursement…)

The second scenario follows up on the previous one and followed the same approach, asking students to provide information on who, when and how counseling should take place. In this follow-up scenario, a positive NIPT result had to be communicated. The following paragraphs give an overview of the differences in answers compared to scenario 1.

In this case, 80% (n=197) of the students are of the opinion that a gynecologist should be the one providing counseling and 43% (n=105) mention the general practitioner. In Table 1, one can see an increase with regard to the gynecologist and the clinical geneticist. In scenario 1, only 1.63% (n=4) mention the clinical geneticist, compared to 12% (n=30) in scenario 2. With regard to when counseling should take place, students' answers generally tended towards "as soon as possible".

Probably given the fact that this second scenario includes unexpected news (positive NIPT), 29% (n=71) of our respondents would leave room for emotional support, an element not mentioned in scenario 1 (example K). This finding was only to a small extent supported by answers about who should provide counseling: 7% of the students in our sample (n=17) mentioned a psychologist, while no one did in scenario 1 (example L).

Concerning how counseling should take place, we further found that 86.12% (n=211) of the students would provide general information, which for 80.82% (n=198) would entail explaining that the result means a high probability that the unborn child will have Down syndrome. 52.65% (n=129) of the students in our sample would also include information about further options for the parents (e.g. additional testing or possible termination of the pregnancy) (example N). Of the abovementioned 211 respondents, 179 were female and 32 male students. All of the Master's students in our sample (n=163) would provide the abovementioned general information, as opposed to 78% (n=47) of the Bachelor's students. Remarkably, only one out of three respondents mention they would provide information on Down syndrome (example M). Only 21 students would schedule a follow-up consult with the parents for further guidance. Further, financial and legal aspects concerning life with a child with a disability were only included by 1% (n=2) of the students (example O).

Examples of elements students would include when counseling in scenario 2:

K) Informeren over betekenis van resultaat, mogelijkheden, luisteren naar zorgen en gevoelens patient, verdere mogelijkheden. (=Informing about the meaning of the result, possibilities, having attention for patient's concerns and emotions, further options.)
L) "…eventueel doorverwijzen naar de psycholoog…" (=…possibly referral to psychologist…)
M) Info geven over wat het syndroom van Down inhoudt voor het kind en voor de ouders. (=Providing information about what Down syndrome means for the child and the parents.)
N) Aangeven dat er een mogelijkheid is tot zwangerschapsbeëindiging maar patiënt vrij laten hierin te kiezen. (=Indicating that there is an option to terminate the pregnancy but leaving the choice about it to the patient.)
O) "Eerst uitleggen wat een positieve test betekent (niet per se correct), wat de mogelijke opties zijn voor de toekomst (niets doen, vroegtijdig stoppen zwangerschap, extra tests doen,…), Wat deze opties zouden betekenen voor het koppel (kosten, emotionele kosten, bijstand,…)" (=First explaining what a positive test results means (not per se correct), what are the possible options regarding the future (not doing anything, termination of the pregnancy, additional testing,…), what those options would entail for the couple (costs, emotional costs, support,…)

Whereas for the above results, students' answers were mainly concerned with the content of the counseling, only 9% (n=22) of the students explicitly mentioned the medium they would use for counseling. These

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Table 2. Knowledge about NIPT and Down syndrome

Knowledge about Down syndrome	correct answer		false answer		don't know		NA	
	N	%	N	%	N	%	N	%
What does NIPT screen for in the fetus?	181	75.1	49	20.3	11	4.6	0	0.0
A positive NIPT means the child has Down	218	90.5	13	5.4	10	4.1	0	0.0
Until when can you legally abort a pregnancy of a child with Down syndrome in Belgium?	20	8.3	221	91.7	0	0.0	0	0.0
Down syndrome is hereditary	170	70.6	55	22.8	16	6.6	0	0.0
In Belgium, parents with a child with Down syndrome receive financial support from the government	123	51.0	6	2.5	112	46.5	0	0.0
On average, when does a child with Down syndrome learn to walk?	72	29.9	124	51.4	39	16.2	6	2.5
What is the average IQ of a young adult with Down syndrome?	95	39.4	79	32.8	67	27.8	0	0.0
What is the average life expectancy of a person with Down syndrome?	95	39.4	104	43.2	37	15.3	5	2.1

respondents would provide parents with brochures or flyers containing information on further steps or on Down syndrome during this consult.

2. Knowledge

As explained in the method section, we consider knowledge to be broader than mere knowledge of medical aspects. Therefore, we made the abovementioned distinction between "medical" and "non-medical" questions. The results show that answers to medical questions on NIPT and Down syndrome were answered better than non-medical questions (see Table 2). This corresponds with our hypothesis made under research question 2, viz. that medical students are overall not very aware of the non-medical aspects (e.g. societal, financial, psychological, emotional, educational aspects) of living with a disability. Below, we first present the questions aiming for medical knowledge, followed by the results of the non-medical questions.

When asked what NIPT screens for with regard to the fetus, 75.1% (n=181) of the students answered correctly. To the question whether a positive NIPT means that a child will definitely have Down syndrome, 90.5% (n=218) of the students provided a correct answer. 70.5% (n=170) of the students knew the answer on whether Down syndrome is hereditary and remarkably second year Bachelor's students scored best on this question: 82.61% of them were right.

Concerning the health risks people with Down syndrome are possibly faced with, 87.35% (n=214) of the students indicated cardiovascular risks, 69.80% (n=171) obesity, 66.94% (n=164) growth problems and 57.55% (n=141) being visually impaired. The two conditions in the list that were not associated with Down syndrome, were effectively selected the least, being hemophilia and ALS, which were selected by respectively 3.67% (n=9) and 2.45% (n=6) of the students.

Concerning the non-medical questions on NIPT and Down syndrome, the students in our sample generally scored less on these compared to the medical questions. Rather than providing incorrect results, students typically indicated that they did not know the answer. For example, where the option "I don't know" was selected by only 6.6% (n=16) of respondents to the medical question on Down syndrome being hereditary, almost half of respondents (being 46.5%, n=112) indicated that they did not know the answer to the non-medical question on child benefits. Of the students who did answer the question, only 51.04% selected the correct option.

For the results of the question on the average IQ of people with Down syndrome, we found the mean to be 66, with a standard deviation of 17.2. If we consider answers between 39 and 69 to be correct, we found that 39.42% (n=95) of the students answered correctly.[20] Among these answers, there was a remarkable difference between female (43.16% correct answers,

20 Mégarbané et al. 2013.

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n=82) and male students (27.27% correct answers, n=15).

Delays in motor skills are typical in children with Down syndrome, in part due to lower muscle tone (Galli et al. 2008). We asked students when children with Down syndrome usually learn to walk. The mean answer is 20.8 months: it seems students are aware of the delay, but that they slightly underestimate it. For the question on the average life expectancy of someone with Down syndrome, 39.42% (n=95) students in our sample answered correctly that the average life expectancy was between 50 and 60 years old (Diamandopoulos et al. 2018).

Finally, only 8.30% of the students of our sample knew the exact legal time period within which an abortion was possible in case of a fetus Down syndrome, which is unlimited in Belgium, since it is considered to be for "serious medical reasons".[21] Bachelor's students mostly indicated an abortion to be possible until 12 weeks (41.03%/ n=32); Master's students answered it to be possible until 24 weeks (42.94%/n=70).

3. Attitude

In this final section, we describe the results for students' views on counseling, their opinion on whether life with Down syndrome should be avoided (see Table 3) and their general attitudes towards life with disabilities.

With regard to students' attitude towards counseling and its modalities, we first asked whether they think that a doctor providing counseling should be aware of the quality of life of people with Down syndrome and the possible support they can get. 98.8% (n=238) of the students considered this to be necessary (including all students that know someone with Down syndrome). According to the students in our sample, a doctor's role while counseling should be guiding (84.2%) and/ or informing (77.6%), rather than advising (24.1%) and/or coaching (14.9%). When asked whether neutral counseling is possible, 46.9% (n=113) of the students of our sample thought this to be the case (always/mostly). Furthermore, nearly three out of four (73.4%, 177) of respondents considered neutral counseling to be desirable. When asked whether they themselves feel prepared to counsel, 57.3% of our students do *not* feel prepared to do so. No significant differences were found between Bachelor's and Master's students.

We also asked respondents to rank eight subjects, according to the importance they would attach to them (1: most important – 8: least important) when counseling parents who have just received the news of a positive NIPT (see Table 4).[22] Medical information comes first (mean=1.3655 and standard deviation=0.8840), followed by social information (mean=3.1754 and standard deviation=1.6244) and organizations providing aid on the third place (mean=3.8578 and standard deviation=1.7262). Information on the job opportunities for people with Down syndrome was seen as least important (mean=6.4308 and standard deviation=1.6481).

Respondents' attitudes towards life with disabilities (focus on Down syndrome, the most prevalent disability NIPT screens for) as measured with the questionnaire by Akrima et al. (2006), following the translation provided by Nowicki (2018), were fairly positive, with a mean of 4.727 on a 7-point scale and standard deviation of 0.52.[23] No significant differences were found across groups (viz. Bachelor's vs. Master's, male vs. female, respondents with or without an acquaintance with Down syndrome). We also found that 20.32% (n=49) of our respondents were of the opinion that life with Down syndrome should be avoided, and 17.8% (n=43) voiced no opinion on the matter.

Regarding the two aforementioned results, we wanted to know whether there is a correlation between the student's score on the attitude scale and their response to the question whether a life with Down syndrome is better avoided. First, we divided the answers to the question whether life with Down should be avoided into three categories, i.e. "Should be avoided", "Neutral" and "Should not be avoided", and plotted them against mean scores for the attitude scale (Figure 1). We compared the mean attitude scores across the three

21 Wet van 15 oktober 2018 betreffende de vrijwillige zwangerschapsafbreking, tot opheffing van de artikelen 350 en 351 van het Strafwetboek, tot wijziging van de artikelen 352 en 383 van hetzelfde Wetboek en tot wijziging van diverse bepalingen, *BS* 29 oktober 2018.

22 The question was as follows: "Rangschik de volgende onderwerpen van belangrijk naar minder belangrijk, als jij, als dokter, ouders counselt met een positieve NIPT voor het syndroom van Down. Zaken die voor u minder relevant lijken, hoeft u niet te rangschikken" (=Rank the following subjects ranging from important to less important, when you, as a doctor, would provide counseling to parents who received a positive NIPT for Down syndrome. Subjects you do not consider to be relevant, you don't have to rank). The eight subjects were: job opportunities, financial information (impact, subsidies…), average life expectancy, help organizations, options with regard to education, medical information, testimonies and social information.

23 Cronbach's alpha reveals a consistent scale (0.70), so the mean scale scores were calculated for each respondent.

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Table 3. Attitudes towards prenatal counseling and whether life with Down syndrome should be avoided

3.1 awareness	yes		no		don't know	
	N	%	N	%	N	%
Do you think doctors who counsel should be aware of the support for and quality of life of people with Down syndrome?	238	98.8	1	0.40	2	0.80

3.2 role adopted	selected	
	N	%
During counseling, the doctor should adopt a guiding role	203	84.2
During counseling, the doctor should adopt an advising role	58	24.1
During counseling, the doctor should adopt an informative role	187	77.6
During counseling, the doctor should adopt a coaching role	36	14.9

3.3 neutral counseling	yes, always		mostly, yes		depends on situation		mostly not		never	
	N	%	N	%	N	%	N	%	N	%
Do you believe neutral counseling is possible?	9	3.7	104	43.2	84	34.9	39	16.2	5	2.0
Do you think neutral counseling is desirable?	81	33.6	96	39.8	47	19.5	17	7.1	0	0.0

3.4 final responsibility	M
Where lies the final responsibility regarding the continuation of the pregnancy? (1=doctor; 10=parents)	8.86

3.5 readiness	fully agree		agree		slightly agree		neutral		slightly disagree		disagree		fully disagree	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
I feel ready to counsel	3	1.2	30	12.4	55	22.8	15	6.2	56	23.2	66	27.4	16	6.6
All pregnant women should take the NIPT test	8	3.3	24	10.0	37	15.4	16	6.6	38	15.8	72	29.9	46	19.1
A life with Down syndrome is best to be avoided	3	1.2	13	5.4	33	13.7	43	17.8	35	14.5	71	29.5	43	17.8

Table 4. Average ranking position of information when counseling in case of positive NIPT

	M rank
Medical	1.37
Life expectancy	4.28
Testimonials	4.73
Social info	3.18
Financial info	4.48
Educational info	4.92
Info on jobs	6.43
Help organizations	3.86

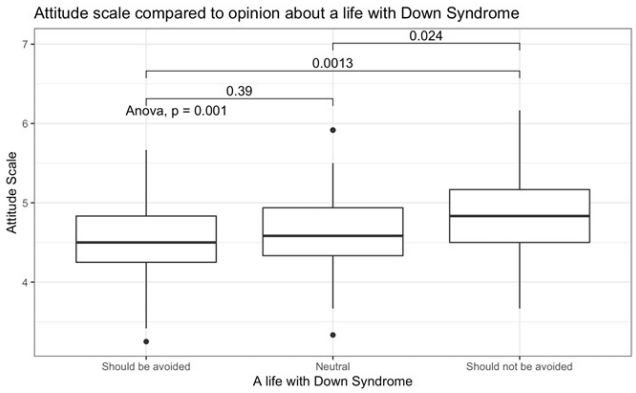

Figure 1. Comparison of score on the attitude scale in relation to opinion of life with Down syndrome

conditions using ANOVA. We observe a significant (p-value=0.001) decrease in the mean score on the attitude scale for students who answered that a life with Down syndrome is better avoided compared to their colleagues who did not agree. Additionally, we also observed a significant (p-value=0.02) decrease in the mean score on the attitude scale for students who were neutral to this statement. Finally, we did not observe a difference (p-value=0.39) in attitude score between the students who replied "Should be avoided" and those who were neutral.[24]

24 To corroborate the result, we also performed a Spearman correlation test on the Attitude scale and the 7-point answer on the question "A life with Down syndrome is best avoided". We obtained a significant negative correlation (p <0.0001, rho=–0.27).

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Discussion and conclusion

The results presented above help us investigate the three main aspects this paper wants to address: KU Leuven medical students' view on how communication on NIPT and its results should be approached (RQ1), their knowledge, whether adequate or not, of NIPT and Down syndrome (RQ2), and their attitudes towards people with disabilities and prenatal counseling (RQ3). Additionally, in order to answer RQ4, the survey included questions on the sociodemographic background of the respondents. As such, our overall aim was to assess whether the medical bias in genetic counseling reported for doctors (Costan et al. 2020) is already visible at an early stage in their medical career and to hence identify potential opportunities for the medical training program.

1. Addressing the research questions

Concerning the first research question, "How do KU Leuven students feel communication of NIPT and its results should be approached?", we found that most students think that a gynecologist or general practitioner should counsel, as soon as possible (both for NIPT in general and in case of a positive result). The students in our sample did not describe concretely how exactly they would counsel, but rather provided elements they would include. Particularly striking is the lack of attention in students' open answers to information on the condition that is being screened for itself. Also, financial aspects were mentioned by only 2 students, out of a sample of 245.

Students' answers to the two scenarios showed a fairly monodisciplinary view on prenatal counseling. (Even if we would consider their answers to indicate a multidisciplinary view, it would only be the case among fellow medical students who also highlight a medical perspective.) For instance, only 7% of the students in our sample (n=17) mentioned a psychologist when answering who should counsel in scenario 2, while no one did in scenario 1. Attention to organizations who have relevant information on Down syndrome and living with a child with a disability is virtually absent, as are the psychological implications of terminating a pregnancy. One could hypothesize that students do not include these elements because they consciously consider them not to be important for the expectant parents' decision-making process. On the other hand, the opposite might also be plausible: students' simple unawareness of the influence of certain elements on the decision-making, thereby forgetting them. Financial aspects, for example, students placed rather low in the abovementioned ranking question concerning the importance attached to different subjects while counseling (see section 3, Attitude, in the results section). Either way, a more transdisciplinary view that includes psychological and societal aspects on counselling might reduce the level of nudging and directiveness, leading to more independent and sustainable choices on the part of the future parents (Barilla et al. 2019).

For the second research question, "Do KU Leuven medical students have adequate knowledge of NIPT and Down syndrome?", results showed that KU Leuven students generally seem to have adequate knowledge on medical information about Down syndrome. Concerning the non-medical questions, more students indicated they did not know the answer or scored lower than on the medical questions. When comparing these findings with students' view on the knowledge a doctor should have while counseling, the result is paradoxical: almost all students indicated that a doctor should know about the quality of life of people with Down syndrome and the possible support they can get, but they themselves as future doctors do not have that particular knowledge (yet). In addition to that, they do not mention it as something that should be discussed when asked how they would counsel either.

For the third research question, "What are the attitudes of KU Leuven medical students towards people with disabilities and towards prenatal counseling?", the students in our sample generally had moderately favorable attitudes towards people with Down syndrome, with a mean scale score of 4.7 on a 7-point scale. Those that were of the opinion that life with Down syndrome should rather be avoided were found to have a lower attitude score on these questions. With regard to attitudes towards prenatal counselling, 7 out of 10 students answered that they think neutral counseling is desirable. When finally asked whether they themselves feel prepared to counsel, 71.38% of our students do not feel prepared to do so and no significant differences were found between Bachelor's and Master's students. Given students' attitudes towards neutral counseling, this is quite remarkable as well.

The fourth and final research question was as follows: "Does the sociodemographic background of KU Leuven medical students have an influence on their attitude and/or knowledge, thereby influencing their ability to provide

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counsel in a non-biased way?" The results generally did not reveal notable differences between answers depending on the sociodemographic background, except for the second year Bachelor's students' results with regard to the medical question on whether Down syndrome is hereditary. They had the highest number of correct answers of all students in our sample, which can be explained by the fact that the KU Leuven medical training program includes a course on genetics in the first semester of the second year Bachelor's course. By recently having had that class, the knowledge of those students might still be better preserved than is the case for third year Bachelor's and Master's students.

Our general research aim was to see whether the reported medical bias for doctors while providing prenatal counseling (Costan et al. 2020) is already visible in their early medical career. When looking at our results, there are some contradictions that might contribute to this reported medical bias: while students do not have adequate non-medical knowledge on NIPT and Down syndrome (RQ2), they nevertheless consider it important that a doctor who provides counselling does have that knowledge (RQ3). In addition to that, they consider neutral prenatal counselling desirable (RQ3), and think that a doctor, be that a gynecologist or general practitioner, should provide it (RQ1). But remarkably, most of them indicate that they do not feel prepared for counselling themselves (RQ3). This might indicate that there is a gap in the KU Leuven medical training program.

2. Shortcomings

We might however have to be careful not to draw too strong conclusions on medical bias in prenatal counseling in medical students based on our research. First, our sample of respondents consisted of only 245 students and was limited to KU Leuven students. Of those KU Leuven students, we only reached out to Bachelor's and Master's students, while the results from students in specific training programs such as general practitioners and gynecologists would certainly be interesting and of added value. After all, they most likely are the future doctors who will have to provide counseling. The Covid-19 pandemic and the difficult circumstances it created might have influenced the number of respondents. In addition to that, the fact that our survey had Down syndrome as a subject might have induced socially desirable answers of some of the respondents, particularly for the attitude survey. Furthermore, the survey's open questions enabled a wider perspective on students' views on prenatal counseling, but they cannot equal the insights gained from an in-depth interview. However, we deliberately chose to use a survey to reach out to the students, since we considered this the best way to gather as many responses as possible. Finally, we could have gone further in analyzing links between answers to the different blocks of questions, e.g. the relation between the scores on knowledge and the attitude scales. Lastly, we only had limited societal input for the constructing of the survey, namely from Fara vzw, although we tried to reach out to other societal stakeholders as well.

3. Where to go from here?

Despite the shortcomings mentioned above, we have contributed important first steps to uncovering the roots of a possible medical bias in prenatal counseling. Our research has delivered data on how future doctors feel about prenatal testing, with a focus on NIPT, and how its results should be communicated. Based on our insights, several future steps can be envisaged.

First, our findings reveal opportunities for further research. As discussed above, we found that in their views on how prenatal counseling should take place, students included some elements (e.g. general information, possible next steps and options…) quite frequently, while other elements such as financial or legal information were barely mentioned. A next step could be to find out the underlying reasons for these choices. We hypothesized that students might exclude certain elements consciously while counseling, because they genuinely do not consider them to be important. Likewise, it could well be the case that students are simply not aware of the possible influence some elements might have on expectant parents' decision-making. Our survey and research were not designed to or capable of giving elucidating answers to these questions, but the insights we have gained may constitute a basis for further research. One concrete approach for such future research might be to conduct semi-structured interviews. In this way, students' answers can be dug into deeper and be made more elaborate by asking additional questions, as to avoid a shortcoming our own research was confronted with: students providing relatively short answers to the open questions in our survey. Another possible track for future research might be the organization of roleplay with students, to see

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whether they would react better or worse in a situation that reflects reality more than is the case with a survey. Both for the semi-structured interviews and the roleplay, it could be interesting to include students from more specialized training programs such as general practitioners and gynecologists, as the most likely future doctors who will have to provide counseling.

Next, we found that 20.32% of the medical students in our sample were of the opinion that life with Down syndrome should rather be avoided. This raises serious ethical questions, considering that these students might counsel future parents in their prenatal choices. Obviously, these students have a right to form their own opinion, but this should not direct their future counseling. Who decides whether a life is worth living and what factors steer this decision? This type of questions definitely falls outside the scope of our research, but our findings might also in this case be (urgent) triggers for further research.

To conclude, we formulate some implications for avoiding a gap in the medical training between (1) the recognition of importance of non-medical knowledge and the apparent lack of that knowledge, and (2) the doctor's responsibility to counsel as neutrally as possible and the lack of feelings-of-preparedness on the part of medical students to do so. To bridge this gap, a transdisciplinary perspective on Down syndrome and prenatal screening must be nurtured as a counterweight against the purely medical perspective that doctors are usually trained to have. Multi- or transdisciplinary disability education[25] for medical doctors in training could be organized by universities in three ways. The first option is through content infusion, in which knowledge about persons with disabilities is spread out throughout the whole training program (Kowalski 1995). However, past research suggests that this strategy is not very effective. Not all professors will feel (or be) competent enough to teach multidisciplinary content on disabilities (Akasmit and Alcorn 1988, Cook 2002).

The second possibility for bringing in multidisciplinary insights on disabilities and prenatal screening is through a stand-alone unit, a subject or course in which this information is clustered.[26] Multidisciplinary information on disabilities and counselling could be clustered in an existing or in an additional KU Leuven course, for example in Gynecology and Obstetrics or Skills and communication 4. The abovementioned idea of roleplay is not only a possibility for future research but could also be included in these already existing courses or in a possible stand-alone unit. A fundamental objection against stand-alone units comes from Kowalski (1995, p. 51): "information about disabilities provided in the lone traditional adapted course, when taught without infusion, could easily be perceived by students as isolated and unmeaningful. As a result of infusion experiences, students are continuously challenged to both assimilate and apply disabilities knowledge to their teaching, thus raising the level of commitment."

In any case, "the content and the pedagogy of a programme are by far the most significant predictors of pre-service teachers' [in our case, medical students'] attitudes, sentiments and concerns about inclusion" (Sharma et al. 2008), which brings us to the final option. Through a service-learning component, medical students will interact on equal basis with persons with disabilities, most probably enhancing the students' transdisciplinary understanding of living with a disability and their attitudes towards them. An engaged experience is also unlikely to be perceived as "isolated and unmeaningful". Service-learning could mitigate at an early stage the purely medical knowledge, leading to a possible bias in their future prenatal counselling on disabilities such as Down syndrome, that doctors in training tend to have, hence laying the groundwork for educating medical professionals with an open view on and sufficient knowledge of disabilities, stimulating their attention for non-directiveness in prenatal counseling.

List of supplements

Supplement 1: Causal loop diagram
Supplement 2: Survey questions (English)
Supplement 3: Original challenge document
Supplement 4: Video presentation

25 Research tends to suggest that there is a positive correlation between the amount of disability education and educators' positive attitudes towards disabilities (Avramidis and Norwich 2002; Center and Ward 1987; Hastings and Graham 1995; Loreman and Earle 2007; Loreman, Forlin, and Sharma 2007; Sharma et al. 2006; Subban and Sharma 2006).

26 Studies examining the effect of completing a subject in special or inclusive education in general have found that such training leads to a positive effect on pre-service teachers' attitudes towards people with disabilities (Campbell, Gilmore, and Cuskelly 2003; Carroll, Forlin, and Jobling 2003; Forlin 2003).

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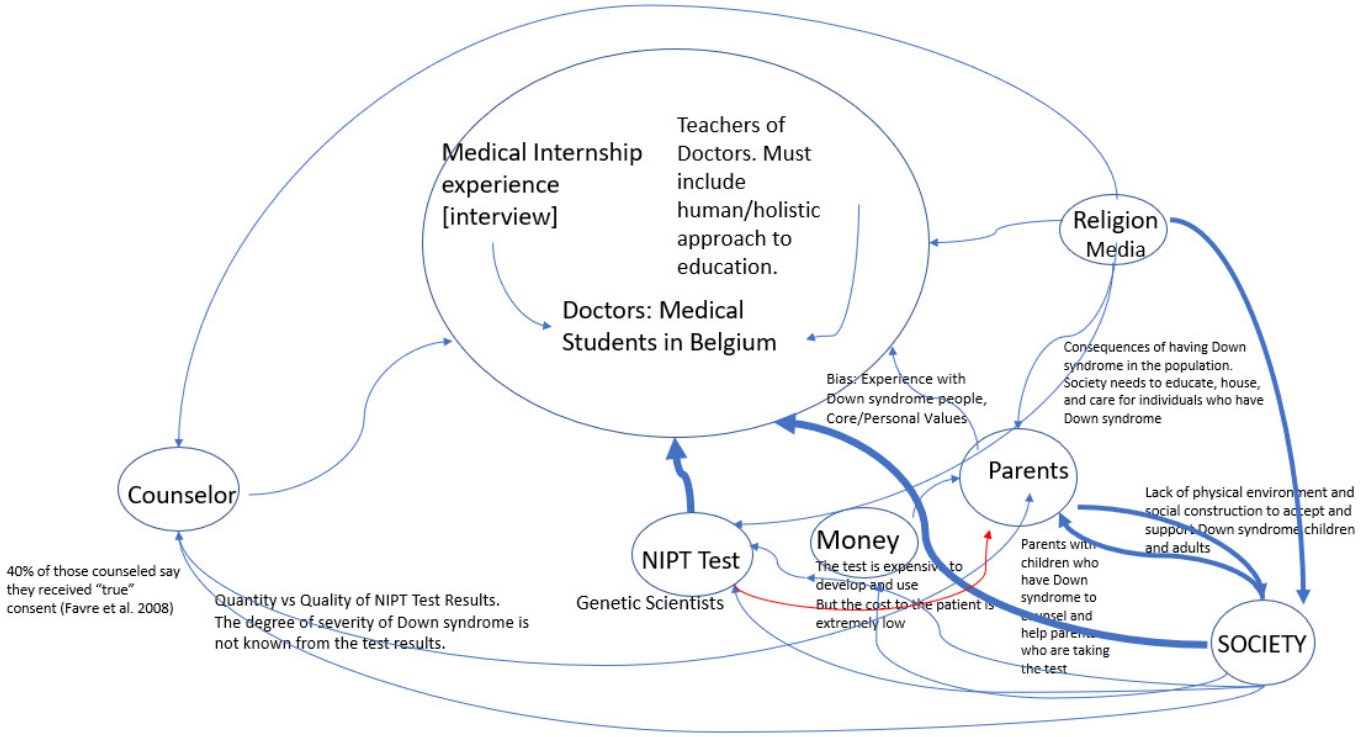
Supplement 1: Causal loop diagram



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Supplement 2: Survey questions (English)

Down Syndrome – TDI KU Leuven

Welcome!
We invite you, a medical student, to fill out this survey. In this questionnaire you will find questions about prenatal screening.
Completing the questionnaire will take about 10 minutes of your time. Your answers will be treated confidentially and will only be processed for research purposes.
If you have any questions about the questionnaire or the procedures, you can contact Nynke van Uffelen by e-mail: nynke.vanuffelen@student.kuleuven.be.
Thank you for your time and participation! You may now start the questionnaire.

BEFORE WE START:
– How old are you?
– What year of medicine are you in? (Please indicate the most correct one).
– Gender
– What specialization would you like to pursue? (You can also fill in something yourself in the text box below).

1. SCENARIOS
Laura is 29 years old and 6 weeks into her first pregnancy. This is her first doctor's appointment regarding her pregnancy. By whom, when and how do you expect counseling about the NIPT (non-invasive prenatal test)?

By whom?

When?

How/content?

After one week the results of the NIPT are back. The NIPT scores positive for Down syndrome. By whom, when and how should this counseling take place?

By whom?

When?

How/content?

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2. KNOWLEDGE ABOUT THE NIPT (=NON INVASIVE PRENATAL TEST) AND DOWN SYNDROME

What does NIPT screen for?

- o Down syndrome (trisomy 21)
- o Down syndrome (trisomy 21) and Edwards syndrome (trisomy 18)
- o Down syndrome (trisomy 21), Edwards syndrome (trisomy 18), Patau syndrome (trisomy 13)
- o Down syndrome (trisomy 21), Edwards syndrome (trisomy 18), Patau syndrome (trisomy 13), and metabolic disorders
- o Down syndrome (trisomy 21), Edward syndrome (trisomy 18), Patau syndrome (trisomy 13), metabolic disorders and auto-immune disorders
- o I don't kow

A positive NIPT means your child has Down syndrome for sure.

- o Yes
- o No
- o I don't know

Until when can you legally terminate a pregnancy of a fetus with Down syndrome in Belgium (subject to a favorable evaluation by two doctors)?

Until _____ weeks of pregnancy

Statement: Down syndrome is hereditary

- o Always
- o Frequently
- o Seldom
- o I don't know

Parents with a child with Down syndrome receive increased governmental child benefits.

- o True
- o Not true
- o I don't know

An average child learns to walk between 9 and 17 months (on average at 12 months). When does a child with Down syndrome learn to walk on average?

9 ●——————————————— 42 months (slider bar)

- o I don't know

What is the average IQ of a young adult with Down?

10 ●——————————————— 140 IQ score (slider bar)

- o I don't know

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What additional health problems do people with Down syndrome have a higher chance at? You can indicate several options.

- o Cardiovascular
- o Respiratory
- o Growth retardation
- o Cancer
- o Autism spectrum disorder
- o Infections
- o AS
- o Dementia
- o Sleep apnea
- o Hemophilia
- o Obesity
- o Visually impaired
- o Hearing impairment
- o Thyroid problems
- o I don't know

What is the average life expectancy of a person with Down syndrome?

0 ● 110 years (slider bar)

3. THE DOCTOR AND COUNSELING (GUIDANCE)

Do you think doctors' counseling on prenatal screening should be aware of the support and quality of life of people with Down syndrome?

- o Yes
- o No
- o I don't know

Rank the following topics by important to less important if you, as a doctor, counsel parents with a positive NIPT for Down syndrome. You do not need to rank issues that seem less relevant to you.

		Drag selected options here to rank
Aid organizations	1.	…
Average life expectancy	2.	…
Financial information (impact, subsidies, …)	3.	…
Educational opportunities	4.	…
Testimonials	5.	…
Medical information	6.	…
Social information	7.	…
Career opportunities	8.	…

When counseling, the doctor should have a … (you can indicate several options)

- o guiding role
- o advisory role
- o informative role
- o coaching role

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Do you think a neutral counseling conversation…

	no, never	usually not	depends on the situation	usually	yes, always
is possible?	O	O	O	O	O
is desirable?	O	O	O	O	O

Who is ultimately responsible for making the decision on whether or not to continue the pregnancy?
Indicate if: 0=entirely with the doctor and 10=entirely with the parents

doctor 0 ●——— 10 parents (slider bar)

Indicate how much you agree/disagree with the following statements:

	Totally disagree	Disagree	Slightly disagree	Neither disagree nor agree	Slightly agree	Agree	Totally agree
I feel ready to counsel as a future doctor.							
All pregnant women are obliged to have the NIPT performed.							
Life with Down syndrome should best be avoided.							

4. LIFE WITH A DISABILITY

	Totally disagree	Disagree	Slightly disagree	Neither disagree nor agree	Slightly agree	Agree	Totally agree
The majority of people with Down syndrome are still victims of discrimination in Belgium.							
People with Down syndrome are generally treated in the same way as people without Down syndrome.							
Negative social views about Down syndrome make life difficult for people who have this syndrome.							

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	Totally disagree	Disagree	Slightly disagree	Neither disagree nor agree	Slightly agree	Agree	Totally agree
People with Down syndrome and their loved ones are still fighting against the injustice they experience in society.							
People with Down syndrome become too demanding in their pursuit of equal rights.							
People with Down syndrome have more to offer to society compared to the opportunities they are given.							
The situation in which people with Down syndrome are, is good as it is.							
People with Down syndrome receive little media attention.							
Society makes sufficient efforts for people with Down syndrome.							
In comparison with other target groups, society makes more effort for people with Down syndrome.							
It is justified that people with Down syndrome sometimes receive appropriate help in finding a suitable job.							
Life with Down syndrome is worth living.							

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Are there people around you with Down syndrome?

o Yes
o No

If yes, please clarify below (in my family, circle of friends, …)

Thank you for helping us. Is there anything else you'd like to share? (Leave your email address here to have a chance to win one of the FNAC vouchers!)

Dear respondent, thank you for filling in the survey! We attach great value to the information you have provided. Do not hesitate to share this survey with your fellow medical students!
Kind regards,
TDI team 2019–2020

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Supplement 3: Original challenge document

Amendments to the original challenge proposal

Dear students

On the next page, you can find the original challenge proposal as it was written for the first group of students who worked on the challenge in 2017–2018. The text also includes some small amendments that were made for the students who worked on the challenge in 2018–2019, based on the insights acquired in 2017–2018.

The proposal below still very much resonates the concerns of parents with a child with Down syndrome, yet two amendments are in place following: (1) the progress made by the students involved in this challenge over the past two years; (2) the societal changes and scientific evolution that took place since 2017.

More specifically, for the following year, I strongly suggest both expanding and narrowing the focus of this challenge.

Expanding of focus:

The original challenge provides three reasons to focus on Down syndrome, yet also states that "babies with Down syndrome are sometimes said to be the canaries in the genetics coalmine. Non-invasive screening for Down syndrome is merely the tip of an iceberg that will in any case be revealed over the following decades."

Based on the insights from the stakeholder meeting the students from 2018–2019 organized, it seems like this challenge can no longer simply focus on Down syndrome. As one doctor put it: "the debate on Down syndrome is over, it is so much broader now". Your approach to the issue of prenatal screening should hence take a broader focus, including the wide spectrum of disabilities (and other genetic material – gender?) screened with via NIPT (though feel free to where convenient use Down syndrome as case study).

Narrowing the focus:

One of the recurrent assumptions of the stakeholders students have talked to over the past years and of the students themselves concerns health care professionals, who are believed to typically (though of course not always) show a lack of sufficiently broad knowledge about disabilities, a lack of theoretical insight into models of disabilities (such as the medical vs. the social model of disability), and a lack of motivation to expand the medical focus of prenatal counseling to more multidisciplinary approaches from the first appointments with future parents onward. Yet, empirical support for these assumptions is largely missing. This seems like a potentially highly relevant angle to approach the challenge this year: (1) conduct a literature review to find existing empirical data on the way in which the interplay of HCPs' knowledge of and attitude towards disabilities might influence their prenatal screening practices; (2) draw a concrete RQ and potential methods from this review; (3) conduct your own study amongst (future) HCPs to gauge knowledge of (living with) disabilities, attitude towards disabilities, attitudes towards prenatal screening, and the interaction between these components.

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Original challenge proposal: ABOUT YOUR CHALLENGE

Name of the Challenge
Would the world be a better place without them?

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.
Strategies for non-directive counseling in prenatal screening for Down syndrome: From concept to application.
(Written by Eline Zenner on behalf of Downsyndroom Vlaanderen)

When we look at our children, we see people. We see people with hopes and dreams, fears and desires, hands, fingers, toes, favorite food, bath time rituals, bubbles and images of the life we share. What we see as parents of a child with Down syndrome stands in sharp and bleak contrast with what society sees. Society sees a medical risk, increased odds for early-onset dementia, heart condition, visual impairment and autism spectrum disorder. Society sees a financial burden, and waiting lists for care facilities for the intellectually impaired. Society sees a syndrome that no longer needs to be. A syndrome that we can screen for.

From 2013 onwards, a new and non-invasive way of prenatally screening for Down syndrome gained ground in Belgium and abroad. The NIPT (Non-Invasive Prenatal Test) is more accurate than the traditionally used double test, it has fewer risks for the fetus than an amnio (where a needle is guided through the abdominal wall and into the fluid sac), and can be conducted at a much earlier point in pregnancy. Without going into medical detail, the test isolates the fetus's DNA from a blood sample taken from the mother and offers a near-conclusive diagnosis (with more than 98% accuracy) for trisomy 13, trisomy 18, and trisomy 21.

On Monday 29 May 2017 Belgian Minister of Social Affairs and Health Maggie De Block announced that 15 million euros will be made available to refund the NIPT for every Belgian pregnant woman. Belgium is currently as such the first European country to refund the test for every future parent instead of targeting parents in high-risk groups (e.g. using maternal age as decisive factor). At Downsyndroom Vlaanderen (an organization of and for parents with a child with Down syndrome) we absolutely support this initiative, as it prevents an opposition between "medicine for the rich" (those who can afford the expensive test) and "medicine for the poor" (those who cannot afford the test). What we however object to is that the available funding solely covers the costs of the lab test itself. Money for non-directive multidisciplinary counseling is not foreseen. That is what this proposal is about, with a specific focus on trisomy 21, the chromosomal variant more commonly known as Down syndrome.[1]

The reason to focus on Down syndrome is three-fold. First, the NIPT is publicly often referred to as "the Down test", as this condition has the highest prevalence and hence the highest visibility of the three trisomies. Additionally, where babies with trisomy 13 and trisomy 18 usually die in the womb or in their first year of life, most people with trisomy 21 can lead a long and relatively care-free life (with a current mean life expectancy of about sixty years). Finally, because of the higher visibility of Down syndrome, there is a more outspoken and more public debate on the NIPT and its consequences for people with this syndrome than for any other condition that can be detected prenatally. Are we heading towards a world without Down syndrome?

The answer to this question is not what we as parents of a child with Down syndrome want to focus on. If future parents make a well-informed and well-considered decision following a prenatal diagnosis of Down syndrome to terminate their pregnancy, then it is by no means our desire to stop them. No matter how dearly we love our children, we support a pro-choice vision on prenatal screening: every parent has the right to choose whether to terminate or to continue a pregnancy.

1 See http://www.downsyndroom.eu/nieuws/over-de-nipt-en-informatie for the vision of Downsyndroom Vlaanderen and an overview of media coverage in the immediate aftermath of the prime minister's decision.

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This one key sentence forms the cornerstone of our challenge: every parent has the right to choose.
Historically, this pro-choice vision largely served to provide a contrast with the traditional pro-life stance: abortion was illegal in most countries under all circumstances, in Belgium even until 1990. Women around the world defended (and still need to defend) their right to have a choice in whether or not to continue a pregnancy, in essence defending their right to terminate. Because of this socio- political context, the decision to terminate a pregnancy is subsumed under the flag of a “pro-choice” vision. It is however incorrect to equate a pro-choice vision with a pro-termination stance: we should be careful not to evolve to a point where, under certain conditions, allowing a woman to choose entails that we expect a woman to terminate. Under a true pro-choice approach, the choice for life and the choice for termination should at all times be measured with equal scales.
In the specific context of the NIPT, a pro-choice vision entails that future parents first and foremost make a conscious decision whether or not they want to screen for disabilities and abnormalities during pregnancy. Once they decide to screen, a second choice then is what to do with the outcome of such screenings. In this respect, society seems to be evolving to a point where screening is a given rather than a choice, and termination is the standard outcome of a positive diagnosis in prenatal screening. The parents in our network who have consciously decided to keep a child with a disability after positive results in prenatal screening find themselves faced with hostile comments and repeatedly have to defend their choice to others, including medical staff. Why bring a child into the world with a syndrome that no longer needs to be? The recent decision to refund the NIPT on a national level without mirroring this financial initiative with efforts concerning counseling further illustrates this termination-oriented climate.
As parents of a child with Down syndrome, who have joined forces in the voluntary association Downsyndroom Vlaanderen, we believe that this evolution presents an opportunity and a challenge to society. How can we provide future parents, and society at large, with the tools required to make a conscious and well-informed decision on the outcome of prenatal diagnosis without passing judgement or steering parents in specific directions? We ask this question specifically for trisomy 21, but insist on the much broader impact of the answer. Down syndrome is one of the most traceable conditions, and hence the first to be subject to this type of large-scale prenatal screening, but it is on average definitely not the most life-shattering condition one can be faced with in terms of quality of life.
Put differently, screening for Down syndrome is merely the beginning of a general societal tendency to screen for conditions, deviations and abnormalities during or prior to pregnancy, and as such presents us some questions we need to address today rather than tomorrow.

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?
Babies with Down syndrome are sometimes said to be the canaries in the genetics coalmine. This vibrant metaphor is not per se nuanced, but does underline the urgency of our challenge. Non-invasive screening for Down syndrome is merely the tip of an iceberg that will in any case be revealed over the following decades. The breathtaking speed of knowledge acquisition in genetics has left our moral compass in the need of recalibration. How have we, as a society of human beings, embarked on the endeavor of extensive genetic screening without equally explicitly and, more importantly, publicly, addressing the question of the value of a human life and of the scales that are used in weighting this value: who decides what a meaningful life is? We need to address this issues from a transdisciplinary scientific framework, but we also and more importantly need to come up with a strategy to disseminate insights on the matter to a wide audience.
On the broader level of genetic screening, the question is how we can (re?)introduce fair play in the public debate on prenatal decisions, how we can contribute to a correct perception of life with (a child with) a disability?
On the more specific level of screening for Down syndrome, which this challenge focuses on, the question is two-tiered. First, we need to find out how we can provide non-directive information on Down syndrome to all future parents. How can we make sure that up-to-date information on the possible impact of Down syndrome on a child’s and a family’s living conditions finds its way to future parents, ideally even before they decide to undergo prenatal screening? As we see that centers for human genetics typically already undertake efforts in this respect, we secondly want to question the position of GPs and gynecologists in providing this information. Which tools, data, approaches,

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etc. can we offer medical teams to inform parents of life with a child with Down syndrome in all its respects, surpassing the traditional clinical perspective of "medical risks attached to trisomy 21" (e.g. higher incidence of heart conditions, leukemia, autism spectrum disorders, and visual and auditory impairments)? At this point, the type and manner of communication is (too?) idiosyncratically tied to individual profiles. Where some doctors take efforts to provide a nuanced and well-informed position, others can't help but take a stance in one direction or another. How can we broaden the perspective and make clear that our children are people, not risks? The group of students who took up this challenge in the academic year 2017–2018 focused on this particular challenge, and in interaction with different stakeholders came up with the idea to make a website with FAQs concerning Down syndrome that can be used to broaden the often all too medical perspective of gynecologists and GPs. The challenge for the academic year 2018–2019 is to decide on what information needs to be provided and in which format: the team is asked to explore the desired information and to disseminate it in an attractive and insightful manner via an online platform. The main idea is to provide insights and information on the implications of living with (a child with) Down syndrome, including its charms and problems.

In creating this website, students may wish to account for the role of the media in the debate. Currently, the media frequently offer broad platforms to individuals who have strong opinions on prenatal screening, but do not necessarily have any notable actual experience with people with Down syndrome. Several individuals for instance make public assessments on the "unbearable suffering" that is tied to trisomy 21, often relying on old and colored terminology (calling people with Down syndrome *mongooltjes* – a term that was abandoned by WHO in the 1960s). Although this assessment may hold for a number of people with Down syndrome, it most surely does not apply to all. At the same time, programs foregrounding successful individuals with Down syndrome (such as the popular Een show "Down the road") may raise unrealistic expectations concerning the possibilities for people with Down. It is important to take these factors into account, as the public opinion on the genetic condition is greatly colored by the media. Schooling and care for people with Down syndrome still (especially in the later years of life) typically adopts the form of segregation rather than of participation or inclusion, day-to-day contact with people with Down syndrome is so limited for most would-be parents that they have to make decisions on screening without ever having met a person with Down syndrome: the information shared in the media (both in terms of form and content) hence is of crucial importance for future parents' perception of Down syndrome.

Finally, more ethical questions can also be addressed on the website, as a means to open up the perspective of GPs and gynecologists. How much is society paying for prenatal screening for Down syndrome and comparable syndromes; conversely, what is the cost of supporting families with a child with Down syndrome; and what is the relation between both? What is the social meaning of increasing expenditure for scientific research on prenatal screening whilst decreasing the budget for supporting families with a child with Down syndrome? Using a raw economy-driven formulation, what is more expensive: providing the correct type of life-long support for people with Down syndrome, or refunding the NIPT to all future parents on the presupposition that the default choice following a positive diagnosis is termination (and hence not having to foot the bill as society)? What are the risks of valuing lives with such purely economic scales, also for people who do not have an extra copy of their 21st chromosome?

It may also be worthwhile to elaborate on potential changes in the society, including in the medical field, that may affect the future of children with Down syndrome.

The team of last year suggested creating an online tool for GPs and gynecologists in a succinct Q&A format. The goal of such a website would be to provide up-to-date, easily accessible and balanced information for general practitioners and gynecologists on multiple aspects of Down syndrome. This way, in anticipation of and directing explicitly towards further counseling by a multidisciplinary team, physicians can provide expecting parents with a more balanced, transdisciplinary view of Down syndrome, thereby enhancing their capability to make informed, autonomous and hence sustainable decisions about their pregnancies.

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Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team?
Please be aware that our transdisciplinary research teams accept only challenges that have to be dealt with from different points of view.
In the next section of this proposal, we sketch precisely how this challenge could be addressed by a properly transdisciplinary team.
Below, we present some specific perspectives and questions related to the challenge. We do this for each of the KU Leuven faculties that, in our opinion, can add interesting insights or expertise for the website. Of course, not all of these perspectives need to be addressed. Likewise, other initiatives and points of view are more than welcome.

Philosophy:
– the ethics of genetic screening;
– a cultural-historical analysis of “normality”;
– the position of uncertainty opposed to the desire for control and perfection;
– the consequences of *agency* in ethics (“you chose this child, so you deal with it”).

Medicine:
– critical analyses of medical training: is it more advisable to opt for in-depth experience with people who live with the disabilities that you screen for;
– how will care for people with disabilities improve in the future, and how could that influence the decision-making?

Arts & Social Sciences:
– communication in prenatal context: how to convey information on people with a disability at a point in time (early pregnancy) when potential future parents are not particularly open to this type of information;
– website usability and design, copywriting;
– audiovisual & multimedia approach to information sharing on the website;
– storytelling & interview techniques.

Economic Sciences:
– economic factors in prenatal screening and prenatal counseling;
– the “value” of life;
– “something’s gotta give”: what are we losing by spending 15 million euros on refunding the NIPT? What are we gaining?

LUCA (Associatie KU Leuven):
– people with Down syndrome often have great artistic abilities: what is the value of this for society?;
– website usability and design, copywriting;
– audiovisual & multimedia approach to information sharing on the website.

Thomas More (Associatie KU Leuven):
– website usability and design;
– audiovisual & multimedia approach to information sharing on the website;
– storytelling & interview techniques;communicationPsychology & Pedagogy:
– psychological factors involved in the process of making life-changing choices;
– living with a family member with Down syndrome;
– skills and insights in teaching about disabilities;
– the evolution in models of thinking about disabilities (from medical to social model);
– what does the future have in store in terms of teaching (M-decreet?) and training (see stakeholder Konekt’s efforts) people with Down syndrome, where are we in the scale from exclusion over segregation via participation to proper inclusion?

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Science:
– make predictions on the future of science and the impact on the quality of life for people with Down syndrome;
– make predictions on how expected innovations in technology can help people with disabilities gain independence, social networks, etc. (see e.g. Spotter, a GPS tracker for tracking children);
– website usability and design.

After reading this proposal, it should be clear that the societal impact of addressing our challenge is significant. Current advances in prenatal screening have put society at a turning point. This challenge is all about the question which way to tip, and how we can provide a nudge in the preferred direction, ensuring that parents can truly hold on to their right to choose. As such, in addressing the issue of counselling for prenatal screening for Down syndrome, we hope to pave the way for similar strategies for other prenatal tests, now and in the future. It is crucial to appreciate that this proposal sees the issue of counseling in prenatal screening for Down syndrome as a first case study for a broader societal challenge. Society is evolving to a point where parents are advised to test as much as possible in advance. How can we offer parents the correct tools to deal with these tests and the information they provide?

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Supplement 4: Video presentation

Video presented at the symposium KU Leuven Facing the Future (https://rega.kuleuven.be/cev/Symposium/facing-the-future) is available on https://kuleuven.mediaspace.kaltura.com/media/TDI+Official+presentation_DownSyndrome.mp4/1_0yaj8sb7

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TRANSDISCIPLINARY INSIGHTS
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Towards a Resilient and Equitable Society: A Transdisciplinary Perspective

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Abstract

Recurring crises have exposed time and again the inherent inequalities of our societies and their ill-equipped adjustment to an ever-changing environment. This paper attempts to address the challenge of creating a more resilient and equitable society by developing a feasible blueprint for it through a bottom-up, transdisciplinary approach and the use of activity models methodology. The starting point of our analysis consisted of the identification of five cross-field societal issues, tackling which would create a more equitable and resilient future for society: dangers of private data extractions, carbon emission taxing, climate migration, public health affordability, and the crisis of representative democracy. By jointly engaging in transdisciplinary discussions and accommodating insights from diverse stakeholders we analyzed ways of dealing with each of the issues, resulting in the creation of six activity models pertaining to them. The last step consisted in their integration into a single blueprint, achieved by devising a learning cycle running through the core of our societal model. The learning cycle organizes decision-making by identifying the social needs of the citizens, prioritizing them, deciding on key investments, executing these and monitoring their results. It ensures, through the contribution of each activity model, an equitable and resilient development for society.

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Key words

Equitable, resilient, society, learning cycle, transdisciplinary, wicked problem, activity model

List of stakeholders

Lodewijk De Witte, Governor of the Flemish Brabant Province in Belgium
Ludmila Malcoci, Regional Director of Keystone Human Services International for Central and Eastern Europe

List of supplements

Supplement 1: Original challenge document
Supplement 2: Video presentation

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Supplement 1: Original challenge document

BANK OF TRANSDISCIPLINARY CHALLENGES

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Dear,
Welcome to the Bank of Transdisciplinary Challenges!
This is an initiative where people concerned about the future translate their concern into a scientific challenge. The challenge typically revolves around a specific society, environment, and/or business problem or opportunity that you want to be addressed by a transdisciplinary research team.
Are you concerned about a specific theme or topic for the future?
We invite you to be part of this initiative by filling out this form and sharing your challenge with our academic team and other stakeholders.
We will inform you if your challenge is taken up by our research team, and of any further activities.
Hope to hear from you soon.
The Bank of Transdisciplinary Challenges.

SECTION 2 OF 5 – Before informing us about your challenge, we would like to know a bit more about you.

First Name: Kim
Last Name: Becher
E-mail Address: kb@shiftn.com
Affiliation:

- ☐ Academia as a Researcher
- ☐ Academia as a Student
- ☐ Government
- ☒ Industry
- ☐ Local Organization
- ☐ Non-profit Organization
- ☐ Society
- ☐ Other:

If you are affiliated to an organization, please fill in its name here: shiftN
You can also include some contact details of your organization.
www.shiftn.com **@shiftNGroup De Hoorn Creative Minds, Sluisstraat 79, 3000 Leuven**

Would you like to receive updates about this initiative?
YES/NO

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SECTION 3 OF 5 – ABOUT YOUR CHALLENGE-

Name of the challenge:
Develop a causal loop diagram as a blueprint for a future, resilient and equitable society

Specific challenge:
To produce a systems map that shows how a new societal value creation model can be connected to a new social contract, including access to basic rights and the provision of redistribution mechanisms.

Objectives:
- To get a clear systemic view of the various obstacles (legal, architectural, economic, social, health care related) blocking the adoption of a new societal value creation model that would be more in line with the criteria of sustainability, social equity and community building than the current model.
- To get a clear systemic view of the (untapped) resources and possibilities (legal, architectural, economic, social, health care related) that would facilitate the creation of a new societal value creation model as described in the previous point, connecting it with a new social contract, which would include access to basic rights and redistribution mechanisms.
- To formulate a set of proposals/recommendations in support of the adoption of a new societal value creation model in connection with a new social contract that would include access to basic rights and redistribution mechanisms.

Context and relevance to a transdisciplinary team:
At shiftN, we often work in transdisciplinary settings. Our team brings in various disciplinary and methodological backgrounds, ranging from biology, philosophy, design and engineering to urban planning, psychology and organization development. In our assignments, we often deal with complex, “wicked” problems, which demand multidisciplinary and transdisciplinary approaches. As part of our methodology, we invite scientists and stakeholders to think beyond the limits of their specialisms and integrate different ideas and perspectives into their thinking.
shiftN’s interest in the topic of post-capitalism stems from our observation that the current late-capitalist system is unsustainable, not only from a monetary and economic point of view, but also from a social, environmental, cultural, psychological, medical and governance perspective.
Since the big credit crunch of 2008, no serious structural reforms have been undertaken to remedy the system’s deficiencies. Governments have imposed austerity measures on their populations in order to save the banking system, but without taking the necessary steps to avoid a similar or worse kind of economic cataclysm in the future. In the meanwhile, many layers of society are suffering from the consequences of precarity and poverty. Public services are being cut, inequality is mounting, trust in authorities and the political realm is eroding, populism and extremism are on the rise.
In the past, capitalism always found a way out of the big crises, mainly through technological innovation. However, as Paul Mason points out in his book *Postcapitalism*, the information and network-based technologies that have boomed over the last 25 years are not compatible with capitalism. Capitalism is based on scarcity, whereas info-technologies are abundant by nature. They work best when they are free or shared.
With the advent of new information technologies, a different path has opened up: that of collaborative production. Goods, services and production methods are emerging that no longer fit into the logic of the market or managerial hierarchy. Developments like the shared economy, commons-based peer production and cooperative currencies all point towards a new paradigm, in which individual interests are tied to the common good and vertical hierarchies are being replaced by more open, horizontal types of collaboration. This requires not only different forms of organization, but also new ways of learning, creating, thinking and living.
Although collaborative structures are proliferating everywhere, there are still many obstacles preventing them from developing their full potential. Many legal and administrative provisions run counter to the fundamental principles and ethos of the cooperative economy, such as pay scales that are based on age or academic background.

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On a deeper level, it would be interesting to see which elements in our legal system at its most fundamental level (the Constitution) are preventing or supporting the development of cooperative structures. For example, at this moment, the monopoly of money issuance rests with the European Central Bank. But, as we shall discuss in the following points, our current form of money creation clearly runs counter to the basic principles of the cooperative economy.
In our current system, when a bank gives you a loan, it creates money by transferring the principal on your account. From now on, you owe this money to the bank. But you also have to pay interest on the loan. However, the bank does not create the money to pay back that interest. This means you will have to "find" that money elsewhere. As a consequence, many debtors are not able to pay their debt, because there is not enough money in the system. In other words, scarcity is built into our monetary system.
Another fact about today's currencies is that they are being used for different, often opposite purposes: as a means of exchange, a unit of account and a store of value. Money being used as a store of value will tend to be withdrawn from circulation and made scarce to increase its value. As a result of this, there is not enough money in circulation to maintain a healthy economy.
In the decades following the Second World War, a welfare state came into being in many Western countries, based on the creation and extension of social policies and social security structures. A social contract was agreed upon, based on the acceptance of capitalism as the ruling economic system in return for redistribution mechanisms that would guarantee the viability of the welfare system. The last decades have seen a gradual erosion of the welfare state under neoliberal rule. The time has come to think about a new social contract, which is more in sync with the value creating models of the New Economy. One of the main questions regarding such a new social contract is whether it would continue to be based on the same old redistribution mechanisms. These are conceived as a compensation for labor and calculated on the basis of salary. Info-technologies, however, reduce the need for work and blur the edges between work and free time, and loosen the relationship between work and wages (see Paul Mason, *Postcapitalism*). Could a Universal Basic Income be part of the solution?

Relevance to a transdisciplinary team
For this challenge, we would like the transdisciplinary team to think of how a new societal value creation model could be developed, taking a systemic view on the interaction between variables that are relevant to building such a model, including new legal frameworks ensuring social equity and wellbeing.
This challenge relates to various disciplines: architecture/urban planning, medicine, the cooperative economy, community building and new legal frameworks.

The methodology
The focus of the systems work in this challenge is to present an evidence-based, richly layered, qualitative model of a future, resilient and equitable society. We refer to this general approach as "systems thinking", and the embodiment of this thinking in visual form as "systems mapping".
In order to further differentiate this work from other systems-oriented activities, we propose informal definitions of often-used terms such as system thinking, mapping and modelling:
"System thinking" refers to the activity of (more or less rigorously) using systems principles and systems-oriented heuristics in structuring our thinking about complex, problematic situations (examples of these are the Systems Iceberg, Donella Meadows' Systemic Ladder, system dynamics archetypes and the notion of a system's root definition).
"Systems mapping" denotes the activity of working towards a coherent visual representation of a system.
"Systems modelling" aims at the construction of formal, quantitative models to obtain hopefully accurate predictions about a system's future state.
Qualitative systems maps do not have formal predictive power. They are used in a variety of ways in supporting sense-making and decision-making in complex environments:
– *As heuristic tool*: to support meaningful conversation amongst experts and professionals; to invite new questions and hypotheses for data gathering and theory building.
– *As a knowledge management tool*: to organize available knowledge in an integrative way.
– *As a diagnostic tool*: to identify potential gaps in current policy approaches.
– *As an operational tool*: to identify "leverage points" in the land system as a starting point for policy interventions.

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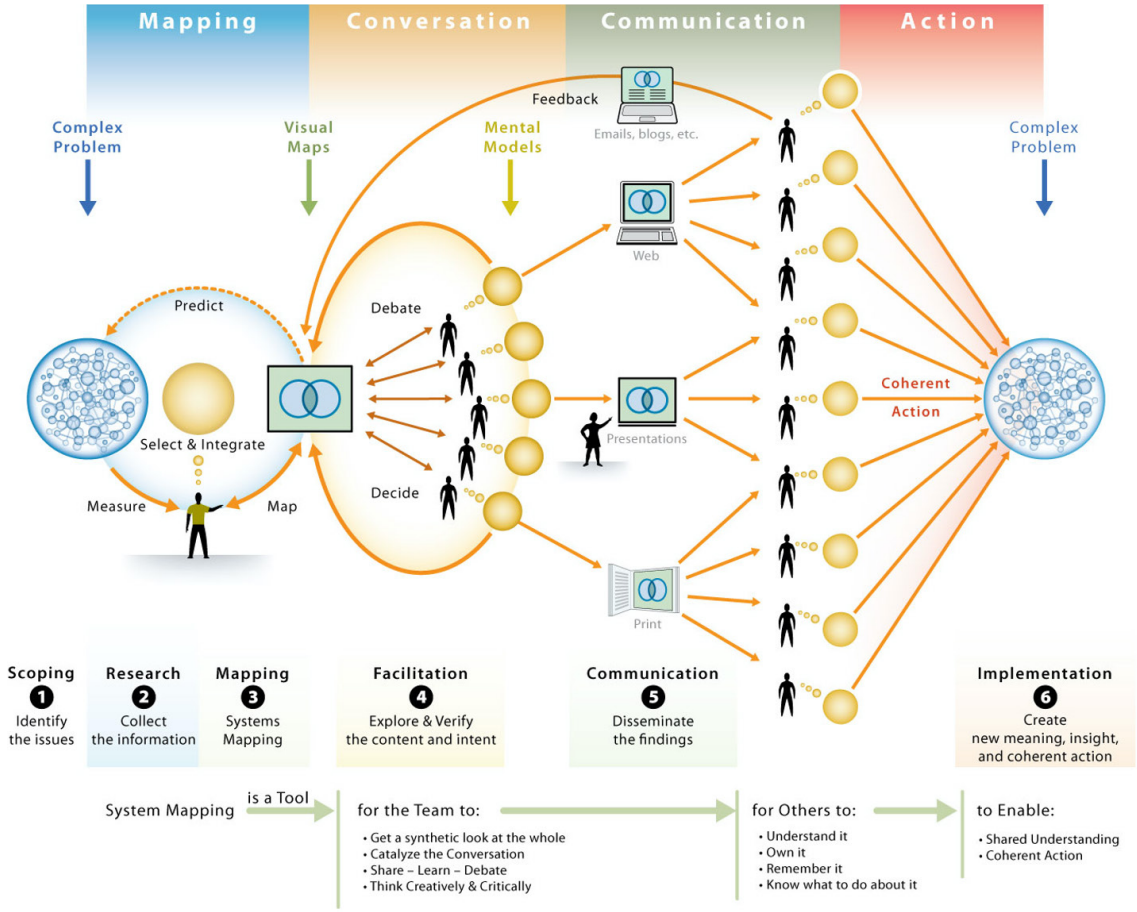
The process of systems mapping can be structured in a number of phases: scoping, research, mapping, facilitation, communication and implementation. We suggest that the present challenge encompasses at least the first three phases.



The transdisciplinary team for this project will be invited to participate for free in shiftN's systems mapping and Kumu course. shiftN will also seek to connect this challenge with our internal "Beyond Capitalism" project and with other elements in the shiftN academy.

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: _____

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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:_____

Economics and business:
– Development of business models which have a strong focus on social and environmental responsibility and are centered on collaborative production.
– Reflection on our current economic system: what are the main obstacles that impede the upscaling and further development of the cooperative economy? Which available resources can be used to support it?

Law
– Towards a new paradigm of freedom? Our current notion of freedom is heavily influenced by Roman law: individual rights must be respected by others, but also involve the right to destroy one's own property. What about social and environmental responsibility? One could think of a more horizontal, relational view of freedom: the possibility to enter into meaningful relationships with others and work together to create personal and social wellbeing.
– Reflection on legal frameworks which would foster or hinder the development of a collaborative economy and a peaceful society.
– Central banks have a monopoly on money creation. They have used this monopoly in the past to abolish cooperative currencies, even though these currencies proved to be very successful in tackling mass unemployment and social dislocation. Should this monopoly be challenged?

Philosophy
– Reflection on our current notions of autonomy, liberty and property. To what extent do they fit into the conceptual framework of cooperative production, including notions as the commons, shared economy, open source, P2P production?
– *Related to the legal perspective on freedom, mentioned above*: reflection on the relationship between freedom/property and responsibility, in particular regarding social and ecological responsibility.
– Privacy issues. Information technologies promise to generate and unleash huge masses of data that can contribute to human and social wellbeing, but also involve a huge risk regarding personal privacy and integrity.

Social sciences
– Introducing an historical, anthropological perspective on economy and money, as opposed to the universalist simplifications of classical economics. What lessons can be learnt from the past?
– Reflection on the social aspects of the collaborative economy. How can social goals (social equity, social cohesion) be built into a new societal value creation model?
– Which models/theories in social sciences can be used to enhance community building?
– Which models/theories in social sciences can be applied to enhance the cooperative economy?

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Medicine
- An “ecological” view of medicine: recognizing the connections between the health of ecosystems, populations, communities and individuals.
- Reflection on elements of the cooperative economy that can contribute to a better access to health care, lower drug prices, better quality of care, community-based health care.
- Community health care: reflection on the strengths and weaknesses, opportunities and risks. For example, can we speak of communities in urban contexts where neighbors do not know each other and communities are built along social, religious or racial lines? How can we tackle these issues?

Architecture
- Promoting ecological health in urban contexts, including composting, recycling, energy efficiency.
- Promoting urban agriculture to provide food, create green areas, create new jobs and strengthen the city’s resilience to climate change.
- Improving access for everyone, in particular the poor and disabled.

Can we contact you for getting further details of your challenge? **YES**/NO

Do you accept the terms and conditions for the proposition of this challenge? (See below) **YES**/NO

Terms and Conditions
1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people and planet base on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.
2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame
3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge
4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.
5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.
6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the “Transdisciplinary Insights Course” based on the Honors program regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access “Transdisciplinary Insights e-Journal”. Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the “Transdisciplinary Insights e-Journal” or at a “Transdisciplinary Insights Course” -related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the “Transdisciplinary Insights e-Journal” to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters’ names and/or logos will be acknowledged by the “Transdisciplinary Insights e-Journal”
8. “Transdisciplinary Insights Course” reserves the right to change or update these T&Cs from time to time without prior notice to you.
Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: jorgericardo.novablanco@kuleuven.be

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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
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 range of stakeholders affected by this challenge is potentially very large and encompasses all segments of society. We propose to provide the transdisciplinary team with access to a number of experts or resource persons who are able to contribute to a systemic reflection on broad societal transitions towards sustainability. These experts could be involved in personal interactions (via interviews, or team coaching sessions) or as a group (in a workshop format). To be decided.

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

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

If you have questions about some parts of the process, please ask them here:

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Supplement 2: Video presentation

Video presented at the Symposium “KU Leuven Facing the Future”, webinar, 7 May 2020: https://kuleuven.mediaspace.kaltura.com/media/Equitable+Society+challenge_Symposium+May+2020/1_p1lube4a

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Alternative Agri-Food Networks and Their Role in Re-Localization of Food and Creation of Shared Value: The Case of the Leuven Food Hub

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Abstract

Alternative Agri-Food Networks (AAFNs) are emerging as unconventional models of aggregation, distribution and marketing of food products, as opposed to the prevailing industrialized agri-food system. Within these alternative chains, different types of organizations such as food hubs are promoting a reconnection between producers and consumers as well as a fair distribution of social and economic value throughout the food supply chain. The article analyzes the sourcing and distributing practices of a case study, the Leuven Food Hub in Belgium. The research shows the role of the case study in the re-localization of food and the creation of shared value throughout the supply chain, illustrating the importance of transparency, traceability and trust relations. Moreover, it critically analyzes the transformative potential of this type of model to promote broader schemes of sustainable development. It is argued that these initiatives are proving to be highly resilient, especially in times of crisis, such as the one caused by the COVID-19 pandemic. It is highlighted how food hubs can bring incremental change towards more ecologically and socially responsible food systems. However, we outline the tension between scaling up and remaining alternative, short and local and the challenge this poses to the economic viability of the model. Broadly, given the fact that AAFNs are still a recent phenomenon and therefore a research field under construction, this study aims at contributing to scholars and practitioners with empirical evidence of a functioning alternative agri-food network.

Key words

Alternative agri-food networks, food hub, short supply chain

Introduction

The prevailing system of food production, distribution and consumption is dominated by the agri-industrial modernization project. This model is based on highly globalized, standardized and specialized production processes that respond to economic standards defined by the principles of comparative advantages, efficiency and competitiveness (Sonnino & Marsden, 2006). In terms of production, this system is controlled by

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large-scale multinationals that make use of intensive agriculture schemes to deliver highly processed food products aimed at the mass market. These products are then offered at incredibly low prices in supermarkets (Gilg & Battershill, 1998).

It is widely accepted that these vertically integrated, large multinational companies have contributed significantly to higher food outputs and productivity along the food supply chain. However, it is also evident that this system has failed to tackle the challenge of feeding the growing population in a sustainable way. In terms of socio-economic externalities, the conventional system expanded at the cost of the livelihoods of small-scale family farms. In addition, the environment has suffered relentlessly due to intensive agricultural practices, the use of toxic agrochemicals and transport emissions. Other issues include the lack of food safety and resilience, the obesity pandemic and the loss of cultural significance embedded in food (Berti & Mulligan, 2016).

There is a movement trying to tackle these challenges with unconventional initiatives, which are grouped within the academic literature in the concept of Alternative Agri-Food Networks (AAFNs). AAFNs are the result of activism by several movements that have been advocating for collaborative business models that put into practice political and ethical concerns related to sustainable, economically viable and socially responsible agriculture and food production. These movements are composed mainly of environmentalist activists, small farmer families, scholars, non-governmental organizations and small entrepreneurs. Hence, the diversity of stakeholders involved in these networks results in a broad list of initiatives providing different goods and services along the food supply chain (Volpentesta & Ammirato, 2013).

Within this diversity of initiatives, food hubs are one type of AAFN that has been growing in popularity over the last years. Food hubs are broadly defined as businesses or organizations that function as intermediaries in a food supply chain, overseeing aggregation, distribution and marketing of source-identified food products, mostly from local or regional farm production. Their overall objective is to provide alternative and shorter supply chains, bringing producers, processors, wholesalers, retailers and consumers closer together (Barham, 2012). By doing so, these initiatives aim fundamentally at the development of new relationships between producers and consumers through re-localization of food and the creation of shared value. The industrialization and globalization of the agri-food supply chain has resulted in a detachment between food and its socio-cultural and physical territorial context. As a response, several initiatives are aiming at reconnecting food with place, which is broadly known as re-localization. Shared value refers to a fair distribution of social and economic value throughout the entire supply chain. Furthermore, these models also have the intention to articulate new forms of political association and market governance (Sonnino & Marsden, 2006).

The main objective of the study is to analyze how food hubs can contribute to re-localization of food and the creation of shared value, exemplified by a case study from the region of Flanders in Belgium, the Leuven Food Hub. This shop is dedicated to the selling of organic, fair-trade products coming directly from farms in Belgium, Italy and Spain. Given the fact that there is a growing body of academic work aiming at defining the field of AAFNs and food hubs, the authors aimed to summarize some of the main definitions found in literature. These definitions are subject to discussion in the light of the case study, which starts with a description of the Food Hub and its context. It is followed by an analysis of the Food Hub as an AAFN, and its interpretation and implementation of shared value and re-localization. The challenges and opportunities of the Food Hub are reflected upon, including the positive and negative repercussions of the COVID-19 pandemic. The article concludes that the Leuven Food Hub is a valuable AAFN within its context and can inspire other initiatives.

Methodology

The study was conducted by a multidisciplinary and multicultural team of Master's students of the Sustainable Territorial Development Program at the University of KU Leuven. The students come from diverse academic backgrounds such as environmental engineering, social sciences and nature conservation, as well as from different continents such as Europe, Latin America and Africa. The Master's program itself presents a transdisciplinary approach, as it encompasses a broad study of sustainability from the social, environmental and economic perspectives. The research was developed in the framework of a course during the first semester of 2020, which had a workshop methodology focused on research about local food initiatives and the construction of sustainable places in Leuven.

The type of case study is mostly descriptive, as it outlines an intervention in its determined context. The

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research process consisted of two parts: the first was focused on data collection from secondary sources, its systematization and analysis; the second part consisted mostly of fieldwork related to the case study, which was carried out between the months of March and July 2020, during which the COVID-19 pandemic significantly disrupted global as well as local food systems. The choice of the case study was suggested by the course, as it appeared an interesting initiative closely linked to the subject studied. The set-up of the research was defined after an extensive literature review in which the theoretical framework around AAFNs and food hubs was consulted. After the review, two main concepts were chosen to analyze within the case study, as they allowed some of the key discussions of the course to be studied in depth, such as sustainable place-making and socio-ecological sustainability strategies. After conducting most of the deskwork, the research team developed fieldwork in order to obtain information about the case study. This information was later studied in the light of the theory revised, which is mainly what is presented in this article. The research process was closely supported by the course teachers, who read and commented on the work throughout the semester.

The different research topics and tasks were divided according to the availability and research interests of the team. The transdisciplinarity of the process is given by the fact that the different backgrounds were relevant to enriching the discussion, but they did not determine the contribution of each member. For instance, the interview guide was designed by the group as a whole, but carried out by one of the environmental engineers, who had no previous experience in conducting semi-structured interviews, as this is a technique generally used by other disciplines. This was purposely decided by the group, as a way to learn new techniques and challenge previous knowledge. In this sense, the insights are a product of rich discussions combining technical aspects related to food networks, as well as power relations embedded in the society–environment interactions studied.

Concerning the research techniques, secondary sources such as academic articles, books and institutional reports were consulted in order to provide a literature review. Moreover, social media and websites were consulted, mostly to obtain complementary information about the case study, for instance information about their food sourcing and labeling. As primary sources, the techniques used were semi-structured interviews, observation and mapping. More specifically, two interviews were carried out in March and April 2020 with the former General Manager and the former Assistant General Manager of the Leuven Food Hub.[1] This technique was conducted using a question guide previously defined by the research team, then recorded and transcribed for further analysis.

Moreover, several visits were conducted throughout the semester, which can be considered to be participatory observation. During these visits, the research team participated as customers, which allowed them to interact with other customers, the staff and the infrastructure itself. An observation plan was settled on prior to the visits in order to provide a guide for details to note and pictures to take. These visits were key in order to analyze aspects such as design, location, labels and other features relevant for the case study. Finally, the information collected was systematized using tables, in order to categorize and summarize the concepts around AAFNs and Food Hubs. Concerning the case study, a mapping tool was used in order to provide a geographical representation of the food sourcing of the Leuven Food Hub. More specifically, an interactive map was developed via the online tool uMap, displaying the locations of all producers supplying the Food Hub.

Case Study of the Leuven Food Hub

Regional and local context

Today, with the increasing world population, the global demand for food is predicted to increase and the importance of local food to sustain humanity is at the core of many discussions. The European Union (EU), which is one of the major global traders of food, and its Member States are actively involved in international standard setting in the area of food and feed (EC, 2020). The food sector in the EU is of significant

1 Oral consent was given by the informants during the interview in order to record, transcribe and use the information provided. The participants were previously informed about the purposes of the research, the course and the program in which it was developed, as well as a brief presentation of the research team. It was asked if the interview could take place in English in order to facilitate the understanding of the international members of the group, but participants were given the option to do it in Flemish as well. They were informed that their contribution would be voluntary, that no economic remuneration would be given and that they could refuse to answer any of the questions asked. In addition, they were informed about the confidential use of their information, strictly for the purpose of the research in the framework of the course and later academic publication of the results, for which they agreed to use their first names and names.

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economic value, comprising around 17 million holdings and enterprises, of which 82% are agricultural holdings, providing jobs to over 48 million Europeans and generating €751 billion of added value, almost 6% of the EU's GDP (Eurostat, 2011, as cited in EU, 2014). Food production within the EU relies heavily on natural resources and ecosystem services, and there is a high risk that the lack of environmental sustainability within the food system will impact its functioning. A sustainable food system is defined by the Federal Council for Sustainable Development of Belgium as one that "ensures adequate, culturally appropriate, healthy and affordable food for everyone". According to the European Commission (2014), this system should also include a strong food industry in terms of jobs and growth and, at the same time, environmental sustainability, in terms of issues such as climate change, biodiversity, water and soil quality (p. 4).

The EU reached 12.6 million ha of organic farmed land in 2017, which represents 18% of the global organic area and 7% of total EU agricultural land (EC, 2019). Additionally, the remarkable growth of organic production by 70% over the past ten years reflects the importance gained by this sector of the food system. The EU created an ecological label in 2010, the Biolabel, which is mandatory for all organic packaged food products in Europe. The label was created to guarantee production in compliance with the rules of organic farming, processing and sales. No artificial fertilizers, chemical pesticides or genetically modified organisms can be used, and only approved additives can be added. The EU Biolabel takes into consideration animal welfare and general environmental principles, but does not account for social implications. Working conditions are not considered and producers do not receive a minimum price for their products or a fair-trade premium (EC, n.d.). Organic farmers can apply for payments within the Rural Development Programs of the EU, which are a part of the Rural Development Policy that makes use of the European Agricultural Fund for Rural Development. These so-called agri-environment payments are annual payments per hectare to, for example, Italian or Spanish organic farmers to offset changes in income deriving from the commitment to organic production, and also transition and operational costs (Marras et al., 2012).

Within the EU, the government of Belgium decided in 2008 to significantly step up its commitment to agriculture and rural development. According to the National Report of Agriculture of Belgium (2018), the country has a very open agri-food sector and is the EU's fourth largest food exporter, with Flanders representing 82% of its trade. The overall number of farmers has been steadily decreasing, as reflected in the growth of the size of farms, while the total amount of arable area has stayed the same (Avermaete & Engelen, 2018). In 2018 there were 514 organic farmers in Flanders, accounting for 7,913 ha. It is worth noting that organic producers can apply for financial support per hectare from the Flemish government, introduced by the Department of Agriculture and Fisheries in 2020 (Flemish Government, 2020).

Despite challenges related to food production, Belgian consumers are very critical, demanding high-quality food and a great variety, while still being able to make the right environmental choices. In Belgium, 39% of consumers recognize that buying local is sustainable. Even though organic food is considered more sustainable, only 15% eat organic foods, which explains the low organic food consumption per capita at €61 per year (Statista, 2018). In 2017, organic fresh food in Flanders had a market share of 2.4% (MIRA, 2019). An example of a successful initiative is Bio-Planet, which is an organic retail chain within the Colruyt Group. It is committed to providing an organic or ecological alternative to any product, including non-food products, which is how it gained traction. However, critics of the retailer point out that, during its growth, some sustainable values were dropped. Moreover, other large supermarkets offer a range of organic products side-by-side with other non-organic ones.

In this context, the Leuven Food Hub likes to present itself as opposite to not only conventional supermarkets, but also to large organic alternatives such as Bio-Planet or other large retailers. According to the Leuven Food Strategy 2030, the Food Hub is a prime example of a short-chain supermarket in the city, even though other big supermarkets are starting to incorporate local products as part of their offer too. The Food Hub contributes to several policy goals defined within the Strategy, such as bringing producers and consumers closer, promoting sustainable agriculture and stimulating innovation (Avermaete et al., 2018).

The Food Hub in Leuven

The first initiative of the Food Hub was a pop-up store in the Depot in Leuven, founded by organic farmer activist

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Figure 1. Location of the Food Hub store in Leuven

Simon Clissold[2] in May 2015. The first store was opened in Boutersem in October 2015, and in 2016 Food Hub CVBA was founded by Mr Clissold, the Italian agricultural cooperative Valdibella and two other partners. In September 2016 the Leuven Food Hub, the case study of this research, was inaugurated at the back entrance of Leuven's central station (see a map displaying the location in Figure 1). Another store was opened in 2017 in Molenbeek. Food Hub CVBA also provides organic wholesale services to 20 restaurants and shops around Belgium that share the same ideals as the Food Hub, such as Roots in Brussels and Les Petits Producteurs in Liège. The most important cooperation within the CVBA is with Valdibella, which over the years has accounted for 75% of the investments in the Food Hub.

As stated on its website, the Food Hub was established with the goal of creating a resilient, transparent and sustainable food chain in Belgium, by cooperating with producers and entrepreneurs. Its main objective is to provide an extensive selection of organic products of high quality, the majority of which come straight from small- and medium-scale producers in Belgium, Italy and Spain. It tries to answer the present-day needs of consumers and aims to distribute profits fairly. Its determined values are organic, support for small- and medium-sized producers, transparency, fair trade and cooperation (Food Hub, 2020).

The Food Hub store in Leuven has a surface area of 500 m² and is open every Wednesday to Sunday. Part of the store is used as a café with a kitchen offering organic coffee, salads, sandwiches, soup and cakes. The store offers an array of organic products, ranging from vegetables, fruits, dairy products and meat to bread and beverages (see Figure 2). All products are certified organic or in transition to organic. Where possible, preference is given to production linked to regenerative agriculture, which is defined as a system of farming practices that aim to rehabilitate and enhance the entire ecosystem of the farm by ensuring soil health (Rhodes, 2017). Producers are located all around Belgium, in Northern and Central Italy, on the island of Sicily, and in the South of Spain. Some specific products are also imported from Ecuador, Portugal and the UK.

2 Mr Clissold was in charge as general manager of the Food Hub until the start of 2021.

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Figure 2. Photos of the interior of the Food Hub store in Leuven (Food Hub, 2020)

Relationships with farmers are as personal as possible, which is an essential characteristic of this Food Hub. In Sicily, the Food Hub works together with Valdibella, which shares the same values and takes care of the complex distribution and coordination with many small farms across the island. Valdibella sends an offer to the Food Hub two times a week. In Spain one contact person, a long-time colleague of Mr Clissold, coordinates everything on the ground. Mr Clissold and his colleagues try to visit the farms as often as possible in order to maintain close relations. Once a year, a "farmer's market" is organized in Belgium, where producers are invited and can meet the customers that consume their products. The prerequisites for being a producer for the network of the Food Hub are to be certified organic and small-scale and to share the same beliefs regarding environmental regeneration and healthy food. Since these aspects are hard to define and evaluate, a visit from someone involved in the Food Hub is always deemed necessary.

The CVBA has four class A shareholders and around 30 class B shareholders. The goal is for the Food Hub to become a multi-stakeholder cooperative, which was the aspiration for opening up the CVBA to new participants. A multi-stakeholder cooperative is a type of cooperative model in which the membership includes two or more classes of constituents, which can be producers, consumers, workers, investors, volunteers or other stakeholders that perform very different roles within the supply chain but share common interests (Leviten-Reid & Fairbairn, 2011). Since most of the partners over the years have mainly had an investor role, most decisions are still made by Mr Clissold, in consultation with producers. The stores each have a person responsible for everyday operational decisions. To quote Mr Clissold: "It is a cooperative in structure but not in practice, but that's where we are heading".

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What is alternative about the Leuven Food Hub?

The founder of the Food Hub defines the store as "[a] working partnership between buyers and farmers, where the partnership is based on transparency and trust, based on a common interest of farmers and buyers, which is high-quality, safe, healthy food at a fair price produced by family farmers." It is important to understand the definition of the Food Hub in the light of the principles proposed by the literature on AAFNs. First, it is described as a partnership between buyers and farmers, which means that farmers have a role as strategic partners, implying a distribution of power along the supply chain. Second, this partnership is based on transparency and trust, which is related to access to information regarding traceability, origin, product composition and modes of production. It also refers to the performance of the supply chain and how it is based on shorter communication flows between farmers, intermediaries and consumers. Third, it highlights the existence of a common interest, which refers to sharing a vision, information and decision-making among the strategic partners. Fourth, this definition outlines high-quality, safe and healthy food, which are important principles of AAFNs. Finally, it refers to a fair price, which implies that the prices are based on reasonable calculations that promote fair income for the producers, contributing to an equitable distribution of added value over the network.

In the case study, the distinction between the definition of food hubs as merely values-based agri-food supply chains or rather as sustainable food community development is not strict, as the Food Hub incorporates both approaches. Its economic value and business strategy are strongly linked to social and environmental values. Horst et al. (2011) outlined five elements for describing food hubs when analyzed as case studies: three organizational elements – ownership, purpose and audience – and two physical elements – design and scale. The ownership of the Food Hub aims to follow a multi-stakeholder cooperative structure. The purpose is mainly socio-economic and environmentally driven, focusing on empowering farmers through regenerative agriculture practices and providing high-quality and healthy food products for consumers. The Food Hub's audience is the population of the city of Leuven, mainly those consumers who are interested in alternative and sustainable products. In practice, young families have proven to be interested in their products, which makes them an important target group. Even though the Food Hub aims to provide products for a wide public, it is important to outline that organic food is more expensive than conventional food, which might affect access for low-income families. Nevertheless, the interviewees consider that the prices are reasonable compared to similar products in other supermarkets.

Considering the design, the store has a simple arrangement where fresh products are displayed in warehouse agricultural boxes, the processed products are presented on shelves and posters and pictures are hanging on the walls (see Figure 2). These posters, other than adding value to the interior design of the store, play a key role in terms of providing information about the source of the product, details about the producer and how value is distributed. The coffee shop offers small meals and desserts prepared with products from the store. The location is strategic because of the constant flow of people passing through the train station and is easily accessible by bike or car. It is also close to residential neighborhoods, which according to Mr Clissold are inhabited mostly by young families, one of the main target groups. As mentioned by the managers, finding this location was not an easy task and it indeed influences the success or failure of this type of initiative. The scale of the distance to origin of the products is mainly regional, since they come from farms located in Belgium, Italy and Spain. The scale in terms of the distribution and selling of the products is mainly local, focused on the city of Leuven.

The Food Hub presents several of the characteristics outlined in AAFN and food hub literature. Its definition and classification follow an approach that prioritizes economic, social and environmental goals over market-driven supply chains. An important remark made by Mr Clissold is the fact that the definition and purpose of a food hub are related to its territorial context. In his experience, a big part of the success of a food hub depends on its ability to incorporate basic characteristics of the neighborhood or city where it is located. He stated that "the models have to be local, every place is different, they are always adapted. The model that comes out depends on the place." For instance, from his perspective, one action that may contribute to this is hiring local people to work in the store, which can promote closer relationships with consumers. This is linked to what Blay-Palmer et al. (2013) noted about the place-based nature of food hubs as "fluid organizations

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that emerge from and reflect the unique character of the places they serve and shaped by where they develop" (p. 524). In this sense, every model of a food hub is distinct because each locality is different. This recalls what Scott (2019, p. 2) suggests in his study about AAFNs: "If you've seen one food hub, you've seen one food hub", referring to the uniqueness of each food hub in the world of AAFNs.

Apart from functioning as an intermediary, the Food Hub is a grassroots organization with strong political ideals that advocates for small-scale farming and regenerative agriculture. Yet, like any other food hub, it is still developing and adjusting in the shadows of the dominant industrialized food system (Stroink & Nelson, 2013). This means that, in practice, the Food Hub cannot function entirely separated from the conventional system. Instead, it can manage to benefit from it in specific sectors where, because of the inequality in access to resources, an AAFN cannot work on its own. This relates to what authors such as Cleveland (2014) have described as the hybrid nature of food hubs, which goes beyond the simple dichotomy between conventional and alternative food systems. This hybridity presents the potential for food hubs to capture many of the advantages of both alternative direct marketing and the mainstream large-scale distribution systems, while minimizing the disadvantages of each.

Another important aspect outlined by Mr Clissold is the fact that the Food Hub is based on "relationship economy" management. This means that the operational model is embedded in marketing networks and interactions, directed towards long-term win-win relationships. The primary point of reference of the marketing is the relationship between the different agents in the supply chain, based on trust and transparency (Gummesson, 2002). It is interesting to point out that the concept relationship economy is little present in the literature reviewed, but it indeed incorporates some of the main values and principles promoted by AAFNs. Taking this into consideration to further analyze what makes the Food Hub an AAFN, the concepts of shared value and re-localization are discussed in the following sections.

Shared value distribution in the supply chain

The Leuven Food Hub is founded on a process of co-production of value among all its actors and throughout the whole supply chain, so that the creation of economic value is strictly linked to the creation of social and environmental value. Porter & Kramer (2019) define shared values as "policies and operating practices that enhance the competitiveness of a company while simultaneously advancing the economic and social conditions in the communities in which it operates" (p. 327). AAFNs therefore aim for a final product price that reflects the actual value and allows an equal distribution of the profit, which is made possible by an effective recognition and equal repartition of value in all the stages of the value chain (Berti & Mulligan, 2016). The shared values of the Food Hub are fair trade, transparency, cooperation, support for small- and medium-sized producers, and organic products (Food Hub, 2020). The founding values of the Food Hub are implemented daily throughout the different stages of the supply chain.

Fair trade is a system aiming to promote more just conditions for international trade and to create a balanced economic system (Fair Trade Belgium, 2020). Even though the concept of fair trade has been developed with regard to the producers of the global South, in the Food Hub they are convinced that the concept of fair trade must also apply to Europe, because the European market presents an unequal power repartition along the supply chain as well. For the Food Hub, an important aspect of fair trade is a fair pricing system, which does not allow the value to be underestimated at any stage of the supply chain. The setting of the selling price requires that the producer establishes his price, and to this starting price extra costs are added, such as transport costs and taxes. This accounting system ensures that the final price reflects the actual value of the product. The assistant general manager's perspective on the matter is that "this idea of making things cheaper makes it that someone in the chain will have to pay a bigger price … It's the normal price, it's supermarkets that are too cheap". It can be added that the organic market is still a "niche market", with a relatively limited profitability. The price of the products will decrease as demand increases (Fair Trade Belgium, 2020).

The standardized process for the definition of the price, although it requires a lot of work, is essential to the Food Hub. It is part of the logistics management, ensuring the traceability of the products, by capturing and transmitting information about a product throughout the supply chain, which is important for safety and quality control (Bosona & Gebresenbet, 2013). It relates to another main value, that is, transparency, defined as the

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Figure 3. Food Hub labels showing the price distribution and the origin of the products (Food Hub, 2020)

extent to which all stakeholders have access to comprehensible information about a product (Trienekens et al., 2012). In fact, the price distribution in percentages per product is available to the customers, by using labels that show the name of the producer and its location (see Figure 3). The Food Hub considers it necessary that everyone can have access to this information. It enables them to gain consumers' trust and to increase proximity, even without personal contact between producers and consumers. As Mr Clissold explained, to be transparent is also a way to be competitive with conventional shops that are introducing features of AAFNs. These shops, for example, promote their short supply chains, but in reality, only a few of their products meet those requirements. The Food Hub, on the contrary, is able to provide products that come from relatively far away, while still restoring the consumers' feeling of control over their food selection, because the access to product information is ensured.

As Mr Clissold explained, cooperation means recognizing and valorizing the system of mutual interdependencies unfolding in the Food Hub network. At the heart of the cooperation value is the awareness that it is necessary to help each other, in order to achieve something that cannot be achieved alone. The Food Hub has the role of relationship builder, by creating a network of producers. In this way, it valorizes the work of many small producers, which by themselves could not reach economic viability and market access. The fact that Mr Clissold himself was a farmer helps him to understand the farmers' difficulties and needs and to find adequate solutions.

The Food Hub supports small- and medium-sized producers. They believe that this smaller size is more likely to realize a "true sustainable agriculture" (Food Hub, 2020), as opposed to industrial, large-scale organic food production. Several environmental benefits are claimed to result from small- and medium-scale farms as compared to large farms. These include for example a greater biodiversity, increased soil fertility and more efficient water management and water retention in the soil (Food Hub, 2020). Additionally, supporting small- and medium-sized producers is a way to enhance the local economy by creating employment, due to the fact that more manual labor is needed per hectare. Nevertheless, to be small- or medium-sized is not a standard criterion for the Food Hub, and shared beliefs are often more important. The Food Hub's managers carefully choose the farmers that share their philosophy and verify this on their visits. This is a way to implement what Goodman (2004) defines as territoriality, namely rural development based on "more endogenous, territorialized and ecologically-embedded" (p. 6) production, whose attributes are conveyed along the supply chain.

The last value of the Food Hub is promoting organic agriculture as a sustainable food production system. An important role that the Food Hub can play is supporting small producers in the transition to organic agriculture. Even though they use the EU Biolabel, the Food Hub website and Mr Clissold acknowledge that it has many

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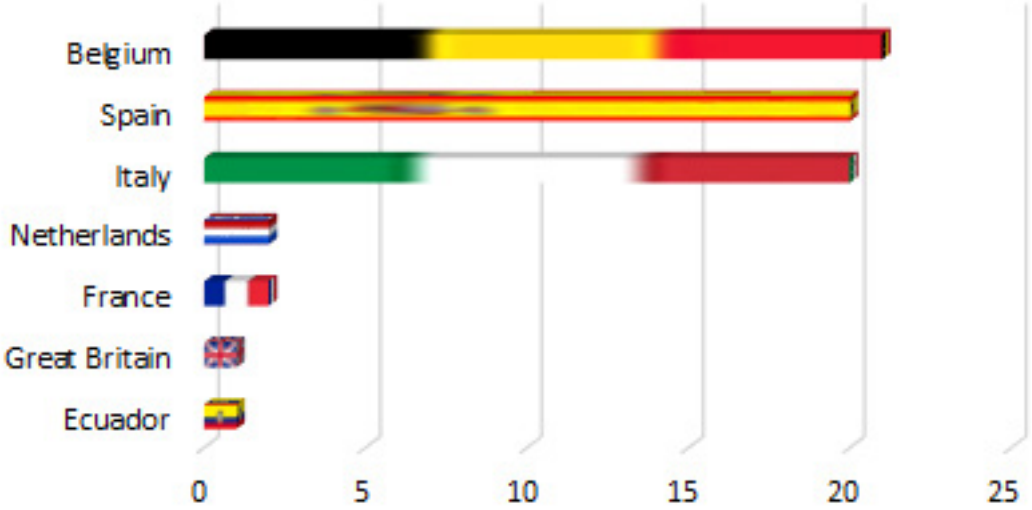

Figure 4. Number of Food Hub suppliers per country

limitations: "The fact that it's organic doesn't mean that it is nutritious, it doesn't mean that you don't have to grab land, it doesn't mean you're not exploiting workers." Nevertheless, the organic certification remains a necessary condition for their producers to access the market.

Promotion of the re-localization process

The concept of re-localization within the framework of AAFNs proposes the creation and empowerment of short food supply chains, through which a close relationship between producers and consumers is built not only in the territorial but also in the social sense. Moreover, the revalorization of local resources is strongly encouraged in order to create auto-sustainability of the local food system, with an improved management of resources, information and knowledge among stakeholders (Volpentesta & Ammirato, 2013).

Under the concept of re-localization, it is clear that the Food Hub is following a broader approach, considering that they are not working exclusively with producers on a local level, but have expanded their relationship to a more regional level, including producers from mainly Italy and Spain (see Figure 4). According to the founder, this expansion was necessary to satisfy the needs of customers, stating that "shoppers in Leuven are not disposed to go out of their way to shop. They want to go to a shop and buy everything there". Therefore, a wider range of products and secure year-round provision were deemed crucial for the success of the Food Hub, which would not have been possible within Belgian limits. If there had only been a collaboration with Belgian producers, many products that are nowadays considered to be essential in Belgian pantries and fridges would not be available. In this way the Food Hub is redefining the concept of re-localization, not focusing on the local scale exclusively, but interpreting the territorial aspect in a more regional way. The Food Hub can be considered a spatially extended type of AAFN (Marsden et al., 2000; Wiskerke, 2009) that prioritizes the needs and preferences of the actors involved, while maintaining and promoting their original values.

Porter & Kramer (2019) mentioned that business thinking is based on the idea that "location no longer matters, because logistics are inexpensive, information flows rapidly, and markets are global". In this sense, concerns about the localities in which the company operates are often ignored (p. 335). By contrast, the concept of re-localization emphasizes the importance of a shorter supply chain, which refers not only to the geographical distance between the producers and consumers, but also to the relationship that could exist between those actors. The Food Hub understands the value of this relationship and highlights that it is based on trust. They promote this with the yearly farmers' market and the visits to farms, where different types of stakeholders have the space to interact and exchange ideas, with the aim of showing the common motivation among them. The Food Hub has been working with the same farmers for a long time, and they are proud of the strong relationship built between them. Mr Clissold emphasized that it takes time to create these relationships and it is important to keep them as personal as

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possible. Therefore, their objective is not to multiply those relationships but to maintain them, for which they are not looking for new farmers, considering that "the more people you have, the less personal it gets".

As far as decision-making is concerned, even though the founder is the one who makes most of the decisions, the producers are included as much as possible. They refer to the Food Hub as a partnership, where the yearly supply schedule is determined in cooperation with the producers. Additionally, producers work together in order to avoid producing the same crop at the same time and to ensure that they can jointly meet the demand. Besides the opportunity to set their own prices, the producers know that they can rely on the Food Hub for their sales and that it is a safer market for them. The Food Hub is not their only buyer; some of them also provide to different retailers. However, the relationship with these other buyers is less personal and the prices they offer vary, which is why they prefer to work with the Food Hub as much as possible. The aim of the multi-stakeholder cooperative organization is to implement new regulations to ensure representation of all members on the board and a reasonable distribution of voting rights (Münkner, 2004).

It is worth noting that those responsible for the Food Hub are aware of the implications of outsourcing, especially those related to the carbon footprint generated by the transport of products. Initially Mr Clissold himself drove around in order to get everything to the Food Hub. Because of the car's capacity, this took many trips, resulting in higher emissions per product than in conventional supermarkets. Now, the Food Hub uses some of the same transport means as the conventional systems to import their products. Mr Clissold stated: "The fact that we can import avocados from a small farmer in Malaga is because of the conventional system. We are definitely using what we can from the conventional system." He recognizes the importance of having more efficient means of transport, even though they will still not be completely free of negative environmental impact. In their work about the "local trap", Born & Purcell (2006) mentioned that in some cases, importing products is more environmentally desirable than degrading local resources to produce them. The "local trap" refers to the tendency of assuming something inherent about the local scale without taking into consideration the changing relationship between the various scales. The assumption that a local food system is more ecologically sustainable and socially just does not always hold. The local trap can therefore obscure the real implications of the implementation of an exclusively local food system.

The assistant general manager remarked that "[w]hat we really want is to be the alternative to normal supermarkets", stressing the opposition between the systems. However, it also emerged that the Food Hub can be embedded in the conventional, capitalist market and even partly depend on it, as is exemplified by the use of the transport system. On the one hand, the principle of shortening distances and relocation would correspond with minimizing intermediaries in the chain. On the other hand, big retailers are indispensable, because they can offer industrial agriculture warehouses and transport. Mr Clissold declared: "We are using the conventional system against it." This leads to a reflection on the Food Hub's transformative capacity and to what extent it can transform the conventional food system.

In addition, it was noticed that even though extensive information is available about all suppliers on the Food Hub website, a clear visualization of the scale of this initiative was missing. A map could show consumers in a visual way where their food comes from. Therefore, as part of this case study, an interactive map was developed via the online tool uMap, displaying the locations of all producers of the Food Hub.[3] An example of the map can be found in Supplement 2. The information displayed for each farm includes the location, the first year of organic certification, the type of business, the number of employees, the products and a link to their page on the Food Hub's website. The map will be embedded on the Food Hub's website and provide customers with a clear view of the spatial origin of their food.

What is next: challenges and opportunities

It is important to highlight some of the upcoming challenges and opportunities for the Food Hub, considering its long-term development and the future the managers envisage. A first main obstacle is the local policy, especially regarding land access and subsidies. In Belgium it is difficult to have access to arable land because the territory, especially Flanders, is very built up. The existing financing and support systems still often focus on conventional, large-scale farms. However,

3 The map can be found in Dutch through this link: http://u.osmfr.org/m/452939/.

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especially producers targeting the local market need to be supported in a more consistent way. In fact, since they often do not come from an agricultural family and therefore rarely have sufficient land, the high prices for agricultural land are a major barrier for them (MIRA, 2019). Furthermore, farms in Belgium are becoming increasingly larger, but their number is decreasing. It is therefore almost impossible for new farmers to start an organic farm.

The agricultural sector in Belgium heavily relies on the subsidy system. However, the Food Hub since its foundation has never received any subsidies from the government. Mr Clissold is skeptical about the subsidy system, which – he stated – can have conflicting effects. He recognizes that the businesses receiving subsidies are usually able to find great success at the beginning, due to extra resources for extensive research and development. Nevertheless, the subsidy system as it is designed now does not enable skill development and solid company structure, which makes it not sustainable. Large-scale subsidies used to be a good lever to achieve efficiency when the food sector was growing, but they are not suitable for the current food system anymore (MIRA, 2019). The success that many farmers and businesses achieve is strictly dependent on these subsidies and does not lead the organizations to evolve towards a resilient and flexible structure in the long term.

One of the major roles and strengths of the Food Hub, which differentiates it from the conventional supermarkets, is to be a connector. Even with increasing physical distance between consumers and producers, food hubs can act as intermediaries and ensure trustworthiness, providing information about certification, product origin, quality, sustainability and cost and benefit distribution (Berti & Mulligan, 2016). The institutionalization of initiatives such as the Food Hub would also be important for making them economically viable, for example by enhancing the role of food hubs in connecting economic clusters of multifunctional rural territories and consumers (Goodman, 2004). In fact, a major problem is the limited profitability of the Food Hub, since as of 2020 the business has not yet been profitable. The economic model of the Food Hub implies, at least for now, lower profits than the conventional system. Even though they increased their margin by 5%, the Food Hub is still not profitable after more than three years. Although it is not their priority, being profitable is definitely a challenge that concerns the future of the Food Hub. The managers of the Food Hub opened up their business to class B shareholders, but without making a profit, it is difficult to attract new shareholders.

Consumer choices and preferences are an important variable in reaching economic viability. The managers of the Leuven Food Hub need to be careful about envisaging and monitoring the demand and its development. This task could be difficult, since most of the managers and employees of the Food Hub are not from the neighborhood it is located in. The Leuven Food Hub has found a balance in providing a quite diverse and broad range of food products, without promoting the process of delocalization implemented by the supermarkets (Wiskerke, 2009). This can make the Food Hub miss out on a certain target group of one-stop shoppers. However, even though it is still a goal, rather than an outcome, the Food Hub does not have a specific target of consumers: they try to reach as many people as possible and to be the alternative for people that want something different. The assistant general manager stated that the biggest compliment comes from those clients who are not even interested in organic products and still recognize they taste different. A strong point of the Food Hub is the creative marketing they use to introduce consumers to the organic world and their other ideals. They attract customers by offering various events and initiatives. For example, once a year, customers are invited to meet the producers at the “farmers’ market”. A few times a year the Food Hub welcomes a business to showcase its ideas, such as a pop-up restaurant and product tastings.

Economic viability might be attained through a process of scaling up. A major area of research yet to be explored involves how to scale up initiatives like the Food Hub, since the market share of AAFNs is still very small compared to conventional networks. It is however difficult to scale up and simultaneously not lose any of the social, environmental and positive localized economic impact (Prost, 2019). In conformity with this view, Mr Clissold stated that he does not dream about turning the Food Hub into a chain of many shops: “I want to continue working with the same suppliers, which means that there is a ceiling to the number of stores. To me the trust of my suppliers is more important than getting rich” (Bio Mijn Natuur, 2017). Instead, the Food Hub envisages a collaboration with similar projects in other cities. In this sense, the Food Hub aims to be an inspiration for those who want to start an innovative shop or a food hub. They do not plan to take over the food system, but want to work together with other actors to grow. For

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example, in the case of the Rico shop in Antwerp, they provided training and mentoring. The assistant general manager remarked that "it's really difficult to find people with the same philosophy and commitment to carry something like [the Food Hub]". In fact, one of the major problems of scaling up is the risk of having to give up their fundamental values. Competitiveness is important, but profit should not become the main driving force of the organization. The next challenge is to obtain a multi-stakeholder cooperative in practice, an opportunity to enhance their organization, by having a heterogeneous membership base, able to reflect the interests of each group of stakeholders. They aim to consolidate their value system, to strengthen ties with customers and to build long-term relationships with producers.

The Food Hub and COVID-19

The year 2020 will forever be remembered as the year of COVID-19, which was declared a pandemic by the World Health Organization on 11 March 2020 (WHO, 2020). Besides its health implications and the negative social impact of social distancing measures, there is something that was hit even harder by the pandemic: the global economy. Agri-food networks were certainly not spared from this disruptive phenomenon, and conventional AFNs proved fragile due to their reliance on global trade (Stokel-Walker, 2020). At the start of lockdown measures, hoarders were scavenging the supermarket aisles for pasta, flour and canned foods, condemned by retailers and fellow citizens (Decock, 2020). Even though food supply in Belgium was not jeopardized, some unsustainable aspects of the conventional food systems were highlighted.

The role of the Food Hub in this crisis exhibits its sustainability and resilience, with several factors contributing to the Food Hub's risk competitiveness. Firstly, its solid supply chain was emphasized, with larger retail stores looking to buy their products from the Food Hub or directly from Food Hub producers. However, producers stayed loyal to the Food Hub, thanks to well-maintained relations, strengthened by good communication in this complex context. Some producers reached out to the Food Hub, thanking them for providing continuous access to a fair market in this time of crisis. Secondly, due to its short supply chain, the Food Hub is only dependent on a few actors, and only the closing of borders to cargo transport could heavily hurt its business. This is a stark contrast with conventional agri-food networks, where crops and other products were wasted due to lower demand and the mismanagement of supply chains (BBC, 2020). Because of the close coordination between seller and buyer in the Food Hub, mismatches between supply and demand can be managed more easily.

During the first lockdown measures in Leuven, sales were up 30–50%, a profitable level. This can partly be attributed to people buying more vegetables and fruits, out of necessity to eat every meal at home. In addition, due to organic's "clean" reputation, people started to buy more organic products out of greater concern for their health (BBC, 2020). Furthermore, since non-essential travel was prohibited, people were driving less and sought food stores closer to home. Big organic stores, such as Bio-Planet, though easily accessible by car since they are often located on large roads, are harder to reach by foot or bike. The Food Hub hopes that the shift will be permanent for some customers, convinced by the Food Hub's concept and atmosphere.

Conclusions

Contemporary global challenges highlight the importance of resilience and sustainability within agri-food networks. In this context, there is no unique and ideal solution, but each initiative should be valued for the incremental change it can bring. AAFNs have proven to be a strong alternative promising to have the answer to the issues of the conventional system. However, an AAFN integrating all aspects of sustainability is unrealistic, and compromises have to be made between different values. Food hubs are models that broadly incorporate the values and goals of an AAFN, but they are not necessarily the only and the best option. As the Leuven Food Hub founder mentioned, in the end "Food Hub" is just a name; more important is that the model is flexible enough to adapt to the local context. It is important to remember that there is no perfect food hub, and that trade-offs will arise between different values. It is therefore important to set priorities, but to not lose sight of the other values promoted within AAFNs.

The Leuven Food Hub can be considered an AAFN because it promotes many of the values related to AAFNs that can be found in literature on the subject. Nevertheless, the Food Hub has a unique interpretation of concepts such as shared value and re-localization. Firstly, its values go beyond social and economic considerations and also include more environmental-related

objectives. The focus lies on the social values transparency and trust, which are demonstrated in its special price labels and close relations with suppliers. What sets the Food Hub apart is its solid and resilient supply chain network, enabled by the interactions with producers. To strengthen these bonds even more, it plans to transform into a multi-stakeholder cooperative, empowering producers as well as consumers.

Secondly, the re-localization process within the Food Hub's AAFN is more focused on the social aspect as well. A reconnection was established between consumers and producers, and consequently with their food. This reconnection is a result of in-person interactions, transparency, traceability and all the information that is disclosed on its website and in the shop. In a territorial sense, the suppliers cannot all be considered local. Less than a third of the producers are from Belgium, and even though most suppliers are located within European borders, some products are sourced from farther away. This wider approach to re-localization was deemed crucial by the managers, considering the specific consumers in Leuven and their shopping behavior. In this way, they seem to have avoided the "local trap", by considering local products as a means to attaining sustainability, without treating them as the Holy Grail. In a social sense, the Food Hub's supply chain is not only solid because it is short in distance, but especially because it involves only personal relationships based on mutual trust.

The Food Hub was never intended to take over the food system. It only hopes to be an inspiration to like-minded people by setting a good example and providing learning opportunities to new businesses. Profitability remains the main challenge, but has proven difficult because of the problems of attracting shareholders, the abstention from subsidies and the lack of support of the local government. The opportunities the Food Hub has are centered around strengthening the business and creating a multi-stakeholder cooperative. Some unexpected opportunities might arise from the COVID-19 crisis. Its consequences could induce permanent changes in global food supply chains, paving the way for AAFNs to take over, especially local and short-chain alternatives. Everywhere, sustainable alternatives are proving that if sustainability is integrated as a holistic concept, it has the potential to increase resilience of the entire food system, especially in times of crisis.

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List of supplements

Supplement 1: State of the art
Supplement 2: Examples of the information displayed on the uMap

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Supplement 1: State of the art

Alternative Agri-Food Networks: an emerging research field

The concept of AAFNs was first introduced in the 1960s in Japan, Germany and Switzerland, and later adopted in the USA during the 1980s (Cao, 2012). Because AAFNs are part of an emerging research field, many different definitions are found in academic literature. In general terms, they can be seen as a form of resistance against the *status quo*, as they aim to revitalize the territorial identity and community relations to local food and agriculture. Also, they aim at developing sustainable agriculture models, based on economically viable and socially responsible practices. Moreover, they are not built solely on economic relations, but value social interactions that enable learning processes for producers as well as consumers (Volpentesta & Ammirato, 2013). There are three main types of AAFNs. The first is face-to-face, where consumers purchase the product directly from the manufacturer or processor on the basis of direct personal contact. The second type is defined by spatial proximity, which means the food is produced and retailed in a specific region. Lastly, there is the spatially extended type, in which local value and regional identity are incorporated into the product itself and transmitted to consumers outside the region (Marsden et al., 2000; Wiskerke, 2009).

It is important to note that within the academic literature there is no consensus as to a structured definition of AAFNs. Firstly, there seems to be some confusion associated with the coexistence of conventional and alternative agri-food networks, and their supposed opposition. Most AAFNs do not exist entirely separate from the conventional food systems but are rather deeply embedded in them and depend on the capitalist market. AAFNs should therefore not be seen as completely opposite to the conventional system, but as actors that co-evolve and attempt to change it from within. By building a sustainable economy, AAFNs compete with the conventional food networks and appropriate flows that would otherwise be channeled through corporate circuits of value creation. AAFNs attempt to transform the hegemonic economic model from within by "challenging its productivity-driven socio-spatial arrangements by creating alternative economic spaces within which to develop different operational logics and value systems" (Matacena, 2016, p. 52). In doing so, their main challenge is the balancing of ethical aspirations for social justice, health and sustainability, and achieving a wider impact on the food system transformation (Prost, 2019).

Furthermore, the AAFN concept has received its own share of criticism. AAFNs have been criticized for being elitist, exclusive and inequitable (Berti & Mulligan, 2016). Some AAFNs tend to produce high-quality and often artisanal products but at expensive prices (Prost, 2019) and mostly targeted to high-income communities and urban areas. This has been questioned by scholars and practitioners who claim that the role of AAFNs should be to contribute to a revalorization of the countryside and to solve the problems of "food deserts" for low-income households, which are defined as areas with limited access to affordable and nutritious food. Even though some scholars argue that the shift towards re-localized agri-food networks is promoting the rise of a new and more territorially based rural development paradigm, other researchers are questioning whether this change will be long term and if these models are truly mitigating long-standing problems of poverty, inequality and social exclusion (Sonnino & Marsden, 2006). However, because it is still a recent phenomenon, it is difficult to judge the viability and efficiency of AAFNs to deliver higher goals of sustainable agriculture and rural development. For this reason and because these criticisms require studying consumers within the value chain, this paper does not approach this subject.

A major area of research yet to be explored involves how to scale up these initiatives, since the market share of AAFNs is still very small compared to the conventional networks. In the US for example, 97% of food still travels through conventional market structures. In the UK, 77% of all main shopping trips are to the supermarket (Berti & Mulligan, 2016). However, it is difficult to scale up and simultaneously not lose any of the social, environmental and positive localized economic impact. Indeed, it is a difficult task to balance social justice goals and economic viability, having to compete with low prices from supermarkets (Prost, 2019).

AAFNs and public policy

It is important to consider that the growth and viability of AAFNs is highly affected by food policy regimes at national and regional level. According to Goodman (2004), growing literature on AAFNs portrays these initiatives as precursors of a paradigm change in production and consumption schemes reflected in the EU's Common Agricultural Policy

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(CAP) 2003 reform. This instrument is relevant in terms of understanding new expansions in contemporary agriculture policy in Europe, as it introduces several changes to the definition of rural development that are key to AAFNs. The author highlights three main changes. The first one is subsidiarity and the increasing decentralization of agricultural regulations within the EU. The second one is the multifunctionality of rural territories, which refers to the clusters of economic activities that go beyond strictly agriculture to move to services and others. The third one is territoriality, which is the growing tendency of territorial valorization of products. These policy changes contribute to the creation of AAFNs in Europe, but it is important to consider that the transition is complex and the rhythms of transformation of the paradigm are not necessarily equal in every region.

In this vein, AAFNs can use their transformative potential to effectively turn into a new paradigm only if the conventional food governance model is transformed. This means that the role of policy is key in providing a framework for the rise and proliferation of alternatives (Marsden et al., 2018). This institutional intervention is central in both production and consumption. According to Reisch et al. (2013), the EU's policy has focused mainly on production regulation, with less attention on consumption. For instance, the organic production sector is heavily subsidized, which has influenced the availability and affordability of these products. However, governments have shown weak instruments to address consumption, focusing mainly on food safety issues and competitive prices, paying less attention to the sustainability of consumption patterns. They mention that "in the face of the dominant, highly concentrated, powerful retail industry that characterizes the European food domain, governments tend to restrict themselves to a marginal role and to non-invasive instruments, such as consumer information and education" (p. 17). It may be possible that the AAFN sector is growing faster than the policy to regulate it.

Shared value

Shared value is a key concept of AAFNs, aiming to realize a new, sustainable economic model. AAFNs are based on a process of co-production of values that occurs throughout the whole supply chain, in order to achieve a set of shared goals. Porter & Kramer (2019) recognize the principle of shared value to be at the basis of a transformation of business thinking, involving the creation of economic value in a way that also creates value for society. They define shared values as "policies and operating practices that enhance the competitiveness of a company while simultaneously advancing the economic and social conditions in the communities in which it operates" (p. 327).

Incorporating a values-based approach into food supply chains involves identification and definition of the values, the embedding of the values into the corporate culture and documentation and review. Once defined, the core values must become permanent features of daily business life. Food value chain managers, therefore, must explicitly reference and uphold these values in written agreements between stakeholders, in the form of standard operating procedure documents, business protocols and marketing arrangements, to facilitate their adoption and implementation (Diamond et al., 2014).

AAFNs aim for a final product price that reflects the actual value and allows an equal distribution of the profit. This is possible with an effective recognition and equal repartition of value in all the stages of the value chain. Such a process does not occur in the conventional food network, where the creation of shared values is subordinate to the creation of profit per se, and it is placed at the margins, instead of at the center of company strategy. In conventional food networks, profit maximization is pursued in the short term, without internalizing environmental and social costs, whereas in AAFNs a long-term shared value maximization is performed, taking into account externalities (Rockström, 2009, as cited in Berti & Mulligan, 2016).

The shared value approach involves the development of mutual or collaborative advantages for the producers as well as consumers. From a narrow economic perspective, on the one hand, producers can obtain a fair price generated by product differentiation and better distributed profits, and on the other hand, consumers can have access to local products of good quality. Nevertheless, broader positive impacts on both sides must be considered, in terms of local socio-economic vibrancy, community building and environmental sustainability (Berti & Mulligan, 2016). Quality is not a straightforward concept and some parameters are, for example, nutritional values, healthiness, being organic, place of origin, and ethicality. It follows that quality is not a characteristic inherent in a food product, and that to analyze shared values, it is important to consider the social processes through which quality and its attributes emerge and spread among producers and consumers (Barbera et al., 2014).

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Other key concepts that are essential to understand the creation of shared values in AAFNs are the principles of trust, traceability and transparency. In fact, in conventional networks, "the growing distance – in both time and space – between production and consumption … often confronts consumers with the feeling of a loss of control of their ability of choice in food selection" (Meijboom, 2006, p. 428). This leads to a loss of trust from consumers and an increasing need for food networks to be considered trustworthy. A way to achieve this objective is to increase transparency and traceability. Transparency has been defined as the extent to which all its stakeholders have a shared understanding of, and access to, the product-related information that they request, in a clear and complete way, without biases (Hofstede et al., 2005, as cited in Trienekens et al., 2012). Traceability has been defined as "a part of logistics management that captures, stores, and transmits adequate information about a food, feed, food-producing animal or substance at all stages in the food supply chain, so that the product can be checked for safety and quality control, traced upward, and tracked downward at any time" (Bosona & Gebresenbet, 2013, p. 35). Transparency and traceability both contribute to improving market efficiency, to enhancing information exchange in the whole supply chain and to optimizing logistical processes, representing tools to enhance consumers' trust. Values have to be shared and explained to consumers too, since they are key stakeholders and participants of AAFNs.

Re-localization

Re-localization is another important concept of AAFNs, but it is not exclusive to this approach. The capital-intensive perspective of 'sustainable agriculture' promotes the increase in productivity employing more effective inputs, decreasing the resources needed and pollution. The alternative approach, by contrast, encourages a less-intensive agri-production with the purpose of adding value to the food production and making use of local resources instead of external ones, as well as farmers' knowledge (Levidow, 2011).

As stated by Sonnino & Marsden (2006), the concept of local can be defined as the regional production and consumption of food linked to particular geographical places. However, it can also be understood as the process of attaching certain characteristics of a territory to a food commodity, embedding it with particular environmental and social qualities. In a conventional food system, the use of intensive agriculture has resulted in a disconnection between food and its sociocultural and physical territorial context (Wiskerke, 2009). In this type of system, the ownership of the product and decision-making is usually monopolized by a firm or cluster of firms. Therefore, the producer often becomes a mere labor provider, also providing some capital in some cases, but is rarely part of the decision-making process or the owner of its own product (Hendrickson, 2002). According to Levidow (2011), the disconnection between the consumer and the producer limits their ability to criticize the status quo (Tornaghi & Van Dyck, 2015). This in sum is referred to as food delocalization.

The concept of re-localization put forward by AAFNs proposes a shorter food supply chain in order to bring producers and consumers closer together to gain the trust of the consumer (Hendrickson, 2002). Another goal is connecting environmental and economic sustainability, where producers are able to get more of the value added and are involved in the decision-making process, locally available resources are used properly, and energy inputs and transport costs are reduced. This in turn encourages cooperation among different stakeholders, such as local producers, intermediaries and businesses, to boost the local economy. In addition, it is a way to maintain the territorial and specific identity of the producer and revitalize local knowledge, as well as promote regional branding (Levidow, 2011).

Even though the idea proposed by the AAFNs of focusing more on the local scale has proven efficient, there have been concerns about the implications of the concept. The assumption that a local food system is more ecologically and socially sustainable just does not always hold. This tendency of assuming something inherent about the local scale without taking into consideration the changing relationship among the various scales is what Born & Purcell (2006) referred to as the "local trap". The "local trap" can obscure the real implications of the implementation of an exclusively local food system. For instance, implementers often treat localism as the ultimate goal, when it is actually a means to a wider objective, for example sustainability or social justice. Additionally, this might shade the effectiveness of other scalar options to reach the desired outcome. As mentioned by Manganelli (2019), there is a need for connections between institutions, organizations and AAFNs of different localities to take actions towards improved socio-political institutions.

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Goodman (2012) argued that a food system does not become more just simply by making it local, since very often localism is used as a way for local elites to establish protective territories that merely serve their own interests. The idea of "local" needs to be rethought, in a way that localism can function as an effective social movement of resistance to the conventional system. The concept that Lefebvre (1991) used to describe space, with a more relational ideology including not only its physical components but also the social one and the interrelations among them, is then more suited to analyzing the "local" in this context. A reflexive localism can be proposed, which states that all factors affecting the desired outcome need to be taken into consideration. These factors should be considered bidirectional, meaning that they affect one another without being exclusively assigned to cause or effect. Therefore, instead of creating an alternative economy for the homogeneous few, this approach intends to make a difference for everybody involved.

Food hubs: a definition under construction

The food hub concept is still a definition under construction, not only within the academic literature but also among practitioners. This is mainly because food hubs are a relatively new type of AAFN, but also because they present such diverse forms, making it difficult to agree on a one-size-fits-all definition. In this sense, several authors have described the challenge of delimiting the field of food hubs. For Scott (2019, p. 2), a humoristic way to illustrate this heterogeneity is by saying "if you've seen one food hub, you've seen one food hub", which refers to the uniqueness of each food hub in the world of AAFNs. There is no standardized definition mainly because it is still in the process of being legitimized by entering the lexicon of organizational types (Scott, 2019). Even though the diversity may be desirable considering the very different contexts in which food hubs emerge, this definitional issue (Morley et al., 2008) may be problematic in terms of the divergence between realities and expectations of the role they play in the food system (Fischer et al., 2015).

Given the diversity of definitions found in the literature review, a systematization is proposed by this study, ranging from narrow definitions to broader ones (see Table A1). These definitions are later used to describe and classify the chosen case study. In this vein, authors such as Berti & Mulligan (2016) have made an effort to systematize the different definitions found in academic literature. They concluded that the approaches are mostly dichotomic, for instance, instrumentalist vs. idealistic, conventional vs. sustainability-oriented, and instrumental producer-oriented vs. humanist people-oriented. As an attempt to summarize their review, they propose two lines of conceptualization trying to group these different dichotomies. The first approach presents narrow goals, mostly focused on the supply. The second approach emphasizes the function of food hubs beyond the supply, highlighting their role in terms of broader social concerns.

For instance, one possible definition that can be located within the first approach is proposed by Barham et al. (2012) and it states that food hubs are a "business or organization that actively manages the aggregation, distribution and marketing of source-identified food products primarily from local and regional producers to strengthen their ability to satisfy wholesale, retail and institutional demand" (p. 4). This type of definition focuses on food supply chains characterized by partnerships that share a series of commitments to environmental, social and economic values associated with the food products. These values can be related to local-sourced products, small or mid-scale farms, sustainable agricultural practices or worker welfare, among others. Under this approach, the focus is supply-driven, mainly on the distribution of profit coming from these values along the chain (Feenstra & Hardesty, 2016).

For the broader approach, a possible conceptualization is the one proposed by Blay-Palmer et al. (2013), which describes food hubs as "networks and intersections of grassroots, community-based organizations and individuals that work together to build increasingly socially just, economically robust and ecologically sound food systems that connect farmers with consumers as directly as possible" (p. 524). This perspective presents a broader understanding of food hubs, highlighting the innovation processes developed at the community level, as opposed to market-led economy approaches (Berti & Mulligan, 2016).

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Table A1. Definitions of food hubs (own elaboration)

	Definition	Author
Narrow	Business or organization that actively manages the **aggregation, distribution and marketing of source-identified food products** primarily from local and regional producers to strengthen their ability to satisfy wholesale, retail and institutional demand.	Barham et al. (2012)
	Any kind of organisational model where food sourcing and supply is coordinated and may be contrasted with a wholly dispersed market system, comprising of **direct links between the producer and the consumer**. It may act much in the same way as a traditional wholesaler or commodity clearing house, but it may also have other functions such as facilitating particular types of relationships and supporting defined objectives that free markets on their own may not achieve.	Morley et al. (2008)
	Financially viable businesses that demonstrate a significant **commitment to place** through aggregation and marketing of regional food.	Fischer et al. (2015)
	Food Hubs lie at the centre of supply-value chains, enacting roles as **coordinating intermediaries** between producers (usually small- and medium-sized firms) and consumers (both individuals and private and public organizations) while simultaneously providing an array of social benefits related to food systems.	Scott (2019)
	Intermediaries between many market actors in the aggregation and distribution of local or regionally produced food, with a civic agriculture mission. They provide opportunity for creative learning and experimentation among community members and can serve as bridges for broader **community-building** and educational efforts.	LeBlanc et al. (2013)
	Intermediary organisation or business which works as the supply chain manager and provides a logistical and organisational platform for the aggregation and distribution of source-identified food products from local and regional producers to both the wholesale buyers and end consumers. A strategic network to **co-produce shared value to be equally distributed** within the network and that has strategic positive economic-social and environmental spill over effects in the locality.	Berti and Mulligan (2016)
	Networks and intersections of **grassroots, community-based organisations** and individuals that work together to build increasingly socially just, economically robust and ecologically sound food systems that connect farmers with consumers as directly as possible.	Blay-Palmer et al. (2013)
Broad	A network that aims to configure an alternative distribution system by bypassing supply chain intermediates, securing fairer prices for producers and potentially for consumers. By facilitating such producer-consumer reconnections they promote relations of care through **fairer prices for producers, relations of solidarity based on co-operative work structures** and voluntary labour and a diverse economy that re-circulates money to the local economy and encourages relations of gift and sharing.	Psarikidou et al. (2019)
Source: own elaboration		

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Towards a classification of food hubs

The same heterogeneity found in terms of definition is also present in terms of classification of food hubs. For instance, Morley et al. (2008) propose to classify them in terms of the type of organization that is leading the food hub. In a similar way, Berti & Mulligan (2016) distinguish between the different types of legal structures that food hubs can present. Moreover, Horst et al. (2011) propose a classification based on the different roles a food hub can play in a determined context, showing a wide range of examples for each type. In this vein, they can also be classified according to their function, as proposed again by Berti & Mulligan. Furthermore, authors like Furman et al. (2018) present three categories based on the size of the farms, the aggregation structure and the type of users. Table A2 summarizes these different classifications.

Table A2. Classification categories for food hubs (own elaboration)

Classification	Categories	Authors
Organizing lead	Retail led Public sector led Producer-entrepreneur led Producer-cooperative led Wholesaler and foodservice led	Morley et al. (2008)
Legal structure	**Non-profit organizations** **Private food hubs** **Cooperatives** **Public food hubs**	**Berti and Mulligan (2016)**
Operation Model	Boutique/Ethnic/Artisanal Consumer-Cooperative Model Destination Education and Human Service-Focused Neighborhood-Based Online Network Regional Aggregation Rural Town Hybrid	Horst et al. (2011)
Function	**Farm-to-business/institution model** **Farm-to-consumer model** **Hybrid model**	**Berti and Mulligan (2016)**
Farm size	Large farm Medium farm Small farm	Furman et al. (2018)

Source: own elaboration

Apart from proposing a typology of food hubs according to their operation model, Horst et al. (2011) outline five elements for further describing food hubs when analyzed as case studies. These elements refer to organizational (audience, ownership and purpose) and physical (design and scale) considerations, and they are defined as follows. Audience refers to the target clientele that the food hub intends to attract, which can be neighborhood residents, tourists, high- and middle-income families, low-income families or large-scale food distributors. Ownership refers mostly to the classification based on the leading organization and legal structure of the food hubs presented in Table A2. Purpose is strictly connected with the definition of food hub, whereas it seeks market-driven purposes or rather socio-economic, environmental community-driven objectives, and therefore linked to the type of audience and ownership. Design refers to "the means of tying together the purpose and processes of a food hub into a corresponding form" (p. 221). In other words, the presentation format of the food hub, which can for example be a store, a market or several buildings. In this sense, some important elements to consider are the use of space, the architecture, the graphic design as well as the historical and cultural expressions linked to them. Scale corresponds to the geographical scope of the food hub in two ways: first the sourcing of the products retailed, and second the location of the distribution. It is linked to the use of space, the audience and the purpose of the organization. Even though there is no consensus over the definition and classification of food hubs, authors such as Fischer et al. (2015) highlight that using broader definitions allows space for innovations, being able to catch the many different structures, purposes and activities that current food hubs employ globally. According to this author, the most important element of a food hub is the active role they play in helping grow regional food systems, exhibiting values beyond achieving only financial goals. However, it is important to understand that not all food hubs are necessarily committed to social roles, whether because they lack interest or because they lack capacity.

Food hubs as AAFNs

According to Psarikidou (2019), food hubs are AAFNs that "aim to configure an alternative distribution system by bypassing supply chain intermediates, securing fairer prices for producers and also potentially for consumers" (p. 526). As alternative to the conventional system, they contribute to facilitating producer–consumer reconnections that promote "relations of care through fairer prices for producers, relations of solidarity based on co-operative work structures and voluntary labor and a diverse economy that re-circulates money to the local economy and encourages relations of gift and sharing" (p. 527). Even with increasing physical distance between consumers and producers,

and no direct personal control of consumers over the products, food hubs can act as intermediaries and ensure trustworthiness, providing information about certification, product origin, quality, sustainability and cost and benefit distribution (Berti & Mulligan, 2016).

However, in practice, these considerations about the contributions of food hubs as AAFNs can be seen as idealistic, since most of them function as hybrids between conventional and alternative food systems, showing potential to capture many of the advantages presented by both. This occurs mainly because food hubs face many challenges in terms of their economic viability and their possibilities of scaling up, while also committing to wider social and environmental issues (Cleveland et al., 2014). In this sense, not all food hubs can address problems such as unequal distribution or inequitable access to quality food, which is why they have also been labelled as elite practices (Psarikidou, 2019). It is important to note that this criticism is not exclusive to food hubs, but rather a general challenge faced by AAFNs.

Nevertheless, food hubs can be considered as food value-chain facilitators, fulfilling different functions. They serve as relationship builders that identify and connect key stakeholders and services, maintain communication channels and build strategic partnerships with other value-chain actors. Food hubs can, additionally, be viewed as technical assistance providers, delivering, for example, education and training programs for farmers, food buyers, and food preparers. Another function of food hubs is to be third-party certification organizations, developing certification programs that build consumer confidence. Lastly, they can be catalysts or innovators that develop and test new business models. At the same time, as value-chain facilitators they also have to overcome some limits. For instance, distribution models that focus on fair pricing for growers, but do not appropriately consider consumer demand or the variable and fixed costs of running a distribution operation represent a common trap, leading to ineffective strategy (Diamond et al., 2014).

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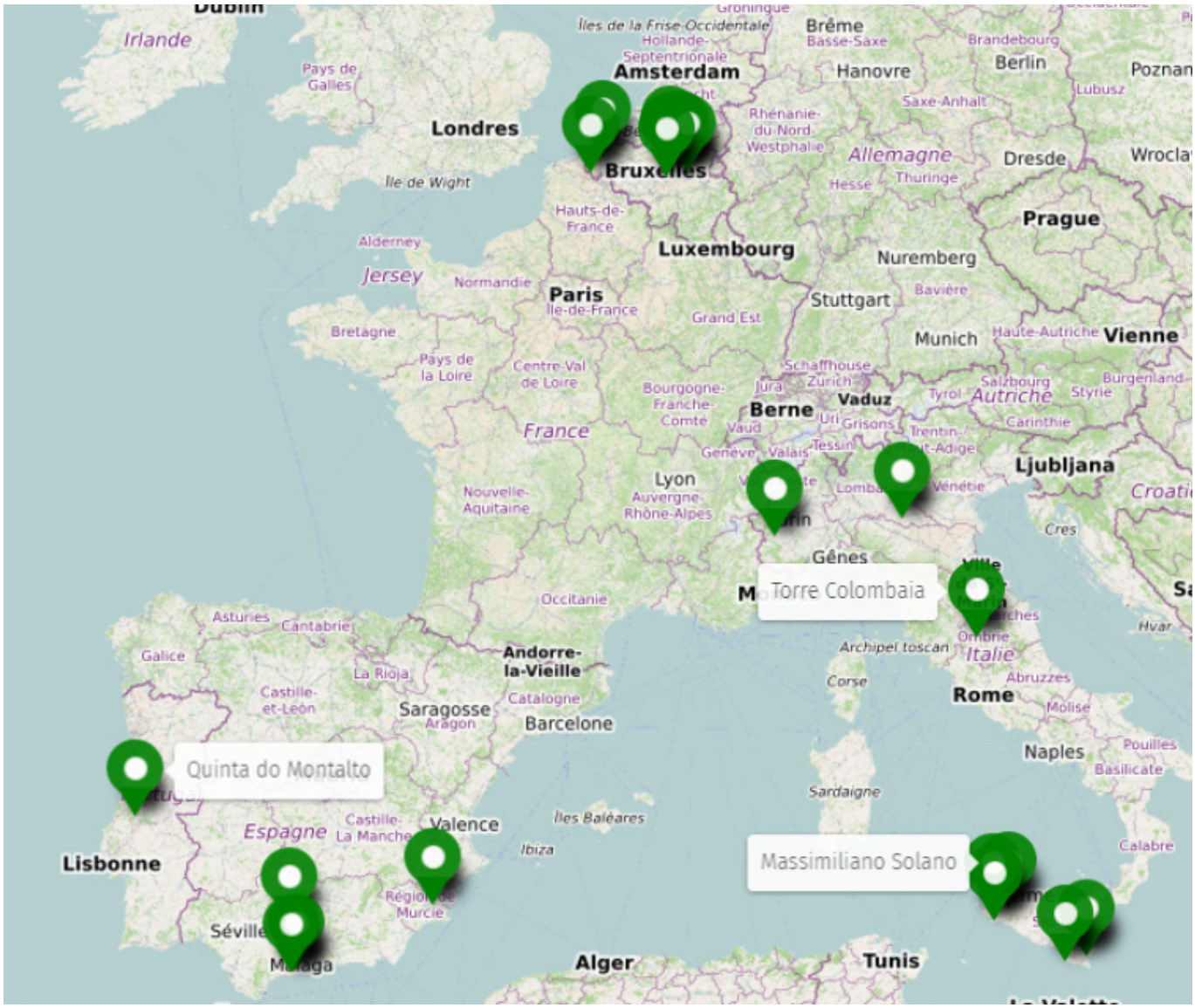
Supplement 2: Examples of the information displayed on the uMap

Complete interactive map available at http://u.osmfr.org/m/452939/



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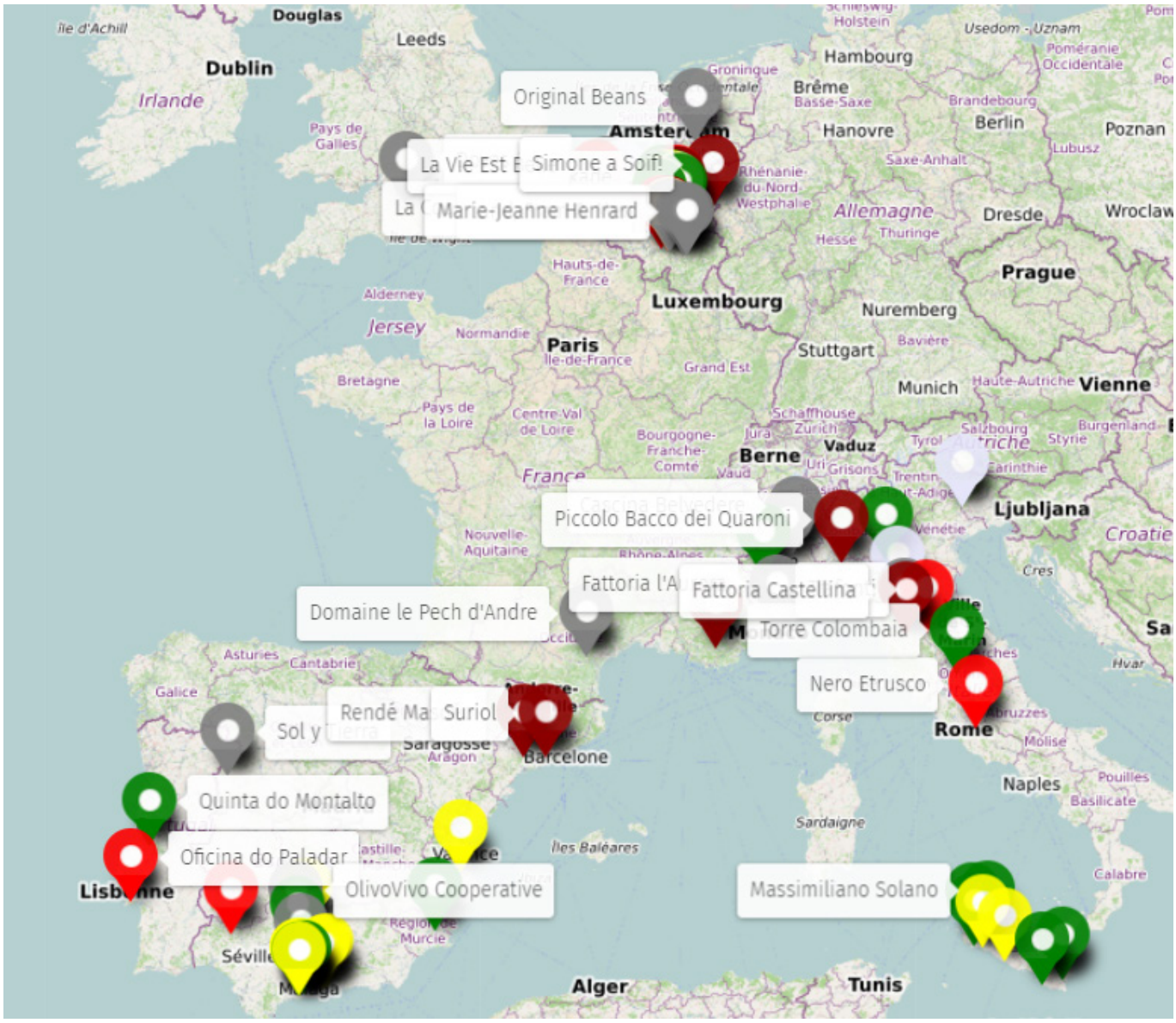

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