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HIV-related Peer Support in Dar es Salaam: A Pilot Questionnaire Inquiry

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Abstract

HIV drug resistance (HIVDR) in Tanzania is a complex problem with many interconnected causes. Some important factors contributing to the selection of drug resistant viruses in people infected with HIV are stigma, poverty, poor health, illiteracy, and insufficient adherence to antiretroviral therapy. Several studies have suggested the implementation of peer support groups as a way to shift the workload associated with adherence support, antiretroviral therapy (ART) distribution, and HIV education away from the doctors to the people living with HIV (PLHIV) themselves. We conducted interviews with local PLHIV to investigate the desirability and feasibility of a peer support group in the Pasada and Kisarawe hospitals in Dar es Salaam, Tanzania. A standardized questionnaire was completed by 27 PLHIV in July and August 2017 at the time of a follow-up visit. In this cohort, major causes for missing a dose of ART are lack of support from family and friends and forgetfulness. Reasons for wanting to join

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a peer support group include psychological support, fighting stigma, and increasing education about their disease. Interestingly, several respondents linked HIV peer support to business support groups such as village community banks (VICOBA). These are informal microfinance groups meant to offer economic stability to individuals. As this link was made by PLHIV themselves, we suggest that it may be worthwhile to explore mixed financial and HIV peer support groups in which HIV education is provided for both HIV positive and negative members. Such groups may reduce the risk of infection and stigma and provide combined psychological, financial, and logistic support to PLHIV.

Key words

HIV, HIVDR, transdisciplinarity, peer support, micro-finance groups

Introduction

Current antiretroviral therapy (ART) is capable of lifelong suppression of the human immunodeficiency virus (HIV), resulting in a patient life expectancy approaching that of the general population (Trickey, 2017). However, pre-treatment drug resistance to non-nucleoside reverse transcriptase inhibitors (NNRTI), an important class of HIV drugs, is rising. Prevalence estimates in Sub-Saharan Africa report that up to 23.6 percent in South Africa and 15.4 percent of infected individuals have pre-treatment NNRTI resistance in Uganda (WHO, 2019). Also the prevalence of acquired drug resistance among individuals on first-line ART who have an unsuppressed viral load after 12 months is worrying (up to 97 percent in Uganda) (WHO 2019).

Many causes of both pre-treatment and acquired HIV drug resistance (HIVDR) have been identified. The most important one is insufficient adherence to therapy resulting from several factors, such as limited drug availability, ineffective patient-doctor relationships, fear of stigmatization, side effects of the drugs, and treatment interruption due to disengagement from care (Altice, Mostashari, & Friedland, 2001; Van Tam, Pharris, Thorson, Alfven, & Larsson, 2011). Adressing these problems is not straightfordward, as each individual cause can be the result of a whole range of influencing factors that differ on an individual basis, by culture, healthcare center, etc. Moreover, the conditions that give rise to these problems can shift in time so that other or new aspects become salient. As such, any solution to the problem is only ever a partial solution. HIVDR is therefore a "wicked" problem which requires a transdisciplinary and people-centered approach to solving it.

One major contributing factor relevant to many aspects of the HIVDR problem is the shortage of healthcare staff. In 2014 the World Health Organization (WHO) estimated the number of physicians in Tanzania to be 0.399 per 10,000 inhabitants,[1] and in rural areas this number is even lower. To shift the workload from physicians to the people living with HIV (PLHIV) themselves, different forms of peer support have been introduced across settings (Decroo, 2017). In such peer support groups PLHIV support each other both psychologically and logistically, for example by taking turns in picking up ART at the hospital, thereby reducing the number of hospital visits per PLHIV.

This article builds upon the work of a transdisciplinary team at KU Leuven which investigated the complexity of HIVDR in Tanzania in 2017 (Dehens et al., 2017A; Dehens et al., 2017B). The team investigated the feasibility and acceptability of peer support groups for PLHIV enrolled in the ART programme of the Pasada and Kisarawe hospitals in Dar es Salaam, Tanzania, using a transdisciplinary approach combined with relevant stakeholder interviews. We designed a questionnaire in order to solicit the opinion of HIV positive individuals about peer support groups. In what follows we describe the results of those questionnaires filled in by HIV positive adults enrolled in the Pasada and Kisarawe hospitals.

Methods

The questionnaires were designed by a transdisciplinary team at KU Leuven with the help of HIV experts at NGOs, universities and research institutions, and governmental institutions. The transdisciplinary process used for developing the questionnaire is described by Dehens et al., (2017B). The questionnaires were designed in English and subsequently translated into Kiswahili (attachment 1 and 2). The study was conducted in Dar es Salaam, Tanzania, from July to August 2017. The study population consisted of adult PLHIV (both male and female) who were registered at the ART program in the Pasada and Kisarawe hospitals. PLHIV visiting the Pasada and Kisarawe hospitals for their check-ups were invited by their healthcare

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workers to provide their informed consent and fill in the questionnaire.

Ethical permission to conduct the study was obtained from the National Institute for Medical Research in Tanzania. Any patient identifiers were removed from the data collection before the data were shared with the researchers in Belgium.

The questionaires were analyzed using RStudio (R version 3.4.2) and written answers were taken into account for the interpretation of the data.

Results and Discussion

Demographic data

Data on 27 participants (13 male, 11 female, 3 participants did not indicate their gender) were analyzed (Figure 1A). Participants were of the following age groups: 18-20 years (3/27), 20-40 years (11/27), and 40-65 years (10/27) (Figure 1B). Of the 27 respondents, 22 belonged to the lowest income category with an income of less than 100,000 Tanzanian shillings (Tsh) monthly, which equates to 40 Euros or 45 USD at the time of the study, 2017. Two participants earned between 100,000 and 500,000 Tsh per month (40-200 Euros or 45-230 USD) and one earned between 500,000 and 1,500,000 Tsh monthly (200-600 Euros or 230-680 USD) (Figure 1C). None of the participants reported earning more than 1,500,000 Tsh (600 Euros or 680 USD) per month. Two participants spent less than one hour in picking up their medication, 7 spent 2-4 hours, 11 participants spent 4-6 hours and five of the 27 participants took more than 6 hours traveling to pick up their ART refills (Figure 1D). When asked to indicate how happy they were with the current amount of time needed to pick up their medication on a scale of one to eight (1 = not happy at all, 8 = very happy), the participants answered with on average 5.44 (standard deviation: 1.73).

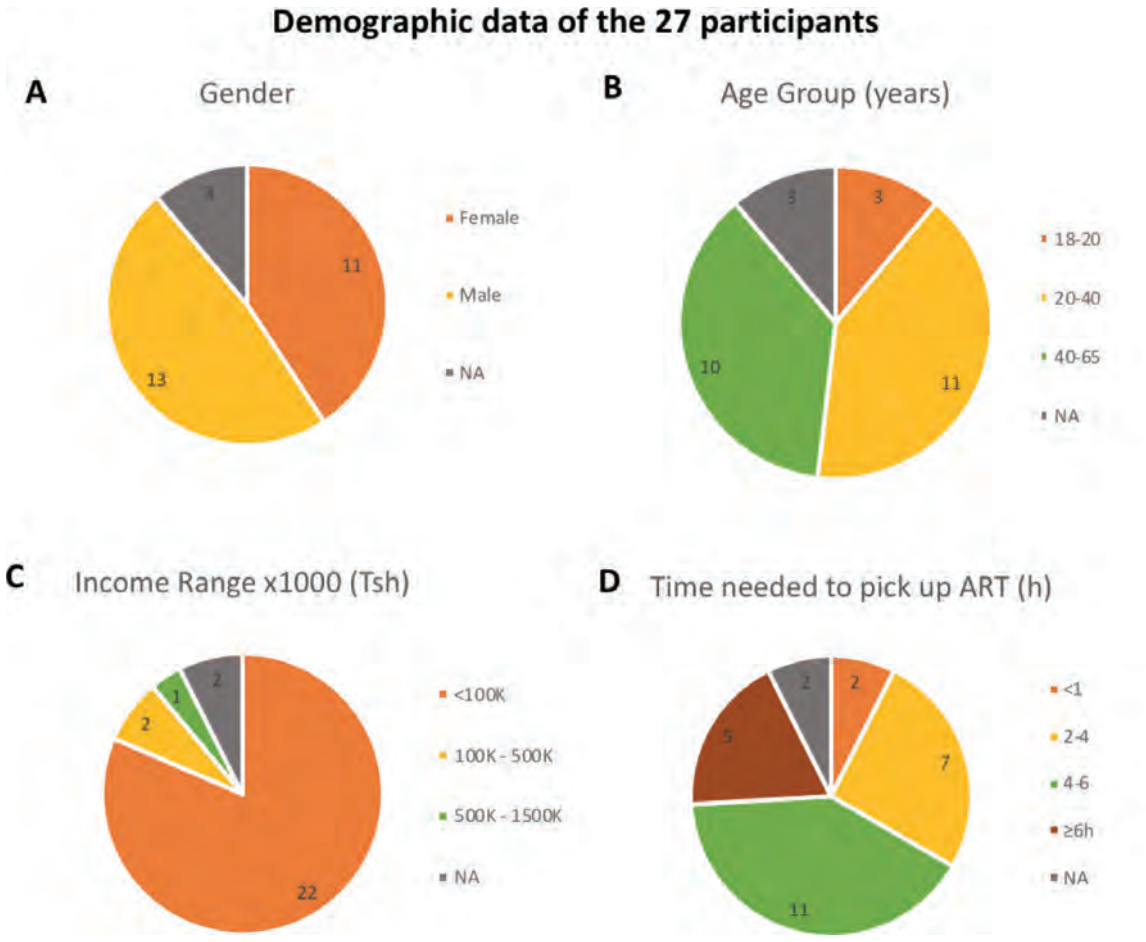

Figure 1. Demographic data of the 27 participants: A) Gender B) Age C) Income range D) Approximate time needed to pick up ART. Abbreviations: NA = not answered, Tsh = Tanzanian Shilling, ART = Antiretroviral therapy, h = hour

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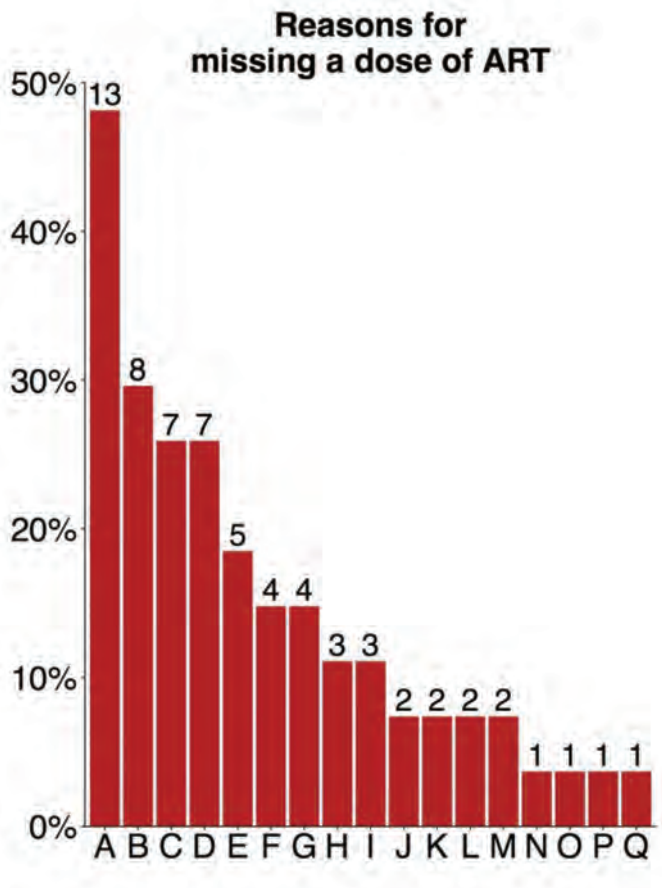
Adherence

Respondents indicated a median of 2 reasons (median average deviation, MAD=1) when asked what the main reasons were for missing a dose of ART. Almost half of the respondents (13/27) indicated never having missed taking their ART (Figure 2). However, although denying missing doses, 10 of these 13 respondents did indicate reasons for missing doses of ART. This apparently contradictory finding suggests that the respondents may not have felt comfortable confessing adherence issues to the healthcare worker who interviewed them. The two most frequently observed reasons for missing a dose of ART were simply forgetting to take the dose (8/27) and lacking support from family or friends (7/27). Other answers written in the free field by the participants themselves included: *"I don't take the medication when I don't have food", "There are no jobs"* and *"When I have an unplanned trip I don't carry medicine".* Only two of the respondents answered that they were not sure how and when to take the ART.

In contrast, when answering the question "*which of the following help would make you take your pills properly"* more than half of the participants (15/27) indicated that "*information on when and how to take the pills*" would be of help (Figure 3), suggesting the majority of participants are not entirely confident about how to take the pills. Other common answers were "*automatic reminders via messages/apps*" (12/27), "*less stigma*" (18/27) and "*HIV education in the community*" (17/27). Also support from doctors, nurses, and family and friends was often indicated (11/27, 9/27 and 7/27, respectively). Participants indicated a median of 3 options (MAD=2) of preferred adherence support.

Peer support group

The vast majority of the respondents (25/27) indicated that they thought organizing peer support groups, led by an expert patient, would be helpful (Figure 4A). To this question 2/27 participants provided no response. Out of the 27 participants, 22 indicated interest in



A. I never missed taking my pills
B. Simply forgot
C. I lack support from family/friends
D. Other
E. Too much time lost in picking up medication
F. I don't want to take medication
G. The medication tastes bad
H. I lack support from my community
I. I am not sure the medication is working
J. I don't have enough privacy at the clinic
K. Not sure how and when to take the pills
L. Difficulty swallowing
M. No time
N. Pharmacy out of stock
O. I lack support from hospital staff
P. I don't have enough privacy to take pills
Q. The drugs make me feel sick

Other answers

"When I have an unplanned trip I don't carry medicine."
"After I received a divorce."
"I lacked means of getting medicines when medicine was finished."
"To go fishing without medicine."
"He has never forgotten to take his medication."
"I don't take medicine when I don't have food."
"There are no jobs."

Figure 2. Reasons indicated for missing a dose of ART.

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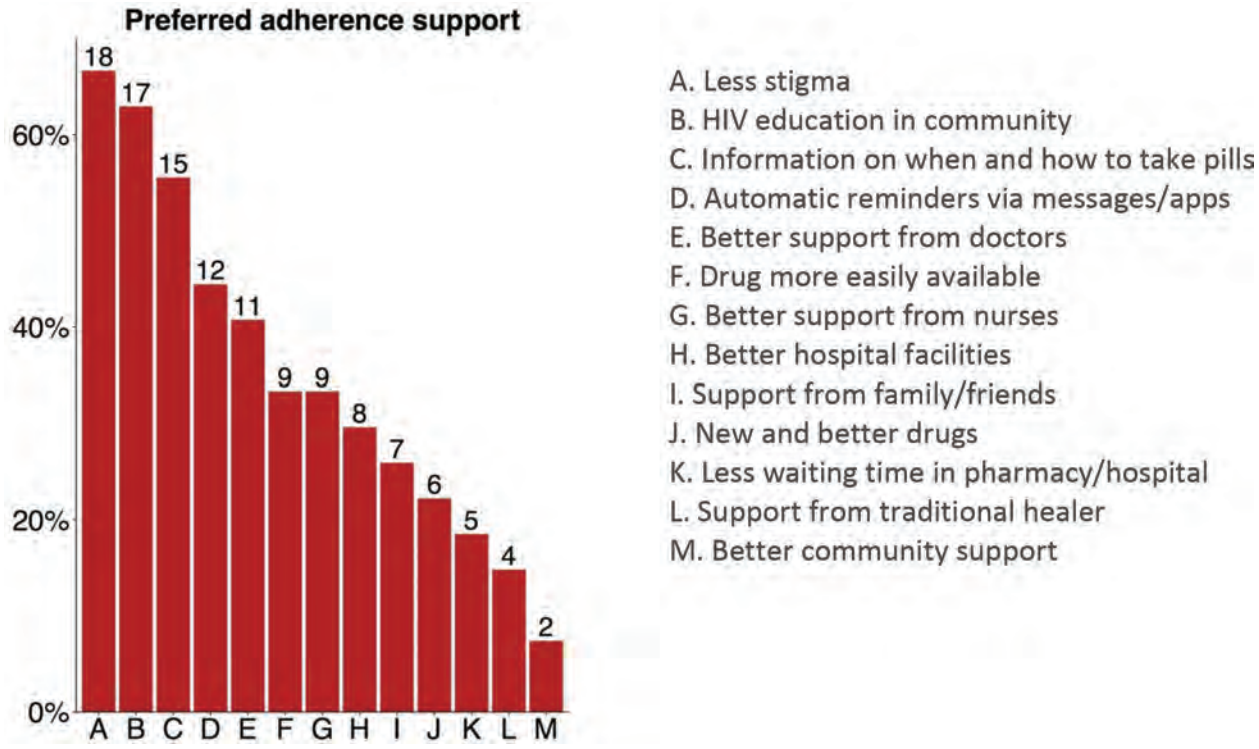

Figure 3. Respondents indicated which measures they think would help them to adhere.

attending peer support sessions led by expert patients (Figure 4B). However, when asked whether they would join a peer support group where medication could be received, so that they did not have to pick up the medication at the hospital, 14 responded yes and 10 responded no (Figure 4C). This suggests that the reasons for being interested in joining a peer support group are diverse, and that for only some of the participants ART distribution would be a driving factor for joining a peer support group. Similarly, when asked to specify what help was preferred from an expert patient, only 3 participants indicated the facilitation of pill pick up. Together these results suggest that the main reasons for joining a peer support group would be for psychological support rather than practical reasons. Indeed, the main preferred help from peer experts appeared to be *"motivation to take the medication as prescribed"*, *"emotional support"* and *"tackling stigma"* (Figure 5). Participants indicated a median of 3 options (MAD=1) of preferred help from peer experts.

The limited number of medical staff is a major challenge in Tanzania (Goodell et al. 2016). As a possible solution to this problem, peer support groups have been proposed where PLHIV educate each other and take turns picking up medication for each other, reducing the workload of the doctors. However, the results of this study indicate that PLHIV do not necessarily want to visit the hospital less often (figure 4C). This could be explained by wanting to feel in control of one's own health situation or the intangible value seen in visiting a healthcare provider, and may differ between different settings or social groups. Moreover, studies have shown that peer support groups do have the potential to increase adherence rates (Decroo, 2017). It might be that the participants need some time to adjust to the idea of visiting the healthcare center less often and to gain trust in the functioning of the peer support group.

In line with that are the answers to the question *"Would you feel more or less likely to take your drugs if you didn't visit the hospital as often?"*. Only 7 of the respondents indicated that they would expect to adhere better to their treatment; the other respondents predicted they would take their ART less often (5/27), the same (7/27), or were unsure (3/27) (Figure 4D).

A short description defining an expert patient was provided in the questionnaire: *"To become an 'expert patient' a person with HIV will receive training by healthcare professionals in a short training program. Then they will voluntarily use their knowledge to support and educate fellow patients. Tasks could include being group leader, gathering information,*

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distributing medication to other patients, becoming an educator etc.)." 18 respondents indicated interest in becoming an 'expert patient' (Figure 4E). Of the two respondents who answered "*maybe*", one admitted to being insecure about becoming an expert patient because he had no formal education. The majority (17/27) of the respondents preferred to have peer support groups meet monthly rather than weekly (7/27).

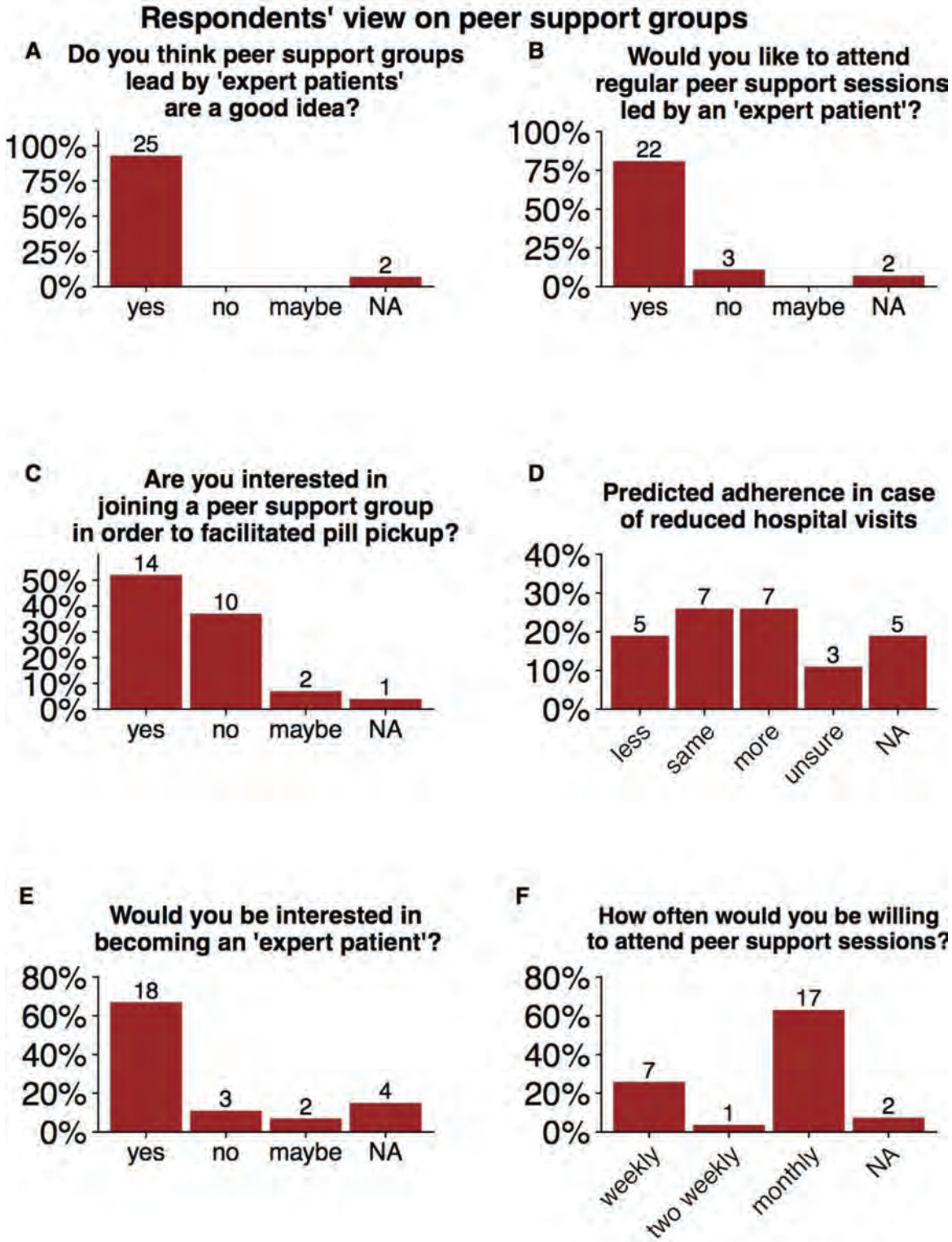

Figure 4. Respondents'view on peer support: A) general view on peer support. B) interest in joining a peer support group. C) interest in joining a peer support group with focus on facilitating pill pick up. D) self-predicted adherence when hospital visits are reduced. E) interest in becoming an 'expert patient'. F) frequency of peer support sessions.

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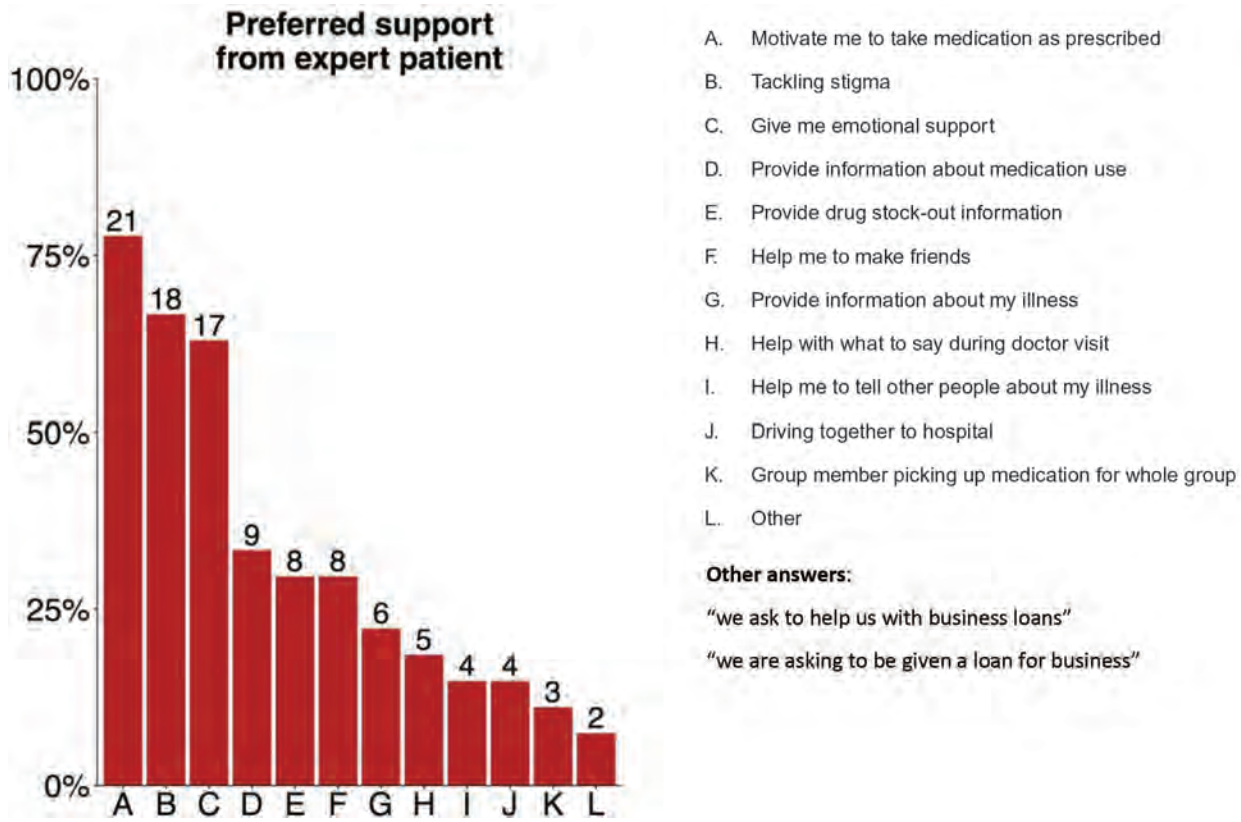

Figure 5. Respondents indicated the ways in which they feel an expert patient can support them.

VICOBA

Interestingly, although the topic "business" was never mentioned in the questionnaire, 7 (6 female and 1 male) of the 27 respondents referred to their business or asked for a business loan in one of the open-ended questions (attachement 1 and 2). Answers included "*we are asking to be given a loan for business*", "*to help each other economically*" and "*entrepreneurship*". A description of our vision of peer support groups was in the questionnaire, so it is not clear to us whether the respondents interpreted the concept 'peer support group for HIV' in a different way, or whether they simply wanted to express their greatest need. Microfinancing groups in the form of village community banks (VICOBA) are common practice in Tanzania. These are an informal social protection mechanism meant to provide economic stability to individuals.

Regardless of the different interpretations of the 'peer support' concept, it is apparent that some people living with HIV link the concept of peer support groups to their economic status. This suggests that it may be valuable to explore in further research whether peer support groups could be organized with a dual purpose: 1) psychological, logistic, and educational HIV treatment support and 2) financial support related to business purposes.

A recent study in Tanzania, Mtenga et al. (2018), reported that being a member of a VICOBA is statistically significantly associated with an increased number of extramarital affairs, which was significantly linked with HIV infections for women only (Mtenga, Pfeiffer, Tanner, Geubbels, & Merten, 2018). Due to their poor financial situation, women often form part of more than one VICOBA and are unable to keep up with their membership payments. Men often refuse to support their wives in repaying their VICOBA loans, which, according to the findings of Mtenga et al., may be related to the fear of losing control over their wives should they become financially independent. As a result, women may engage in extramarital affairs with men who help them to repay their debts and provide them with food or other material support. The financial hardship of women can explain why in our study 6 out of 7 respondents who mentioned business and loans were women. This contrasts sharply with the expectation of social protection mechanisms such as VICOBA, the intent of which includes lowering vulnerability to HIV infection (Temin, 2010).

Given our findings and those of Mtenga et al. (2018), we propose that VICOBA or other microfinance systems in Tanzania could be an interesting platform for raising HIV awareness and education, but also to provide combined economic and HIV peer support. A study by Lushakuzi et al. (2017) in Dar es Salaam indicated that in order for a VICOBA to bring benefit to its participants, training to improve business skills and frequent supervision should be provided, as the provision of money alone is insufficient for adequate performance of the VICOBA members' businesses (Lushakuzi, Killagane, & Lwayu, 2017). This indicates that members of well-functioning VICOBA are accustomed to training sessions and to being supervised, which would make the step to inclusion of HIV peer support smaller. VICOBA group membership includes HIV positive and HIV negative individuals and it is primarily focused on a topic other than HIV. Building HIV education and awareness into this existing peer support structure may potentially reduce the second component of stigma as described by Link et al.: "*associating human differences with negative attributes*" (Link & Phelan, 2001). For example, an HIV positive guest speaker presenting on a business topic could help to reduce the negative associations that the group members may have with HIV.

Conclusion

In this study we explored the opinions of PLHIV about the potential for introducing peer support groups led by peer experts in Dar es Salaam, Tanzania. Such groups could not only reduce the workload of the healthcare system by distributing ART in the community, but could also help to improve adherence, tackle stigma, and provide needed psychosocial support to people living with HIV. We learned that PLHIV expect such peer support will help them cope with psychological issues like stigma; they were less interested in practical issues like ART distribution in the community.

Without the intention of investigating the topic of business, the authors noticed that some PLHIV in this study link peer support groups for HIV with support groups for business purposes (such as VICOBA). Further research on this topic is needed to investigate whether and how HIV peer support can be combined with VICOBA or other microfinance groups while reducing the association between HIV and extramarital affairs linked to the VICOBA. The link between peer support and business support coming solely from the respondents indicates the importance and potential of further research on this topic.

Acknowledgements

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Supplementary Material

1. English questionnaire
2. Kiswahili questionnaire
3. Raw data

Note

[1]http://www.who.int/gho/health_workforce/physicians_density/en/ (accessed on August 12, 2019).

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Supplement 1: English Questionnaire

Peer support questionnaire (English)

Interviewer: _____ **Date:** _____

Patient's number: _____ **Study number:** _____

Instructions:

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

BASIC QUESTIONS

a. What is your age?
[ ] under 20; [ ] 20-40; [ ] 40-65; [ ] >65

b. What is your sex?
[ ] Male; [ ] Female; [ ] Other

c. Which is your income range?
[ ] Less than 100,000 Tsh
[ ] 100,000 Tsh to 500,000 Tsh
[ ] 500,000 Tsh - 1,500,000 Tsh
[ ] More than 1,500,000 Tsh

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

PATIENT SUPPORT GROUP

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

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

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

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

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

[ ] Yes; [ ] No; [ ] Maybe

Why: _____

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

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

e. To become an 'expert patient' a person with HIV will receive training by healthcare professionals in a short training program. Then they will voluntarily use their knowledge to support and educate fellow patients. Tasks could include being group leader, gathering information, distributing medication to other patients, becoming an educator etc.) Would you be interested in becoming such an expert patient?

[ ] Yes; [ ] No; [ ] Maybe

f. Would you like to attend regular peer support sessions that are led by an expert patient?

[ ] Yes; [ ] No; [ ] Maybe

g. How often would you be willing to attend peer support sessions?

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

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

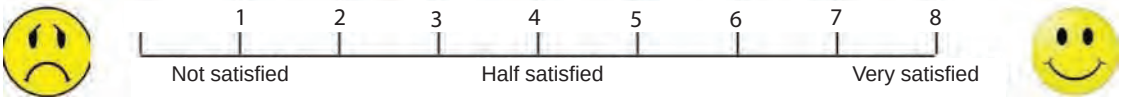
.....

DRUG DELIVERY

a. How much time does it take in total to get your medication? (Including the time from leaving home until you return back home).

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

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



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

[ ] Yes; [ ] No; [ ] Maybe

d. How would you feel if you saw a doctor less often? I feel a doctor's visit is necessary:

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

e. Would you feel more or less likely to take your drugs if you didn't visit the hospital as often?

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

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Supplement 2: Kiswahili Questionnaire

Dodosa juu ya 'wagonjwa wanaosaidiana' (Kiswahili)

Msaili: _____ **Tarehe:** _____

Namba ya mgonjwa: _____ **Numba ya utafiti:** _____

Maelekezo

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

MASWALI YA MSINGI

a. Umri wako ni upi?
[ ] chini ya 20; [ ] 20-40; [ ] 40-65; [ ] >65

b. Jinsia yako ni ipi?
[ ] Mme; [ ] Mke; [ ] Nyingine

c. Kiwango cha kipato chako ni kipi?
[ ] Chini ya 100,000 Tsh
[ ] 100,000 Tsh to 500,000 Tsh
[ ] 500,000 Tsh – 1,500,000 Tsh
[ ] Zaidi 1,500,000 Tsh

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

KIKUNDI CHA WAGONJWA WANAOSAIDIANA

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

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

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

[ ] Kupatiwa maelezo ya wakati na jinsi ya kumeza vidonge
[ ] msaada zaidi toka kwa daktari
[ ] Dawa ziwe zinapatikana kirahisi
[ ] lmuda mfupi wa kusubiri kliniki na famasi

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[ ] msaada zaidi toka kwa nesi
[ ] huduma bora na vifaa vya hospitali
[ ] msaada kutoka kwa jamii
[ ] msaada wa tabibu wa asili
[ ] msaada wa familia na marafiki
[ ] dawa mpya na bora zaidi
[ ] mifumo ya kukumbusha kupitia sms/app za simu
[ ] kutokuwepo unyanyapaa
[ ] Elimu ya VVU kwa jamii
[ ] nyingine (jaza) _____

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

[ ] Ndiyo; [ ] Hapana; [ ] Pengine
Kwanini (sababu): _____

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

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

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

[ ] Ndiyo; [ ] Hapana; [ ] Pengine

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

[ ] Ndiyo; [ ] Hapana; [ ] Pengine

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

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

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

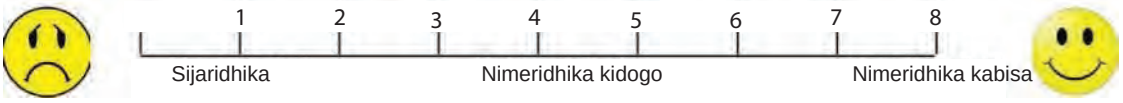
.....

UTOAJI WA DAWA

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

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

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



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c. Je ugekubali kujiunga kliniki kwako na kundi la la wagonjwa la kusaidiana? Mahali ambapo kundi hili hukutana ili usiende mara kwa mara katika hospitali?
[ ] Ndiyo; [ ] Hapana; [ ] Pengine

d. Je unaonaje kama ungekuwa unaonana na daktari wako mara chache zaidi? Unadhani kumuona daktari ingekuwa muhimu:
[ ] mara moja kwa mwezi
[ ] mara moja kila miezi
[ ] mara moja kila miezi 3
[ ] mara moja kila miezi 6
[ ] wakati nikiwa mgonjwa tu
[ ] wakati nikiwa na hoja/swali/tatizo kuhusu VVU

e. Je ungejisikia rahisi zaidi kutumia dawa zako iwapo hakuna haja ya kufika hospitali mara kwa mara?
[ ] Zaidi sana; [ ] Pungufu; [ ] Hakuna tofauti; [ ] Sina hakika

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Supplement 3: Raw Data

RAW DATA		
What is your age?	Under 20	3
	20-40	11
	40-65	10
	>64	0
	NA	3
What is your sex?	Male	13
	Female	11
	NA	3
Which is your income range?	Less than 100 000 Tsh	22
	1000 000 Tsh to 500 000 Tsh	2
	500 000 Tsh - 1 500 000 Tsh	1
	More than 1 500 000 Tsh	0
	NA	2
When did you first have a positive HIV test result?		Open question
Most patients experience some difficulties taking their drugs, the reason why can vary. If you missed taking your pills, what is the main reason?	A. I never missed taking my pills	13
	B. Pharmacy stock-out	1
	C. Too much time lost to pick up medication	5
	D. I lack support from family/ friends	7
	E. I lack support from hospital staff	1
	F. I lack support from my community	3
	G. I don't have enough privacy to take pills	1
	H. I don't have enough privacy at the clinic	2
	I. The drugs make me feel sick	1
	J. I am not sure the medication is working	3
	K. Not sure how and when to take the pills	2
	L. I don't want to take medication	4
	M. The medication tastes bad	4
	N. Difficulty swallowing	2
	O. I simply forgot	8
	P. No time	2
	Q. Other	7

Which of the following help would make you take your pills properly? You can tick more than one box.	**A. Information on when and how to take pills**	15
	B. Less waiting time in pharmacy/ hospital	5
	C. Automatic reminders via messages/apps	12
	D. Better hospital facilities	8
	E. HIV education in community	17
	F. Less stigma	18
	G. Drug more easily available	9
	H. New and better drugs	6
	I. Better support from doctors	11
	J. Support from family/friends	7
	K. Better support from nurses	9
	L. Better community support	2
	M. Support from traditional healer	4
In some regions 'expert patients', who have received training from health professionals, are supporting and educating their fellow patients. They lead and organize peer support groups, which support patients through their lives. Do you think this is a good idea?	**Yes**	25
	No	0
	Maybe	0
	NA	2
What help from a fellow (or expert) patient do you feel is appropriate to support you?	**A. Driving together to hospital**	4
	B. Group member picking up medication for whole group	3
	C. Provide information about medication use	9
	D. Provide drug stock-out information	8
	E. Motivate me to take medication as prescribed	21
	F. Help me to tell other people about my illness	4
	G. Provide information about my illness	6
	H. Give me emotional support	17
	I. Help me to make friends	8
	J. Tackling stigma	18
	K. Help with what to say during doctor visit	5
	L. Other	2

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To become an 'expert patient' a person with HIV will receive training by healthcare professionals in a short training program. Then they will voluntarily use their knowledge to support and educate fellow patients. Tasks could include being group leader, gathering information, distributing medication to other patients, becoming an educator etc.) Would you be interested in becoming such an expert patient?	**Yes**	18
	No	3
	Maybe	2
	NA	4
Would you like to attend regular peer support sessions that are led by an expert patient?	**Yes**	22
	No	3
	Maybe	0
	NA	2
How often would you be willing to attend peer support sessions?	**Once a week**	7
	Once every two weeks	1
	Once a month	17
	NA	2
What would be your main concern regarding these peer support sessions? (fill in here:)		Open question
How much time does it take in total to get your medication? (Including the time from leaving home until you return back home).	**Less than 1 hour**	2
	2-4 hours	7
	4-6 hours	11
	>6 hours	5
	NA	2
How do you feel about how long it takes to pick up your medication? (draw a cross on the scale)	**Average**	5.44
	SD	1,733794
Would you consider joining a local peer support group, where you would receive your medication, so that you don't have to pick up your medicines at the hospital so often?	**Yes**	14
	No	10
	Maybe	2
	NA	1
How would you feel if you saw a doctor less often? I feel a doctor's visit is necessary:	*Question deleted due to translation error.*	
Would you feel more or less likely to take your drugs if you didn't visit the hospital as often?	**More**	7
	Less	5
	No difference	7
	Unsure	3
	NA	5

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Stimulating Informed Decisions in Prenatal Screening: Exploring Initiatives to Aid Parental Decision-Making

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Abstract

Informed decisions concerning non-invasive prenatal testing (NIPT) seem contingent on health professionals and expectant parents (1) having access to multifaceted information about the procedure of NIPT and the subsequent choices; and (2) actively reflecting about what prenatal screening means beyond the medical level (including personal values and beliefs). International studies show that many pregnant women do not make informed decisions about prenatal testing (Beulen et al. 2016). Interviews we conducted with various stakeholders in Belgium show similar tendencies.

Based on transdisciplinary research (Dehens et al. 2017)—which included stakeholder interviews, and a review of academic literature, current prenatal screening guidelines, and good practices—we propose three initiatives that can help stimulate informed choices. The initiatives are: (1) a decision aid that encourages expectant parents to think about NIPT, its possible outcomes, and the conditions NIPT screens for (see e.g. Smith et al. 2018; Carslon et al. 2019); (2) the creation of a nation-wide protocol (*draaiboek*) for prenatal screening outlining what information should be provided at what point during a pregnancy, in what way, and by whom (see for instance the *Draaiboek Prenatale screening down-, edwards- en pataus-yndroom en structureel echoscopisch onderzoek versie 9.0* in the Netherlands); and (3) an online platform featuring a balanced representation of testimonials about various experiences with the main conditions NIPT screens for taking Braverman (2008) as a starting point. These initiatives were discussed (conceptually) at a round table discussion with a broad range of stakeholders (May 8, 2019). A concluding poll showed

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a strong consensus concerning the need to develop a prenatal screening protocol and a decision aid in order to help health professionals and expectant parents, navigate through prenatal screening programs in Belgium. Anticipating the widening scope of genetic tests, a general plan of action is necessary to ensure counseling possibilities and informed decisions.

Key words

NIPT, genetic counseling, informed decisions, transdisciplinary research, Down syndrome

Original Challenge Statement (see Supplement 1)
To find "a way to provide gynecologists and general practitioners with the tools to counsel in a non-directive manner, thereby assisting expecting parents to make informed decisions about their pregnancies."

1. Background

Two pre-conditions for informed decisions in prenatal screening are fulfilled when expectant parents have "adequate decision-relevant knowledge" and when their decisions for or against prenatal testing reflect their values about and attitudes toward prenatal testing (Beulen et al. 2016: 1410) and, we would add, disability. Genetic counseling is a crucial element in this decision-making process (see for instance Carlson et al. 2019). The goal of genetic counseling is "to provide the risk assessment, support, education and resources needed to facilitate patient decision making that best supports the individual patient's personal needs and values." (Fonda Allen, Stoll & Bernhardt 2016: 56).

The issue of genetic counseling in Belgium gained momentum when the federal government decided to reduce the cost of NIPT to €8.68 for all women who have public health insurance in Belgium, but additional resources for counseling did not follow (Costan et al. 2018). This decision, and the speed with which the policy was implemented in July 2017, sparked societal discussion. No country had at that date made NIPT more accessible to pregnant women than Belgium. As a result, a large majority of pregnant women opt for NIPT. However, to our knowledge, no additional budget has been made available for genetic counseling.

In non-invasive prenatal testing (NIPT) the placental cell-free DNA circulating in the maternal blood is analyzed. Today it is the most accurate screening test for trisomy 21, 13, and 18, with a detection rate that varies between 94.4% and 100% and a false positive rate that varies between 0% and 0.94% for trisomy 21 (Gil et al. 2017), though we need to take into account that detection options and accuracy depend on the source and the variations of NIPT.[1] NIPT can also detect the sex of the fetus and sex chromosome aneuploidies (Gil et al. 2017). The (current) goal of NIPT is to generate information for expectant parents about possible fetal chromosomal abnormalities, and in this way enable them to make autonomous and informed reproductive decisions.[2] If NIPT indicates a fetal abnormality, expectant parents can choose to continue with invasive prenatal testing, to continue the pregnancy, or to terminate.

In Belgium, NIPT is routinely used but expectant parents are not always prepared for the difficult choices that the test potentially confronts them with (Costan et al. 2018). Studies from other countries confirm that many pregnant women do not make informed decisions about prenatal testing (see for instance Beulen et al. 2016). Numbers about informed decisions among pregnant women in Belgium are limited, yet those available indicate that 30–40% of women are insufficiently informed about NIPT and Down syndrome (Buyle, 2018). This quantitative study in Belgium found that women's knowledge about prenatal screening is characterized by "a discrepancy between the knowledge about what Down syndrome entails (44.74%) and the knowledge about prenatal testing (65.15%)." (Buyle 2018: 11). In her study, which included 549 women, Buyle (2018) found that age, literacy, socio-economic situation, and the provision of information brochures were factors that influenced women's attitudes towards and knowledge of prenatal tests and Down syndrome. Other factors the literature reports to influence pregnant women's informed decisions about prenatal screening include: (health) literacy (Delanoë et al. 2016; Smith et al. 2018); the format in which the information is

1 UZ Leuven for instance works with NIPT-PLUZ, but AZ Delta works with VeriSeq™. NIFTY®, was the first available test (for more examples of commercialized NIPT see Allyse et al. 2015: 155).

2 As was also pointed out in Opinion 66 by the Belgian Advisory Committee on Bioethics (2016), the goal of NIPT will be interpreted on the basis of the ethical point of view one subscribes to. Some people argue that the purpose of NIPT is to avoid people with a disability like Down syndrome from being born (see e.g. the principle of procreative beneficence (Savulescu 2004)). Others argue that the purpose of NIPT is gathering knowledge in order to prepare for whatever the test finds, and in order to make autonomous reproductive decisions (see e.g. Beulen et al. 2016).

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provided (Kupperman et al. 2009, Björklund et al. 2012); and the way women bring together personal values and scientific knowledge (Potter et al. 2008).

Moreover, based on stakeholder interviews with representatives of *Downsyndroom Vlaanderen* (a contact group for parents with a child with Down syndrome) and *Cozapo* (a contact group for parents who decide to terminate a pregnancy following prenatal screening), Costan et al. (2018) note that in Belgium, in the event of a positive NIPT result, expectant parents feel ill-prepared for the decision they are confronted with (2018: 41). Additionally, health professionals are reported by both contact groups to tend to steer expectant parents toward termination (Ibid: 41–42). Costan et al. (2018) traced this to the often purely medical perspective health professionals have of Down syndrome (Ibid: 42). Similar trends were communicated to us during our interactions with various stakeholders in Belgium, who further point to a lack of unified strategies for providing information and stimulating reflection in both expectant parents and health professionals. Additional factors the stakeholders report to impact prenatal counseling practices in Belgium are: the routinization of NIPT (see also Belgian Advisory Committee on Bioethics opinion 66; Cernat et al. 2019), a lack of reflection from expectant parents, the lack of resources for good quality counseling (both time and funding), the fragmentation of healthcare in Belgium, confusion about who should do the counseling, and the content and format of information given to expectant parents about NIPT.

Given these issues, the aim of our inquiry is to gain insight into what local stakeholders believe to be promising strategies to stimulate informed decisions about NIPT that are, up to this point, underexplored or underutilized in Belgium.

2. Method: A Three-Tiered Approach

The aim of this article is to gain insight into stakeholder perspectives in Belgium about ways to stimulate informed decisions about NIPT. A transdisciplinary research perspective (Dehens et al. 2017) was adopted to tackle this aim. The choice for the transdisciplinary framework is motivated by two reasons. First, it gives a central place to stakeholder perspectives: stakeholder perspectives are considered a crucial source of information for our inquiry. Second, we need an approach that can deal with the complexity of the issue at hand. Transdisciplinary research involves interaction between academic disciplines, as well as stakeholders. This creates a unique exchange of knowledge.

Essentially, transdisciplinary research aims to co-create knowledge among different stakeholders, who each bring their particular first-hand experience to the table. Characteristic elements of transdisciplinary research (Dehens et al. 2017, and footnote 3) that we incorporated were an interdisciplinary literature study, an actor-constellation game (building on Costan et al. 2018: 64), consulting experts and including various stakeholders in the project. We identified and followed three steps to gain insight about what stakeholders in Belgium believe are promising strategies to stimulate informed decisions about NIPT: (a) identify stakeholders; (b) identify good practices and guidelines as strategies; (c) combine (a) and (b) and find out the identified stakeholder's opinions about the selected strategies.

Step (a): Identify stakeholders

For the identification of stakeholders this paper builds on the publication "Down to Counsel: Towards a Transdisciplinary Toolbox for Non-directive Counseling in Prenatal Screening for Down Syndrome" (Costan et al. 2018). This publication was the result of a project by a team of students from various academic disciplines in 2017–2018 within the framework of the KU Leuven Transdisciplinary Insights Honours Programme. In this program teams of students from various academic backgrounds work on transdisciplinary issues that are called 'societal challenges'. The main aim of the team in 2017–2018, which was the first to address the NIPT challenge, was to map out the stakeholders and issues involved with NIPT. They did this according to an actor-constellation game, a method from the Transdisciplinary Toolbox (Costan et al.: 64). This is "a role-play, in which all scientific and societal actors involved in a project are represented and positioned around the central research question. The distance from an actor to the research question, and to other actors, expresses how relevant (s)he is in the project."[3] In 2018–2019, a new team of four students, supported by two students from the previous year as co-coaches, started off from this map of stakeholders. Following this map, we selected stakeholders for interviews (see Table 1), and stakeholders to participate in the round table discussion (see Supplement 2).

3 https://naturalsciences.ch/topics/co-producing_knowledge/methods/td-net_toolbox/actor_constellation_final_

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Stakeholder	Location	Number	Further specification
Members from centres of human genetics	Gent	1	Paediatrician & clinical geneticist
	Leuven	3	Clinical geneticist, midwife, genetic counsellor
	Antwerp		Gynecologist & clinical geneticist Paediatrician & clinical geneticist
	Brussels	2	Gynecologist, genetic counselor
Bioethicist	Leuven	1	
Communication expert	Leuven	1	
Gynecologist	Leuven	1	
Psychologist	Leuven	1	From the Fara vzw organization
Mother who lost her child with Down syndrome	Antwerp	1	
Member of a disability rights organization	Brussels/ Leuven	1	
Midwife	Gent	1	Mother of a child with Down syndrome

Table 1. List of interviewed stakeholders 2018-2019.

Step (b): Identify good practices and guidelines

In order to obtain an overview of initiatives that can help expectant parents make prenatal decisions we consulted four types of sources. First, following the transdisciplinary approach, we reviewed literature from various academic disciplines. The main emphasis of our literature study was on pregnant women's attitudes toward prenatal screening, the use of decision aids in the prenatal context, and ways in which information is best provided. We further explored literature from disability studies. Secondly, we consulted and inventoried currently available prenatal screening guidelines and good practices. We also evaluated hospital booklets and brochures about NIPT (see Table 4). We further compared Belgian prenatal screening guidelines and good practices with an example of a protocol in the Netherlands.[4] Lastly, we arranged interviews with various stakeholders. We conducted 11 interviews with a total of 13 participants (see Table 1). Because we wanted to gather a variety of perspectives, the stakeholders we interviewed have different relations with the prenatal screening process. We generally worked with a basic skeleton of questions for each interview that we loosely adhered to. These questions pertained mainly to information provision. For instance, what information should expectant parents be provided with? At what point during a pregnancy? In what way? By whom? However, depending on the kind of stakeholder, we would ask questions tailored to what we would like to know from them specifically. Because the interview usually took on the form of a conversation, many questions were formulated during the interview itself, responding to input from stakeholders.

The literature study, guidelines, good practices, booklets, and interviews with stakeholders allowed us to identify four areas of intervention, and to identify various current practices and initiatives (Tables 2 and 3).[5]

Step (c): Bringing steps (a) and (b) together: What do stakeholders think?

The final step in reaching our aim is to see what stakeholders themselves think about initiatives: the stakeholders identified in step (a), the need to evaluate current practices and other initiatives identified and selected in step (b). In order to gain insight into the perspectives of the stakeholders, we opted for a qualitative method of gaining data in the form of a focus group—specifically a round table discussion. We acknowledge that quantitative data collection in the form of a survey would have given data on a larger sample of respondents. However, the focus group

4 The most recent version can be consulted here: https://www.rivm.nl/documenten/draaiboek-prenatale-screening-down-edwards-en-patausyndroom-en-structureel-echoscopisch

5 We acknowledge that this list may not be exhaustive.

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	Targeting Expectant Parents	Targeting Health Professionals
Stimulating Reflection	(Genetic) Counseling	CME, Info-Sessions, other Forms of Professional Support
Providing Information	Brochures, Online Information, 'Contact Parents',...	Guidelines, Good Practices,...

Table 2. Outlining four areas of intervention: Identifying current practices or initiatives.

allowed for discussion between different parties, which gives us additional perspectives on the way different stakeholders evaluate the practices and initiatives discussed. Moreover, this is in line with one of the cornerstones of transdisciplinary research, namely the co-creation of knowledge.

3. Findings: Stakeholder Meeting (May 8, 2019)

On May 8, 2019, a round table discussion was organized with 30 stakeholders (see below, and see Supplements 2–7b). Broadly speaking, the stakeholder meeting aimed to create an opportunity to discuss emanating issues about prenatal screening. To our knowledge, this meeting was one of the first of its kind in Belgium where a broad range of stakeholders was represented to discuss several initiatives.

3.1 Step (a): Identified stakeholders

We gathered a panel of 30 stakeholders for the round table among whom were gynecologists, midwives, bioethicists, parents, (genetic) counselors, politicians, psychologists, parents of persons with Down syndrome, disability organizations and ((bio)medical) students (see Supplement 2).

3.2 Step (b): Identified good practices, guideline, and other initiatives

This panel neatly represents the actors from the constellation game by Costan et al. (2018). Prior to the round table we conducted interviews (see 3.2 step (b)). The kind of stakeholders we interviewed are listed in Table 1.

On the basis of our literature study and interviews with stakeholders we were able to juxtapose four areas of intervention (Tables 2 and 3) and to identify various practices and initiatives which each correspond to one of the four areas. In Table 3, we present three initiatives that can stimulate informed choices: (1) a decision aid, (2) standardized counseling for prenatal screening (including NIPT) shaped by a protocol, (3) and a multimedia platform with testimonials (see Supplement 5). We selected these initiatives as they are not, or only marginally, in practice in Belgium, to as such explore more thoroughly what their possibilities in Belgium are.

	Targeting Expectant Parents	Targeting Health Professionals
Stimulating Reflection	(1) Decision Aid	(4) ?
Providing Information	(3) Testimonials	(2) Protocol

Table 3. Outlining four areas of intervention: Initiatives that could be incorporated in Belgium.

In what follows, we briefly outline each of the initiatives as presented during the meeting (for the presentation, see Supplements 3, 5 and 6).[6] As mentioned above, the initiatives (1), (2), and (3) correspond to previously identified areas of intervention. For the fourth area of intervention no immediate initiatives were found, hence we formulated this as (4) a question mark, as an incentive to stimulate debate during the stakeholder meeting.

3.2.1 A decision aid for the prenatal screening context in Belgium

A decision aid is a tool that assists patients to make decisions about treatment. The International Patient Decision Aids Standards Collaboration (IPDAS) defines

6 A shortened version of the presentation can be found in English in Supplement 8.

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decision aids as "tools designed to help people participate in decision making about health care options. They provide information about the options and help patients clarify and communicate the personal value they associate with different features of the options."[7] (see also Supplement 6) In essence, we can state that the desired effect of decision aids is an increase in the number of informed health-related decisions. As medical culture slowly shifts from paternalism to patient-centered care in medical decision making, decision aids are increasingly developed in various health contexts.

Since the introduction of NIPT in 2011 in Hong Kong, and over 60 countries since then (Allyse et al. 2015), studies about the utility of decision aids in the prenatal context have globally increased.[8] Most studies about decision aids for prenatal screening (before and after the introduction of NIPT) show that women who use an interactive (web-based) decision aid are better informed about prenatal screening, and subsequently make autonomous informed decisions more often (Kuppermann et al. 2009; Vlemmix et al. 2012; Beulen et al. 2016; Åhman et al., 2016; Smith et al. 2018). Women who use a decision aid are better able to formulate their own perspectives on screening and its possible consequences (Åhman et al., 2016). One reason for this can be that they employ more emotional and cognitive strategies in the decision-making process compared to women who are not decision-aided (Bekker, Hewison & Thronton, 2002).

Having to make difficult choices induces stress that in this context has been referred to as "decisional conflict". Bekker et al. (2002) found that decisional conflict leads to better decisional outcomes. However, this need not be the case. A more recent study found that decisional conflict was reduced when pregnant women were decision-aided by means of a combination of a decision aid and genetic counseling (Carlson et al. 2019). Contrary to Bekker et al. (2002), Carlson et al. (2019) did not find a difference in knowledge about prenatal testing and decisional conflict between the groups that either only used a decision aid, or only saw a genetic counselor. In any case, these findings suggest that if expectant parents are thoroughly informed about their choices and are encouraged to reflect on the extent to which those choices match their values, they are better prepared to make informed decisions.

Either way, decision aids should be accessible to all women. Hence, Smith et al. (2018) developed a decision aid that accommodates various levels of (health) literacy. This relates to the important challenge when developing a decision aid that "Special attention should be given to pregnant women with lower health literacy levels to increase their intention to use a [decision aid] and ensure that every pregnant woman can give informed and value-based consent to prenatal screening." (Delanoë et al. 2016: 5).

However, not all decision aids that are developed have the desired effect of increasing informed decisions (see for instance in Denmark Skjøth et al. 2015a and Skjøth et al. 2015b). Perhaps this is due to the limited amount of information that is provided through the aid, and the absence of questions that help stimulate expectant parents to include their values and beliefs in the decision-making process. Alternatively, the limited effect could be due to the high degree of health literacy of the women included in the study. In Denmark the 'Down screening programme' has existed since 2006. A 2012 Danish study shows that there is a ca. 80% informed choice to begin with; it is difficult to increase this even further (Skjøth et al. 2015b: 1333).

A shortcoming we see in the decision aids we had access to and evaluated is that they show a very narrow picture of Down syndrome and other aneuploidies.[9] This shortcoming extends to other tools, like clinical guidelines, used in the prenatal context. This brings us to a broader point: even if consensus exists that expectant parents should receive all the relevant information prior to NIPT, it is not clear what is included 'all the relevant information'. If the implementation of a decision aid is taken seriously as a way to stimulate informed decisions of expectant parents for prenatal screening in Belgium, more research is needed to delineate its format and content.[10,11] For

7 http://ipdas.ohri.ca/what.html

8 Studies about decision aids for prenatal screening before NIPT are still relevant. However, given the differences NIPT offers compared to invasive prenatal diagnostic tests, these studies need to be updated with NIPT in mind.

9 See e.g. the web-based decision aid developed in Denmark by Skjøth et al. 2015: http://graviditetsportalen.dk/; and the Patient+ Foundation initiative in the Netherlands: https://www.keuzehulp.info/pp/pnt/intro/2 (used in the Beulen et al. 2016 study).

10 In relation to the content of a decision aid, see for instance a study in the Netherlands that evaluates what knowledge is relevant for informed decisions in screening for Down syndrome: Schoonen et al. 2011.

11 The challenges of implementing decision aids are also addressed in the literature (see e.g. Portocarrero et al. 2017; Agbadjé et al. 2018). More research on how to implement a decision aid in Belgium is needed.

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instance: What do Belgian expectant parents deem important to know to make an informed decision?

In conclusion, the literature shows promising effects of decision aids on informed decision making in prenatal screening, especially for the Belgian context where additional resources for counseling are not yet available. If implemented effectively, a decision aid could reach a lot of pregnant women and would cost less to develop compared to resources for counseling.

3.2.2 Standardizing prenatal counseling: a nation-wide protocol

Another strategy to increase informed decisions is to develop a nation-wide protocol for prenatal screening. In contrast to the decision aid, which targets expectant parents, this initiative targets health professionals. A prenatal screening protocol would outline what information should be provided at what point during a pregnancy, in what way, and by whom. NIPT was implemented in Belgium at a rapid pace. This is considered a good thing: experts in Belgium agree that it is good that women with public health insurance in Belgium have equal access to NIPT, regardless of their financial situation. However, they also agree that the importance of (genetic) counseling was insufficiently addressed by the government. Since prenatal screening is an ethically sensitive issue, it is paramount that women have the choice to opt for screening, and that they genuinely consent to the tests. In this regard, counseling before and after the test(s) is essential. Such systematic genetic counseling seems contingent on a protocol for prenatal screening with the explicit provision for counseling.

The Belgian government currently does not offer a nation-wide protocol, and the more general guidelines on prenatal screening and NIPT currently seem to leave too much room for interpretation. We understand that a certain degree of indeterminacy in guidelines is justifiable, given that each hospital has its own culture and structure in which those guidelines need to be implemented. This also holds true for the Belgian guidelines we had access to, which state that physicians should communicate to patients about: what screening implies, what the consequences are, what will follow after a positive or negative result, the meaning of a positive test, explanation about possible detectable syndromes, and different screening options and their possible limitations.[12,13,14] One way of estimating the way in which hospitals interpret these guidelines is to analyze the educational booklets, brochures, and webpages about prenatal screening and NIPT hospitals provide expectant parents with. The booklets and brochures can be consulted via the websites of the hospitals. We analyzed six of these about NIPT (see Table 4) and four webpages with a similar informing function (see Table 4).

6 booklets, 4 websites (in Flanders, Brussels)	**Brochure**	**Website**
University Hospital Antwerp	X	x
University Hospital Leuven	X	x
University Hospital Brussels	X	x
University Hospital Gent	X	x
East-Limburg Hospital (ZOL) (regional)	X	
St. Lucas general Hospital (Brugge)	X	
Delta general Hospital (Roeselare)	X	

Table 4. Inventory of educational booklets and brochures about prenatal screening and NIPT.

In Table 5 we listed recurring and noticeable topics addressed in our sample of sources. We found that more essential topics such as ‘what is NIPT?’ are well addressed in every source. The medical terms and the variety of tests were also mostly explained well. These most frequently addressed topics are also listed in the Belgian guidelines. The lower frequency of certain topics, like specific information about Down syndrome, also reflects the content of the guideline. Only one brochure mentioned the fact that there are

12 Accessed via Domus Medica https://domusmedica.be/richtlijnen/zwangerschapsbegeleiding (Nicole Dekker et al.2015)

13 http://www.beshg.be/download/guidelines/20170126_NIPT_good_clinical_practice_guidelines.pdf; http://www.beshg.be/download/guidelines/BELGIAN_GUIDELINES_FOR_MANAGING_INCIDENTAL_FINDINGS_DETECTED_%20BY_NIPT_20171221.pdf

14 The Belgian Advisory Committee on Bioethics asserts that “The information will in fact have to be provided with the patient’s need for information in mind, with due regard for the patient’s moral considerations and in a non-directive way. This should create the right conditions to allow a pregnant woman to make an informed choice without pressure from outside. The focus on the availability of qualitative information in a patient friendly way should not only translate into support while the patient is undergoing NIPT but also when the result of the test is given and during any of the subsequent steps the patient may choose to take.” (2016: 14)

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6 booklets, 4 websites (in Flanders, Brussels) = 10 sources	Website + Booklet/ Brochure (10)	Website (4)[15]	Brochures/ Booklets (6)
How NIPT works	10	4	6
Potentially inconclusive results	10	4	6
Follow-up tests (invasive)	10	4	6
What NIPT tests for	10	4	6
When NIPT is not recommended	10	4	6
Medium through which results will be announced	8	4	4
How much NIPT costs	9	4	5
Fetal sex information	8	3	5
Other findings/ Incidental findings	10	4	6
What NIPT does not test	8	4	4
Specific information about Trisomy 21[16]	4	0	4
Specific information about Trisomy 13 and 18	2	0	2
Privacy	1	0	1
Importance of an echo prior to NIPT	5	1	4
Emphasis on freedom of choice	3	0	3

Table 5. Review of educational booklets and brochures about prenatal screening and NIPT.

different types of NIPT available, and what the differences are. When it comes to specific information about for instance Down syndrome, state that hospitals often refer women who are interested to Down syndroom Vlaanderen, or to a genetic counselor. The main problem we see, though, is that not all booklets provide the same information to the same degree. This may create differences in the way expectant parents are informed. Some may be better informed than others. For instance, in some brochures we noticed that more space was given to explaining the genome concept and NIPT, for instance with the help of metaphors. One brochure even had a glossary. Some brochures emphasized the freedom of choice in a separate paragraph. In others it was only marginally mentioned. The issue of privacy was mentioned in only one booklet. This is significant because NIPT works with biological data and record information.

In Table 5 we can further observe some differences between hospital booklets and websites. Also, across the board, general hospitals that offer NIPT seem more thorough in their information provision. This difference suggests that the guidelines are not followed in the same way, and illustrates that there is room for interpretation. For instance, hospitals realize that too much information can be overwhelming. They could have different opinions about what extra information they want to provide and how much responsibility expectant parents have to seek additional information.

A more comprehensive prenatal screening protocol, with special attention to counseling, that standardizes information provision and care seems warranted. Aside from medical information about the tests, and the conditions they screen for, the protocol could include more information about the conditions screened for, and outline the appropriate social skills and attitudes when talking to expectant parents about screening.

3.2.3 A multi-media platform featuring a balanced representation of testimonials about prenatal decision making and decisional conflict, and various experiences with the conditions screened for

Our review of educational booklets, brochures, and websites found that medical information on NIPT is generally well-addressed. It is clearly stated what NIPT is, and what it tests for. However, little to no attention is paid to the attitudes, values, and beliefs of pregnant women, and how they can match these with the medical options.

As a study in Belgium shows, 30–40% of pregnant women do not have sufficient knowledge about prenatal screening and the conditions screened for, most notably Down syndrome (Buyle 2018). Also, the previous section reveals how most Belgian hospitals that offer NIPT inform pregnant women through educational booklets, information brochures, and/or webpages. Findings from, among others, Kupperman et al. (2009) and Björklund et al. (2012) stipulate that in the context of prenatal screening these formats are not

15 We exclusively examined the webpages that included information on NIPT. It is possible that additional or more general information about prenatal screening is available in different sections of the websites.

16 We made a distinction between trisomy 21 and the other trisomies here because the latter are remarkably less explained.

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the most efficient or effective way to convey information. Much health communication to patients is done through this format, and often presents factual information (reports, professional opinions, and statistical information) (Braverman 2008). However, Braverman shows that testimonials can be more effective because "testimonial or storytelling is more effective than expository or informational messages for those individuals who are not motivated to scrutinize the message" (Braverman, 2008: 688; see also Green, 2006). Testimonials in this context "may include a personal story, a description of an individual experience, or a personal opinion." (Braverman 2008: 666).

The subjective nature of testimonials tends to prompt rightful concern about directive communication (see section 4). This is why the content of the testimonials should be balanced,[17] even though, as Hippman, Inglis & Austin (2012) point out, it is less clear what 'balanced' means. Preliminarily speaking, this likely entails that the online platform should include testimonials from a variety of perspectives, viz. people with Down syndrome, their family members, health professionals, people who have decided to terminate a pregnancy, and bioethicists.[18] The testimonials should provide snippets of the good and difficult experiences of, for instance, life with Down syndrome, as well as life after the decision to terminate a pregnancy.

Above, we mentioned the dilemma of what 'relevant information' entails for informed decision-making. In the context of this initiative, relevant information means that should expectant parents wish to learn more, they can consult audio-visual and written testimonials of different experiences during and following the choices that were made (1) about prenatal screening, and (2) on the basis of the results of the tests.

In sum, the medium and format of health communication has an impact on the way people absorb knowledge. Following the above-mentioned findings, we identify an opportunity to optimize communication about prenatal screening, NIPT, and the conditions it screens for in order to increase knowledge. This knowledge is deemed relevant for informed decision-making. The optimization can be done by creating a multimedia online platform featuring balanced testimonial content, that can be offered to expectant parents in addition to the booklets.

17 This is also one of the recommendations to support women in their decision-making formulated by Skirton & Barr (2009: 601)

18 This list is not meant to be exhaustive.

3.3 Step (c): Steps (a) and (b) brought together: What do stakeholders think?

In order to gather feedback about and create support for these initiatives we organized a round table discussion with 30 stakeholders. A summary of reactions and other input from the stakeholders is added in Supplement 7a (Dutch) (translation in Supplement 7b). The discussions between stakeholders following the presentations of the initiatives confirmed that there is a common need for a broadly carried uniform protocol. The creation of such a protocol, stakeholders urge, is the responsibility of the government. In addition, further research is needed about the observation some stakeholders make about people's tendency in Belgium to equate 'disability' with 'unhealthy' and 'unhappy'. More research is necessary to investigate how this outlook on disability affects the reproductive choices expectant parents make.

A concluding poll at the stakeholder meeting (see Table 6 and Supplements 7a, 7b) showed a strong consensus concerning the need to develop a prenatal screening protocol and a decision aid in order to help health professionals, as well as expectant parents, navigate through prenatal screening programs in Belgium. Anticipating the widening scope of genetic tests, a general plan of action is necessary to ensure counseling possibilities and thus informed decisions. Counseling requires additional resources. Without governmental support, this challenge will become increasingly problematic.

Initiative	Number of preferences
Decision aid	15
Testimonials	1
Protocol	21
Miscellaneous/Question mark	2

Table 6. A poll of the preferences for each initiative per initiative presented at the stakeholder meeting.

The results of this poll of 30 stakeholders showed that the protocol initiative represents 54% preference votes, the decision aid gained 38% support. Table 6 shows the votes per initiative in absolute figures. Nine stakeholders chose more than one initiative, 44% of whom had a slight preference for the protocol. (see Supplements 7a and 7b). Below, we briefly describe some key findings for each of the initiatives.

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The ***'Decision aid'*** gained 38% of the votes. A shared opinion was that there is a greater need for pre- and post-counseling. Stakeholders present stressed that such a decision aid could guide expectant parents through the first important decision of whether they want to screen for fetal anomalies. According to a politician,

> *beside the right to know, the right to not know is only barely discussed with patients, which results in a lot of prenatal tests that have been carried out without a genuine approval.*

Most stakeholders were convinced that it is the government's responsibility to provide a protocol for healthcare with clear instructions for doctor-patient communication about NIPT to ensure that parents' rights in this respect are safeguarded. Furthermore, a gynecologist added:

> *We have to keep in mind that the counseling practice should not be oversimplified either. It should be adapted to religion and various cultural backgrounds.*

Turning to the ***'Protocol'***, 54% of the votes marked this as the initiative they wanted to see developed in the future. Setting up a protocol ensures that all future parents will receive the best support. This protocol could, for instance, ensure better agreements between first and second lines of care. Right now, according to a self-employed midwife

> *The first line of healthcare [general physicians and, in some cases, midwives] is too frequently forgotten, although they have more time for more extensive prenatal consultations.*

However, a paediatrician warns that

> *The willingness of doctors to follow a protocol is probably insufficient at the moment.*

The ***'Testimonials'*** were clearly the least preferred initiative with only one vote out of 30. During the discussions, concerns were raised about the subjective or directive nature of testimonials. In addition, the people providing the testimonials might experience a great sense of responsibility that should not go unacknowledged and would need support. A philosopher argued however that

> *neutral information is an illusion, but neutrality could be preserved in a way by putting different points of view side by side.*

An organization for people with disabilities argued for the importance of including people with the disabilities screened for (primarily people with Down syndrome) in this kind of initiative.

Finally, the ***'question mark'*** allowed us to collect additional thoughts or suggestions from stakeholders. A medical student suggested improving communication between doctors and patients through a patient-feedback system. Concerning the issue of stimulating physicians to seek additional professional support for communication about the conditions screened for, a parent of a child with Down syndrome raised the concern:

> *In any case, seminars for healthcare providers are important, but those who already know a lot will come, while those who need it will remain absent.*

Another participant proposed philosophical discussions for professionals in order to stimulate reflection and listening skills.

4. Discussion

In this section, we integrate relevant points from our literature study, inventory of guidelines and booklets, and input from stakeholders during interviews and the stakeholder meeting.

The decision to opt for prenatal screening, including NIPT, should be informed and well-considered. Some people state that expectant parents should screen for fetal abnormalities only if they know what they would do if the NIPT result were positive. Due to the ethically sensitive nature of these difficult decisions, it is paramount that each pregnant woman (and her partner) has access to good-quality pre-test and post-test counseling.

Given the low cost of NIPT in Belgium, it has become a more or less routinized practice. Accordingly, the percentage of women that opt for NIPT is very high. The routinization of NIPT may form a risk for informed decision making because it is more easily portrayed as 'just another test' by both physicians and expectant parents. As such the moral weight of the decision may be trivialized. The routinization of NIPT was already warned against in 2016 by the Belgian Advisory Committee on Bioethics, and more recently by Cernat et al. (2019).

Studies show that indeed pregnant women too rarely make informed decisions about prenatal testing (Beulen et al. 2016; Buyle 2018). Our interviews with stake-holders in Belgium show a similar tendency. These findings suggest that the information provided seems inadequate or does not seep through. Explanations for this can be found in the content and/or format of this

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information. In Belgium, we observe that most information is offered to expectant parents in the form of an educational booklet or a brochure. However, studies indicate that this is not the most effective medium for transferring complex medical knowledge about, in this case, prenatal tests (see e.g. Kupperman et al. 2009; Björklund et al. 2012; Beulen et al. 2016; Carslon et al. 2019). Interactive, audio-visual, web-based formats and testimonials (Braverman 2008) are proven to be more effective. Additionally, the content of the booklets is mainly medical. Information on living with (someone with) the condition screened for in all its complexity is lacking.

Offering expectant parents a decision aid shows much potential for remedying the shortcomings seen in prenatal screening guidance in Belgium today. Moreover, given the high (societal) cost of reimbursing genetic counseling, a decision aid could be a low-cost compromise. However, the decision aid should not replace counseling. While there is no difference in knowledge between pregnant women who use a web-based decision aid and those who see a genetic counselor (Carlson et al. 2019), decisional conflict is significantly lower when women have had the opportunity to combine the two options (Carlson et al. 2019).

A decision aid should be accessible to all pregnant women. Hence, it needs to be sufficiently flexible to accommodate on the one hand various degrees of (health) literacy and on the other hand different cultural backgrounds, languages, belief systems, values, religious backgrounds, etc. Most stakeholders agree that the choice to use a decision aid should be free. Notwithstanding, one person argued that the reimbursement of NIPT should be connected to having completed a decision aid or genetic counseling.

Our stakeholder panel agrees that it is a good thing that there is no financial barrier to NIPT. However, due to the fast pace with which the reimbursement of NIPT was implemented, laws and guidelines could not anticipate the needs (e.g. for counseling) that would follow. Furthermore, in the absence of a detailed formal standard including appropriate attitudes and ways of conveying information, health professionals struggle to adequately communicate about NIPT to patients. Directivity will inevitably find expression in body language, in which information is given or skipped, and in the emphases that are made. Moreover, as was alluded to by a stakeholder (see section 3.1), health professionals who do not recognize anything problematic in the way they communicate with expectant parents about NIPT and disability may feel less inclined to improve. From interviews the student teams conducted in 2017–2018 and 2018–2019—though not representative of the entire population—we noted several negative experiences about the way NIPT was presented to some women. Some stated that they did not feel comfortable refusing, or the option to refuse was not presented to them, they were not informed very well, or the patient-doctor communication was not positively evaluated if a decision was made to continue a pregnancy where a chromosomal abnormality was indicated by NIPT. However, it must be said, that there were also positive experiences communicated to us about each of these points.

There are voices that advocate the illegalization of commercial NIPTs. The difference between commercial and non-commercial tests is confusing for expectant parents. Commercial tests put too much power in the hands of laboratories and clinical biologists.[19] Depending on the laboratory (hospital or commercial) physicians are connected to, pregnant women are offered different NIPTs. To our knowledge, there is no control mechanism in place. Standardization of NIPT, curbing variability, is complicated by commercial interests. Moreover, this variability in NIPT jeopardizes informed decision making because not all women are presented with the same test, leading to confusion about what can and cannot be detected by NIPT. Furthermore, the more NIPT can detect, the more choices expectant parents are presented with, which may cause stress associated with decisional conflict. This also means that they have to be informed about additional conditions, which demands more time and resources.[20]

A nation-wide prenatal screening (including NIPT) protocol standardizes prenatal care. The challenge for health professionals lies in the fragmentation of care, as we know it today in Belgium. This fragmentation creates inequality in care-receiving because, among other reasons, it is not clearly stipulated who should counsel expectant parents. A protocol creates a guiding thread for health professionals ranging from best

19 Via commercial tests there is not always access to genetic counseling or network of care. And if there is, it is organized by the private companies offering NIPT. In this scenario, there are questions about possible conflicts of interest genetic counselors have (Pollack, 2012 in Allyse et al. 2015).

20 This would be especially problematic if private companies offered direct-to-consumer NIPT. To this day, this is not yet possible in Belgium.

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communicative practices to role divisions.[21] This, in turn, may positively affect informed decisions of expectant parents. Most stakeholders agreed that the standardization of care is the responsibility of the government. However, at this point, some stakeholders remark that it does not seem like the government is much concerned with the accessibility and quality of counseling.

A protocol should clearly stipulate what information should be given at what point during a pregnancy and in what way. The example of the Dutch protocol for prenatal screening can be helpful.[22] Aside from medical information about trisomy 21, 18, and 13, and the role division of genetic counseling among health professionals (gynecologists, genetic counselors, midwives and social workers), this protocol also stipulates communication strategies, social skills, and attitudes the professionals can employ in their counseling practice. Input from our stakeholder panel highlighted the importance of including counseling before and after NIPT. The importance of counseling is also particularly stressed in a recommendation of the Belgian Advisory Committee on Bioethics (opinion 66, 2016). However, at this point, it is not clear in what shape or form this should be implemented.

Lastly, this discussion should be contextualized in a broader debate about (intellectual and developmental) disabilities in society. Some stakeholders indicated that the image people have of Down syndrome in Flanders has hardly evolved in the past two decades. To deflate the medical model with which the medical world still frequently approaches disability, people who are expert by experience need to be included more in the debate (i.e. people with the conditions screened for, their family, carers, and teachers).[23] Including first-hand experiences with the conditions screened for through testimonials offers expectant parents—who are afraid of the unknown—a different perspective. Contrary to the already existing 'contact parents' initiative (Dutch: *contact ouders*), which consists of a (postnatal) meeting between parents with children with Down syndrome and (expectant) parents, audio-visual and written testimonials create a kind of distance. Even though non-directivity is illusory when it comes to testimonials, this distance is good. Directive communication is one of the major hurdles when it comes to information provision in prenatal screening. However, this does not need to be problematic if the subjective nature of the testimonials is openly communicated about, and they represent a wide array of experiences (including expectant parents who chose to terminate the pregnancy). There is also a role for medical education to play here.

Stakeholders at the round table had the opportunity to propose additional initiatives to improve guidance during prenatal screening. Someone proposed systematized patient feedback for physicians. Patient feedback can improve patient-doctor communication in prenatal screening and create awareness among those health professionals who are unaware of problems with the way they communicate about, for instance, NIPT.

In conclusion, all three initiatives are complementary. They address different needs and target different groups. Ideally, the three initiatives can be integrated. The decision aid could be part of the protocol—as something that needs to be offered to expectant parents—and testimonials could be incorporated in the decision aid. We hope that by addressing different needs and targetting different groups more awareness can be created across the board.

5. Facing the Future: Some Reflections

Physicians and patients need a solid base of information and reflexivity to guide them through prenatal screening. Medicine increasingly moves towards patient-centered care and shared decision making; initiatives of the kind we propose can be beneficial to further promote this and to strengthen the patient-doctor relationship. Health professionals are expected to correctly use knowledge and science, hence the correct implementation of new developments in biomedical technology should be central to good care.

We think that a precondition of an informed decision in the context of NIPT, aside from having knowledge of NIPT and diagnostic tests, is to have knowledge of the conditions screened for. By knowledge we do not mean only medical knowledge of for instance Down syndrome as a chromosomal abnormality, but also of Down syndrome as a meaningful life. We proposed three initiatives that can help stimulate informed choice in

21 Steps like this have already been taken in Belgium for neonatal screening and for breast and colon cancer screening programs.

22 https://www.rivm.nl/sites/default/files/2018-11/111488_010415_Down%20SEO_8_TG.pdf.

23 By the medical model of disability we refer to the view that reduces the disabled person to their impairment, and reduces their impairment to something medical, a medical object that needs to be fixed, cured. For an overview see for instance *The Minority Body: A Theory of Disability* by Elizabeth Barnes (2016).

prenatal screening in Belgium. In all, we hope that our findings, which we presented at the KU Leuven Facing the Future Symposium (Supplement 9), create concrete steps for further research.

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Supplementary Material

(1) Original challenge
(2) List of Participants in the stakeholder meeting
(3) Program of the stakeholder meeting
(4) Invitation to the stakeholder meeting
(5) Presentation held during stakeholder meeting (Dutch) (May 8, 2019)
(6) List of decision aids
(7a+7b) Summary of stakeholder meeting (Dutch and English)
(8) Presentation held at Transdisciplinary Insights Symposium (English) (May 8, 2019)
(9) Recording presentation—Counseling in prenatal screening for Down syndrome—Transdisciplinary Insights Honours Programme Symposium, May 8, 2019.

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Supplement 1: Original Challenge

ABOUT YOUR CHALLENGE

NAME OF THE CHALLENGE

Would the world be a better place without them?
Strategies for non-directive counseling in prenatal screening for Down syndrome: From concept to application.
(Written by Eline Zenner on behalf of Downsyndroom Vlaanderen September 2017)

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.

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 holds less 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 euro will be made available to refund the NIPT to every Belgian pregnant women. Belgium is currently as such the first European country to refund the test to 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?

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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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.

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 sociopolitical 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.

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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 GP's and gynecologists in providing this information. Which tools, data, approaches 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 & 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 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 FAQ concerning down syndrome, that can be used to broaden the often all too medical perspective of gynecologists and GP's. 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 downsyndrome *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 GP's 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 in 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.

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The team of last year suggested to create an online tool for GP's 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.

In the next section of this proposal, we sketch precisely how this challenge could be addressed by a properly transdisciplinary team.

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.

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 euro 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

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Thomas More (Associatie KU Leuven):

- website usability and design
- audiovisual & multimedia approach to information sharing on the website
- storytelling & interview techniques
- communication

Psychology & 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?

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?

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?

In this section, we present a list of ten potential stakeholders, nine of whom have already agreed to function as stakeholder in the project. Some more information is provided on the organizations and on their position with respect to this proposal. Although we believe that this list will go a long way, other national and international stakeholders can of course be thought of.

Downsyndroom Vlaanderen vzw. Needless to say, our own organization is a stakeholder for this project. We deeply care for the topic, as we are afraid to see society evolve to a point where only traditional interpretations of perfection are welcome. More information on the position of Downsyndroom Vlaanderen in this debate can be found via this link, which also contains an overview of the national media's attention for the topic in light of the decision of Minister Maggie De Block to refund the test. Downsyndroom Vlaanderen can be found on www.downsyndroom.eu. Our organization can be contacted by e-mailing eline.zenner@gmail.com and jurgen@downsyndroom.eu.

CME's: The centres for human genetics (Centra voor Menselijke Erfelijkheid, CME) of the university hospitals in Flanders and Brussels are natural stakeholders in this project: they are the prime location for innovations in genetic

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research and at the same time have always strongly adhered to neutral counseling. The CME's are on board as stakeholders, though they wish to underline their own neutrality in the matter. Professor Bert Callewaert from UGent phrases the position of CME UZ Gent as follow: "non-directive counseling has always been one of the basic guiding principles of the CME's. We however need to acknowledge that once a screening test becomes 'standard and refundable', it soon finds its way to peripheral hospitals. The current criteria for refunding the NIPT are not connected to any requirements concerning counseling. This means that there is a significant risk that this crucial component of prenatal screening runs the risk of being backbenched in daily organization." The different CME's can be contacted as follows: bert.callewaert@ugent.be (UZ Gent), griet.vanbuggenhout@uzleuven.be (UZ Leuven), maryse.bonduelle@uzbrussel.be (UZ Brussel), geert.mortier@uza.be (UZ Antwerpen). Please note that the Pediatrics Department of UZ Antwerpen (contact stijn.verhulst@uza.be) is also interested to be involved in this project. Also marek.wojciechowski@telenet.be from UZA can be contacted as specialist in down syndrome.

VVOG: We have also contacted the Flemish organization of gynecologists and obstetricians (Vlaamse Vereniging voor Gynaecologie en Obstetrie, VVOG). Although a number of gynecologists are very aware of their role as counselors in the process of prenatal counseling, others take a rather clinical perspective on the matter. This way, the possibility of providing true non-directive counseling has sometimes already been closed off by the time parents arrive at CME's for advanced testing. Hence, it is crucial to include VVOG as stakeholder in this project. The organization agrees to operate as stake holder for the project. Professor Luc De Catte is our contact at VVOG (luc.decatte@kuleuven.be).

Kind & Gezin: Kind en Gezin, together with its partners, aims to create as many opportunities as possible for every child, regardless of where he or she was born or where and how he or she is growing up. Kind en Gezin (Child and Family) is an agency that works actively in the 'Public Health, Welfare and Family' policy area. This Flemish agency focuses on preventive treatment and guidance of young children geared to good outcomes in the future. Kind en Gezin describes its role as follows: "We work hard to enable children to achieve their full developmental potential, physically, mentally, emotionally and socially, with respect for diversity and children's rights. This principle holds for all the different areas that we work in. Kind en Gezin is responsible for registration of high quality child care, optimal support for parents-to-be and parents with young children and the criteria that adoption agencies have to meet. We closely monitor all changes in society as a matter of course. Day in day out we come into contact with thousands of families and work with partners and other actors in the field. This gives us a wealth of information, allowing us to respond proactively and at the most appropriate time. We develop scientific methods, in both educational and medical fields, to assist us in our work. We constantly adapt our services, so that we can offer every parent and every child the best help possible. We also participate in national and international campaigns and projects: with boundless respect for every child and for the rights of the child. Child and Family wants to support parents by objective and nuanced information on prenatal screening on behalf of making an informed choice. Hereby we refer parents to several organizations with expertise in pregnancy choices, prenatal screening and diagnostics. After birth, Child and Family offers family-based support. Our services can therefore be different for each family. If there are any questions or difficulties we can't support, we provide the necessary information about who can and refer to another service or organization. If wanted, the family can further count on us. More information on Child and Family can be found on www.kindengezin.be. Kind en Gezin can be contacted by e-mailing evelyne.deguffroy@kindengezin.be".

Fara vzw: Fara is an organization that informs and counsels about pregnancy-related choices. Fara has described its own position as a stakeholder in this project as follows: "Fara regularly comes into contact with issues regarding prenatal testing/diagnosis. In our work, we have always put forward the model of non-judgment counselling and shared decision-making, both internally (in the work we do with clients) and externally (in our training of professionals). We emphasize the responsibility of the care providers to support parents as best as possible in making a conscious, well-considered choice they can (continue to) live with. It is our experience that parents are often not concerned with the social impact of their individual choice. The question of whether the world would be a better place without people with a disability doesn't factor into their decision, and we should not be tempted to blame them for this. Conversely, in their individual choices, they seem to feel the influence of a social tendency to equate responsible

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parenthood with participation in screening and opting for termination after a prenatal diagnosis. Social imaging about disabilities can certainly lead to social pressure that limits the freedom of choice of parents. Individual professionals often make a lot of effort to provide accurate and objective information in their counselling and assist parents in their choices. Of course, improvement is always possible and it is a goal we need to strive for. With regard to this project, Fara is especially interested in how to create a social context in which genuine freedom of choice remains safeguarded." More information on Fara can be found on www.faranet.be. Fara can be contacted by e-mailing silke.brandts@faranet.be as of October 2018. Prior to that date sindy.helsen@faranet.be can be contacted, as Silke is on maternity leave.

Cozapo: Cozapo is a contact group concerning termination of pregnancy following prenatal screening and was founded in 2009 by two experience experts. We are a Flemish contact group aimed specifically at parents who let a wanted child die because prenatal screening revealed serious anomalies in their children. Cozapo is there to support parents. Feelings of doubt, guilt, sadness and so much more can sometimes be shared more easily with peers, if only because they acknowledge and recognize these feelings. At the same time, Cozapo offers the parents some perspective, to carry on with their lives after this decision, thanks to this contact with people who are at different stages of the grieving process. Taking the decision to let your unborn child die, is one that you will carry with you for the rest of your life. Often parents experience a very dual feeling, on the one hand, you will cherish this unborn child, on the other hand, you take the decision to just let your child die. The vast majority of parents go through a very intense grieving process that in most cases remains hidden from the people surrounding them. Whatever choice is made (Cozapo respects any choice!), it is important that parents support this choice as well as possible. Sufficient and clear information is essential to guarantee this. Cozapo understands very well this is not an easy task, in prenatal screening, the anomalies are often not entirely predictable. To Cozapo, it's crucial to explain the type of anomalies from all possible angles. Not only considering the medical consequences for the child, but also reveal what it means to the whole family on a social, financial, emotional, relational, ... level. Within the support group of Cozapo there are several couples who have terminated pregnancy because of trisomy 21. Have they been influenced by media aspects, their financial situation, their environment ...? Did parents actually freely make their choice? These are important questions, because we see that if parents are only partially supporting or not supporting their choice, this has a huge effects on their grieving process. Cozapo therefore looks forward with great interest to the results of this project. You can get in touch with Cozapo via mail on info@cozapo.org. More information about Cozapo can be found on the website www.cozapo.org.

Grip vzw: GRIP (Equal Rights for Each Person with a Disability) is a Flemish civil rights organization for people with disabilities. Patrick Vandelanotte has phrased Grip's position with respect to our proposal as follows: "Grip's goal is to achieve equal rights and opportunities for people with a disability. GRIP wishes to influence and stimulate policy and to correctly inform society at large. GRIP supports this challenge to 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. Raising awareness is one of our major objectives. In 2016 GRIP released a reflection about the influence of disability vision on the treatment of ethical questions. One of the proposals of GRIP was to create a framework for hospitals, genetic centers and services about the guidance and support for parents." More information on Grip can be found on www.gripvzw.be. Grip can be contacted by e-mailing patrick.vandelanotte@gripvzw.be.

Konekt vzw: Konekt is an organization that aims to strengthen people with a disability and their network. Konekt has formulated their position with respect to this project as follows: "We are curious about and fear for the effects of a society where striving for normality will become stronger and where more and more people will fail to meet the requirements of normality that we impose on others and ourselves. Providing 'neutral' information in the context of prenatal screening to us seems as impossible as it is necessary. We have a natural interest for the impossible, so do keep us posted!" More information on Konekt can be found on www.konekt.be. Konekt can be contacted by e-mailing koen.deweer@konekt.be.

Inclusie Vlaanderen: Inclusie Vlaanderen is focused on providing support to people with an intellectual disability. They emphasize the long way that society has come in the way that people with a disability are treated (from

exclusion over segregation to participation), but indicate where there is room for improvement. They take it at hart to show the value of people with an intellectual disability, and underline their right to an equal treatment in society. More information on Inclusie Vlaanderen can be found on www.inclusievlaanderen.be. Inclusie Vlaanderen can be contacted by e-mailing bernadette.rutjes@inclusievlaandren.be.

Gezin en Handicap: The baseline position of Gezin en Handicap vzw, a member of the KVG-group (Katholieke Vereniging Gehandicapten) is that parents who can share their own experiences with others will feel stronger and empowered. They organize meetings where information is provided and experiences are shared, they have a documentation center containing more than 4000 books, papers, journals and DVD's on handicaps in general, they provide advice to organizations and generally defend the interest of people with disabilities in a number of advisory boards. When asked to describe their own position as stakeholder to this project, they list the following: "We could help organize information sessions. In 2015 we have already organized an information session on prenatal counseling for future parents. We mainly focused on ways to ensure a valuable process for parents facing a tough decision. Most participants, however, where future midwifes, future nurses and future social workers. It proved quite hard to reach the parents themselves. We can additionally also help by publishing an article in Handiscoop, our journal." More information on Gezin en Handicap can be found on www.gezinenhandicap.be. Gezin en Handicap can be contacted by e-mailing lief.vanbael@kvg.be.

RIZIV: The Belgian Government for Health Insurance (Rijksinstituut Voor Ziekte- en Invaliditeitsverzekering, RIZIV) is the organization that is responsible for advice on the (conditions for) refunding medical tests and treatments, including prenatal screening. We have contacted Dr. Ri De Ridder (ri.deridder@riziv.fgov.be) on the matter. Although RIZIV is intrinsically interested in the matter, the organization would currently rather not be involved as stakeholder for the project, as this proposal was drafted in a delicate period concerning the decision-making process of refunding the NIPT (see above).

Acknowledgements: special thanks to professor De Dijn (KU Leuven) and doctor Kasper Raus (UGent) for their useful comments on earlier versions of this proposal.

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Supplement 2: List of Participants in the Stakeholder Meeting

Total of attendees of the stakeholder meeting (organizers included): 37

*Specific organizations that were represented:

> Downsyndroom Vlaanderen vzw; GRIP vzw; Konekt vzw; Kind en Gezin; Wit-Gele Kruis; University Hospitals from Leuven, Antwerp, Gent & Brussels, Regional Hospitals from Groeninge, Bonheiden & Leuven; KU Leuven (University of Leuven): Faculty of Medicine, Faculty of Economics and Business, Faculty of Arts, Faculty of Social Science, Institute of Philosophy, Centre for Biomedical Ethics and Law; UGent (University of Gent); ULB (University of Brussels); National public health institute Sciensano; VVOG(Flemish Association of Obstetrics and Gynecology), De Bakermat vzw (expert in maternity care), Geboorte Informatie Centrum vzw ('birth information centre').

**Some persons can be considered to belong to two or more of the categories listed. We considered the most relevant capacity in which they attended first.

Function	#	**More information**
Members of disability (rights) organizations	5	Downsyndroom Vlaanderen vzw, GRIP vzw, Konekt vzw
Parents of persons with Down syndrome	3	
Politician	1	Member of the Federal Belgian Parliament (at the time [the round table discussion took place])
Bioethicist	1	
Gynaecologist	5	From regional hospitals, from university hospitals, ...
Midwife	5	Self-employed, Wit-Gele Kruis, university hospital, ...
Genetic counselor	3	University hospital
Neonatologist	1	University hospital
Pediatrician	1	University hospital
(Bio)medical student	4	
Other students	4	Faculties: economics and business, philosophy, social sciences
Professor	1	Philosophy
Scientific assistant/researcher	3	National public health institute Sciensano, Universities, University Hospitals

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Supplement 3: Program of the Stakeholder Meeting

Stakeholderoverleg

Initiatieven om duurzame keuzes stimuleren bijprenatale screening

woensdag 8 mei (13:00—15:00)
Kardinaal Mercierzaal (HIW)
Kardinaal Mercierplein 2, 3000 Leuven

Programma

Op dit stakeholderoverleg verzamelen we graag uw visie op enkele initiatieven rond NIPT bij Downsyndroom. De initiatieven zijn: een reflectietool om de ouders bij te staan in hun beslissingsproces, een draaiboek voor de zorgverleners, en testimonials om de ouders te voorzien van bijkomende en genuanceerde informatie.

12.30	*Onthaal*
13.0	Inleiding **Waarom er nood is aan een transdisciplinaire discussie over counseling bij prenatale screening in Belgie**
13.10	Reflectietool **Om bewustheid te creeren bij zwangere vrouwen en hun partners over de keuzes dat prenatale screening met zich meebrengt**
13.20	Debat
13.35	Testimonials **Online platform met representatieve en gebalanceerde inhoud over leven met het syndroom van Down**
13.45	Debat
14.0	*Pauze*
14.10	Draaiboek **Argumenten voor een draaiboek voor prenatale screening om op een uniforme manier tegemoet te komen aan informatie noden bij prenatale screening**
14.20	Debat
14.35	Overige ideeen
14.40	Debat
15.00	*Einde*

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Supplement 4: Invitation to the Stakeholder Meeting

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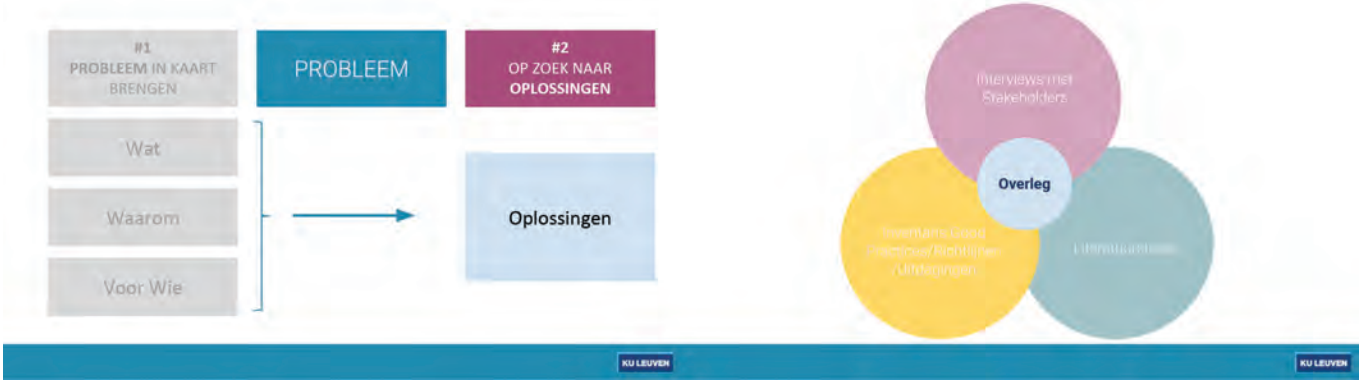
Supplement 5: Presentation Held During Stakeholder Meeting (Dutch) (May 8, 2019)



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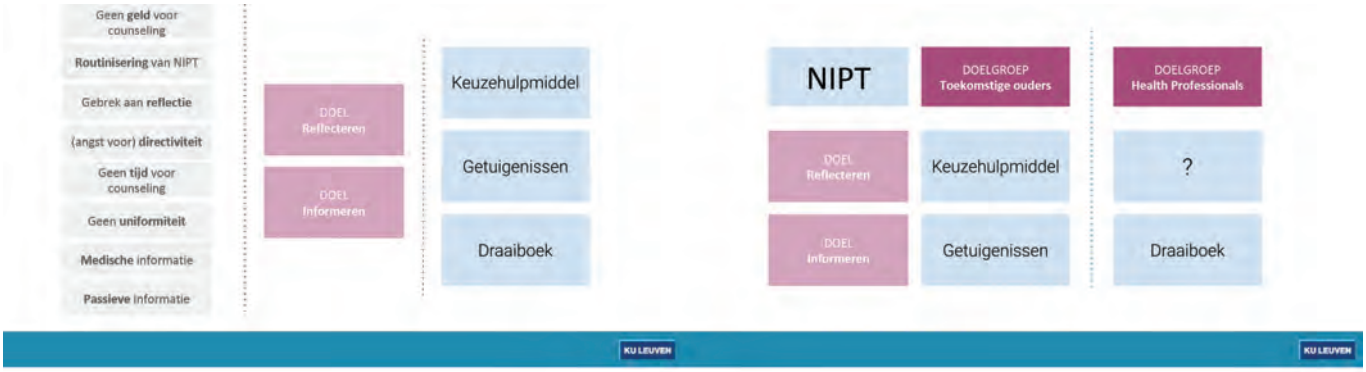

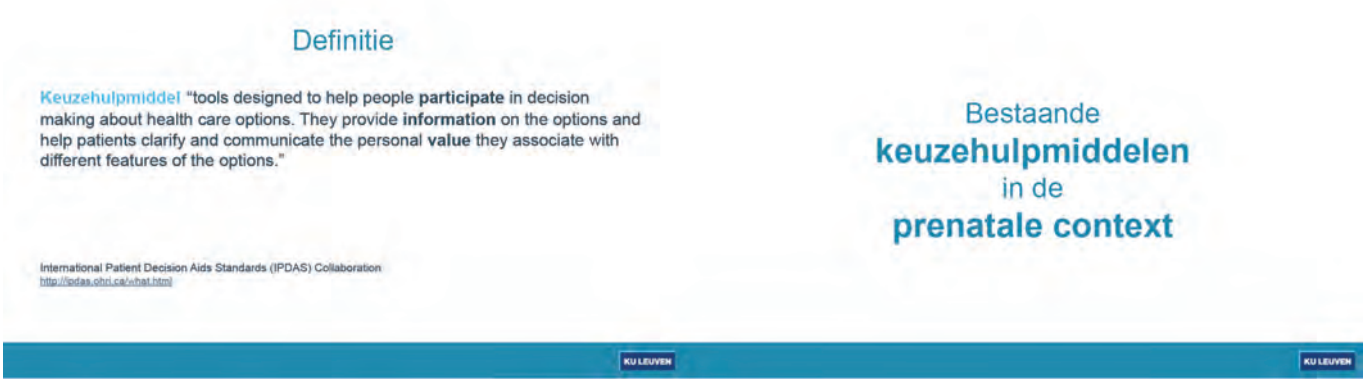

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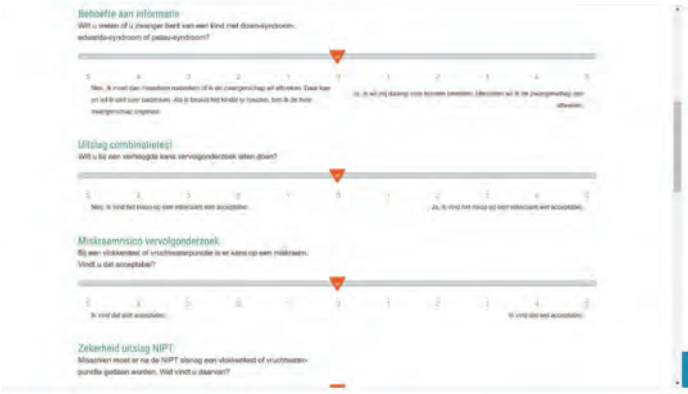

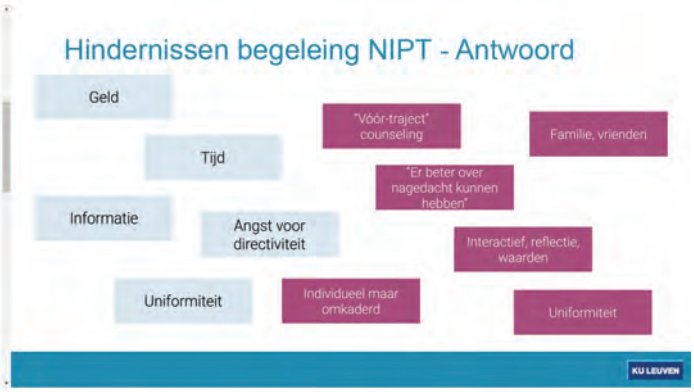

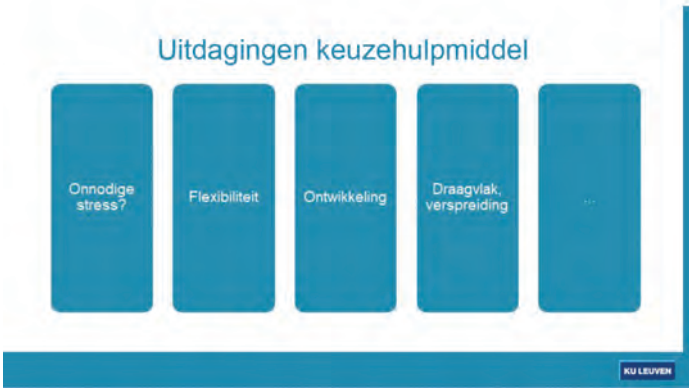

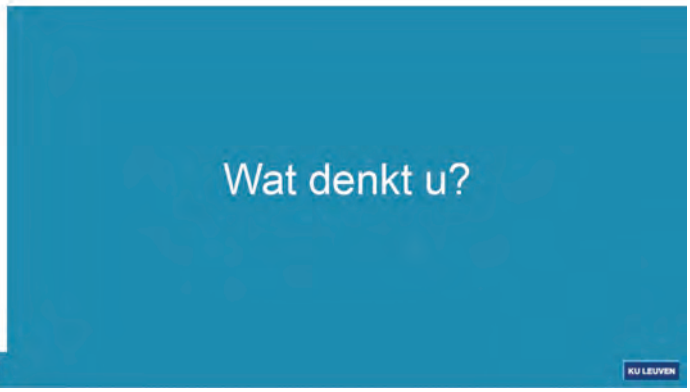

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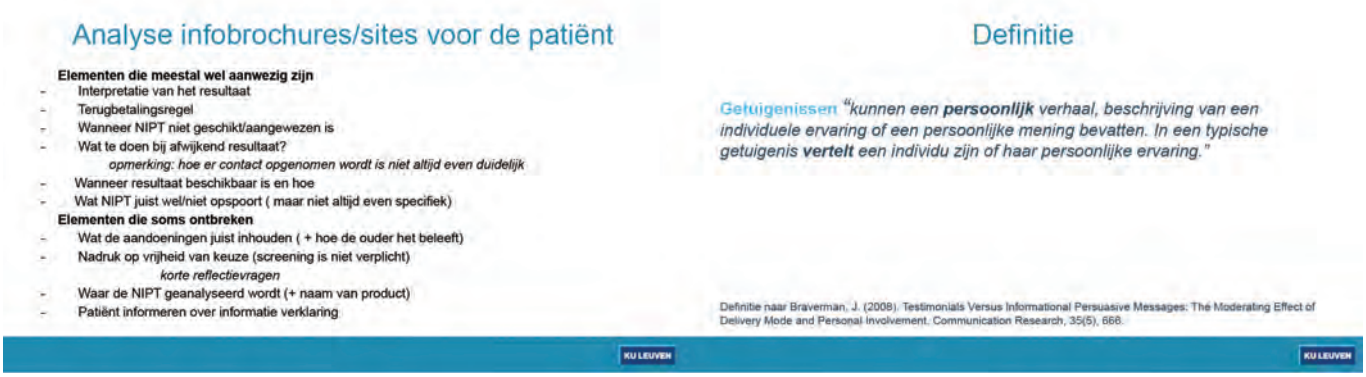

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Voorbeelden

"Het heeft mij veel geholpen te spreken met een vriendin die ook een kindje met Down had, maar daar achteraf dankbaar voor was. Zij had eerst het idee het niet te laten gebeuren, maar toen gebeurde het toch. En dan zie je dat mensen hun leven niet stopt, maar dat het toch wordt verrijkt. Het is belangrijk dat te zien en te voelen, en dan kan je altijd nog keuzes maken. (...)

- Anonieme getuigenis

Voorbeelden

(...) Maar als je enkel de medische kant bekijkt en enkel de dokters hoort praten heb je objectief geen reden om de zwangerschap voort te zetten, want het lijk allemaal problematisch. En als je dan kijkt naar de familie en het gezinsleven blijkt dat allemaal wel mee te vallen. Die beiden zaken gecombineerd zorgen voor een meer genuanceerd beeld van wat het effectief is. En ik miste dat. "

- Anonieme getuigenis

Voorbeelden

Voorbeelden

"Het is belangrijk om goed geïnformeerd te zijn over alle mogelijkheden gedurende het volledige proces. Dit gebeurt het best meteen wanneer je het nieuws van een positieve NIPT te horen krijgt. De informatie zorgt ervoor dat je, ongeacht de uitkomst, een beslissing kan maken waar je als persoon achteraf beter mee kan omgaan."

- Anonieme getuigenis

Ouders zijn bang voor het onbekende

Goed geïnformeerd?

Counseling?

Concept "getuigenissen"

Focus op andere aspecten

Realistische weergave

Concreter

Verschillende situaties

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Bestaande richtlijnen/draaiboeken

- Huisartsen: domus medica, richtlijnen
- Gynaecologen: VVOG, richtlijnen
- Counselors: eigen draaiboeken/richtlijnen
- College genetics: richtlijnen
- Federale overheidsdienst: ethisch advies
- RIVM (Nederland) draaiboek

Bedenkingen uit interviews...

Iedereen recht op dezelfde zorg → uniforme aanpak?

Verwijzingen

Rolverdeling

"De ene NIPT is de andere niet"

Overdracht informatie

KU LEUVEN

Uitdagingen draaiboek

Draagvlak

Verschillende populatie-noden

...

KU LEUVEN

Wat denkt u?

KU LEUVEN

NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

KU LEUVEN

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Supplement 6: List of Decision Aids

- International Patient Decision Aid Standards (IPDAS): http://ipdas.ohri.ca/
- Examples of decision aids in the prenatal context:
  - Australia:
    - https://www.mcri.edu.au/sites/default/files/media/documents/prenataltestingdecisionai d.pdf
  - Denmark:
    - http://graviditetsportalen.dk/
  - Canada:
    - http://www.hss.gov.yk.ca/pdf/prenatalscreeningguide.pdf
    - https://decisionaid.ohri.ca/AZsearch.php?criteria=prenatal (developed by *Healthwise* U.S.)
    - http://www.hss.gov.yk.ca/pdf/prenatalscreeningguide.pdf
    - http://www.perinatalservicesbc.ca/Documents/Screening/Prenatal- Families/ScreeningDecision-Aid.pdf
    - https://www.boitedecision.ulaval.ca/fileadmin/documents/Boites PDF/Trisomie/prena tal.screening.EN.May 15.pdf
  - The Netherlands:
    - https://www.keuzehulp.info/pp/pnt/intro/2 (NL)

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Supplement 7a: Reconstruction of the Main Insights (Dutch)

Stakeholderoverleg 8 mei 2019
Initiatieven om duurzame keuzes stimuleren bij prenatale screening

Dit is een samenvattende reconstructie van de voomaamste inzichten en reflecties die tijdens het stakeholderoverleg van 8 mei 2019 werden gedeeld. Het verslag werd samengesteld op basis van de notulen van Laura Barilla, Zoe Claesen en Job Meijer, en op basis van een poll ingevuld door verschillende aanwezige stakeholders. De reconstructie volgt de structuur van het overleg, waarbij per voorgesteld initiatief (zie supplement 5) de opmerkingen van de stakeholders worden weergegeven. Om de anonimiteit van stakeholders te bewaren worden zij niet bij naam vermeld maar bij functie of organisatie die ze vertegenwoordigen.

INITIATIEF 1: KEUZEHULPMIDDEL
Toelichting: zie supplement 5, p.2

Bio-ethicus: Het is niet vanzelfsprekend, maar wel nodig, om ervoor te zorgen dat iedereen hetzelfde zorgaanbod en dezelfde begeleiding aangeboden krijgt bij prenatale screening. Hoe kunnen we ervoor zorgen dat toekomstige ouders de best mogelijke omkadering krijgen? Verdere standaardisering en protocollering van de zorg kan helpen, waarbij de overheid zijn verantwoordelijkheid moet opnemen: zij zou moeten inzetten op de ontwikkeling van draaiboeken en keuzehulpmiddelen, zoals dit ook het geval was bij screening voor borst- en darmkanker, en bij neonatale screening. In de context van prenatale screening is dit veel minder het geval: het werkveld moet het maar regelen. Momenteel ontbreken die, wat kan leiden tot onzorgvuldige en ondoordachte beslissingen. Je zou kunnen zeggen dat mensen in een soort van ‘screenings-val’ dreigen te trappen. Er is dus zeker marge om te groeien, om protocollen te ontwikkelen.

Politicus: Als we willen dat er iets verandert, moet counselen bij prenatale screening in het regeerakkoord komen. Artsen moeten ook vaker naar hun patienten communiceren dat ze naast het recht op ***weten*** ook het recht hebben op ***niet weten***. Het recht op ***niet weten*** wordt door zorgverleners nauwelijks met hun patienten besproken, waardoor prenatale testen vaak worden afgenomen zonder bewuste voorafgaande toestemming van de patient. Dat kan tot ondoordachte beslissingen leiden bij onverwachte resultaten. Zorgverstrekkers moeten hier meer rekening mee houden. Het aantal prenatale testen dat wordt afgenomen blijft stijgen, maar de patient beschikt over te weinig informatie om de test te accepteren of af te wijzen.

Gynaecoloog: Ik geef graag vier bedenkingen mee. (1) De problematiek omtrent de NIPT in Belgie is ontstaan omdat de test te snel is ingevoerd, zonder omkadering over de inhoud of vorm van counseling. (2) Bovendien zijn toekomstige ouders vaak ook niet voldoende gei’nformeerd over het verschil tussen commerciele en niet-commerciele testen. Dergelijke commerciele testen zouden bij wet verboden moeten zijn. (3) Het lijken ook vooral de klinisch biologen veeleer dan de gynaecologen die keuzes opdringen bij ouders. (4) Als we het hebben over counseling vandaag moet gezegd worden dat deze slechts oppervlakkig is voor de testen worden uitgevoerd. Na het afnemen van de test is counseling meestal onbestaande.

Mensenrechtenorganisatie voor mensen met een beperking: De maatschappelijke context waarbinnen een kind met het syndroom van Down wordt geboren, is de laatste 25 jaar nauwelijks veranderd. Een kind met down krijgen, wordt nog steeds gezien als een ongeluk of een drama. Mensen met het syndroom van Down worden niet behandeld als volwaardige mensen in onze maatschappij. Daarbij is er binnen de politiek duidelijk nog steeds geen bewustzijn over (de kwaliteit van) counseling bij NIPT.

Kinderarts: Graag maak ik drie bedenkingen. (1) De ontwikkeling van een keuzehulpmiddel wil ik ondersteunen. Het is immers moeilijk om op een niet-directieve manier te counselen als er geen leidraad beschikbaar is. De directiviteit

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zal dan onvermijdelijk naar boven komen in bijvoorbeeld je lichaamshouding, in de informatie je wel en niet aanbiedt, in de accenten die je al dan niet bewust legt. Zorgverstrekkers hebben nood aan ondersteuning bij counselen, net om deze reden. Als je een keuzehulpmiddel maakt, is het tegelijk belangrijk om er zowel een voor de zorgverleners als een voor de ouders te maken. (2) Studies in bijvoorbeeld Canada tonen aan dat ongeveer 30% van de zwangere vrouwen die de NIPT ondergaan, niet weten wat de test inhoudt. Een keuzehulpmiddel kan helpen om dat probleem aan te pakken, om ouders ook bewust te maken van het recht om ***niet*** te weten, om hen te helpen onbevooroordeeld tot een beslissing over weten of niet weten te komen op basis van hun eigen normen en waarden. (3) De terugbetaling van de NIPT is goed, dat wil ik ook benadrukken, hoewel de terugbetaling te snel is doorgekomen waardoor er onvoldoende aandacht kwam voor het stroomlijnen van de counseling. Iedereen, ongeacht financiele of sociale klasse, moet even eenvoudig toegang krijgen tot de NIPT.

Vroedvrouw: Uit ons onderzoek in Gent komen gelijkaardige cijfers: 30–40% van de zwangere vrouwen weet niet juist wat de prenatale testen inhouden. Een keuzehulpmiddel zou dus zeker een meerwaarde kunnen betekenen. Tegelijk is het belangrijk dat zo'n hulpmiddel vrijblijvend blijft, en ook belangrijk, dat het als aanvulling en niet ter vervanging van counseling aangeboden wordt.

Kind en Gezin: Het basisprincipe bij elke screening is dat je maar mag screenen als je weet wat je met het resultaat wil doen. Daarom moet screenen gekoppeld worden aan goede counseling. Voor Kind en Gezin is het tegelijk belangrijk dat iedereen, ongeacht sociale klasse, gelijke toegang heeft tot NIPT.

Gynaecoloog: Je mag de counselingpraktijk ook niet al te simplistisch voorstellen: counseling moet aangepast worden aan geloof en afkomst, en patienten moeten ook begrijpen wat hen wordt meegedeeld. Een keuzehulpmiddel zou voor de volledige bevolking moeten kunnen dienen. Een keuzehulpmiddel zou voldoende flexibel moeten zijn om hierop in te kunnen spelen.

Student geneeskunde: Het keuzehulpmiddel lijkt nu, zoals het in de presentatie werd voorgesteld, vooral te focussen op hoogopgeleiden. Het is misschien niet zo evident om er een keuzehulpmiddel te maken dat toegankelijk is voor alle lagen van de bevolking.

Psychiater: Bij de keuze die ouders bij prenatale screening moeten maken, gaat het ook om de vraag over bestaan of niet. Dat maakt het een existentiele keuze. Een dergelijke keuze kan je niet alleen maken. We mogen niet in de pragmatiek blijven steken. De bredere existentiele vragen, zoals 'wat is berouw?', 'hoe maken mensen keuzes?', moeten we ook stellen.

Mensenrechtenorganisatie voor mensen met een beperking: In de discussie over het al dan niet verplicht toepassen van een dergelijk keuzehulpmiddel mogen we toch ook vooral de rechten van het ongeboren kind niet vergeten. Het ongeboren kind heeft recht op een weloverwogen keuze.

Organisatie voor mensen met een beperking: Een cruciale vraag hier is: wat is de norm? De norm van hoe mensen zouden moeten zijn, bepaalt de obstakels waar mensen met een beperking tegenaanlopen. De maatschappij reduceert mensen met een beperking in hun normorientatie tot hun beperking. Ze worden niet als volwaardige leden, als mensen van de maatschappij beschouwd.

Ouder van een kind met Downsyndroom: Het zijn de ouders zelf die beslissen of het kind blijft, niet de test. Ook na de keuze is er counseling nodig: ofwel om de afbreking te verwerken, ofwel om ouders die kozen om hun kind te houden bij te staan bij allerlei praktische zaken. Onderwijs, bijvoorbeeld: het gaat erom of mijn kind welkom is/blijft in de maatschappij.

INITIATIEF 2: DRAAIBOEK
Toelichting: zie supplement 5, p.6

Vroedvrouw: De uitdaging van goede counseling ligt vooral bij de perifere gynaecologen. Een draaiboek kan zeker een meerwaarde zijn, mits dit op een juiste manier opgebouwd wordt.

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Kinderarts: De bereidheid onder de artsen om zo'n draaiboek op te volgen, schiet momenteel vermoedelijk tekort. Dit kan verholpen worden door het draaiboek aan de patient te geven in plaats van aan de arts, zoals we ook doen bij de ***Downpas.*** Dat is een gezondheidsboekje ontworpen voor kinderen en volwassenen met het syndroom van Down. Ouders brengen het mee op consultatie, en zo is de arts wel ongeveer verplicht om aandacht te besteden aan deze leidraad.

Vroedvrouw (zelfstandige): De eerste lijn in de gezondheidszorg wordt te snel vergeten, terwijl net daar wel de tijd gevonden kan worden voor uitgebreidere prenatale consultatie. Vroedvrouwen kunnen voor verstaanbare counseling op maat van de patient zorgen. Wanneer zwangere vrouwen in een ziekenhuis terechtkomen, komen ze vaak niet met vroedvrouwen in contact voor de twaalfde week van de zwangerschap. Dat zwangere vrouwen in Vlaanderen typisch niet doorverwezen worden naar de vroedvrouw, heeft vermoedelijk met concurrentie te maken, geloof ik. Vrouwen worden meteen doorverwezen naar de tweede lijn, omdat er weinig samenwerking is tussen zelfstandige vroedvrouwen en ziekenhuizen. Betere afspraken tussen eerste en tweede lijn zijn wenselijk.

Politicus: Het punt van een optimale rolverdeling is inderdaad erg belangrijk. Er zijn goede afspraken gemaakt in de postnatale context na het inkorten van de ligdagen, de eerste en tweede lijn zijn daar nu goed op elkaar afgestemd. In de prenatale context is er op dat vlak nog een lange weg te gaan. In Leuven zijn we hiermee aan het experimenteren. De rolverdeling moet goed en duidelijk zijn—ook om overconsumptie van de zorg tegen te gaan. Patienten moeten weten waar ze aan toe zijn en bij wie ze terecht kunnen.

Gynaecoloog: Toch mogen we niet vergeten dat er in de eerste lijn te weinig mensen zijn met de kennis die nodig is om te counselen bij prenatale testen. Hier moet aan gewerkt worden. Bovendien ontbreekt counseling niet in alle situaties. Een draaiboek moet inzetten op zowel pre-test counseling als post-test counseling, en ook het onderscheid tussen commerciele en niet-commerciele testen moet aan bod komen. Binnenkort kunnen we genoom-breed screenen, ook dit moet in rekening gebracht worden. Zo niet, dan wordt het eerder gemaakte draaiboek irrelevant.

Genetic counselor: Counseling is helemaal niet vanzelfsprekend. Het vereist een specifieke opleiding die peilt naar biomedische kennis, psychologische kennis, sociale kennis, ethische kennis, juridische kennis en nog zoveel meer. De complexiteit van post-counseling mag zeker niet onderschat worden.

Student geneeskunde: Vanuit het perspectief van een geneeskundestudent denk ik dat een draaiboek heel nuttig zou zijn voor toekomstige artsen. In de opleiding wordt er nu slechts heel beperkt ingegaan op het praktische luik van de test: het is niet altijd duidelijk hoe en welke informatie je het beste mededeelt aan patienten over NIPT of prenatale testen.

Gynaecoloog: We staan nog voor grote uitdagingen om de bijkomende bevindingen van NIPT in kaart te brengen. De wet wordt ingehaald door bijkomende bevindingen van NIPT—waardoor het niet altijd makkelijk of mogelijk is om gepaste counseling te geven. Een breder draaiboek kan daarbij helpen. Dat kunnen we echter pas maken als we weten wat we willen weten via de NIPT, en wat niet.

Mensenrechtenorganisatie voor mensen met een beperking: Voor euthanasie bijvoorbeeld is er wel een draaiboek. Hoe heeft dit een draagvlak gekregen? Net zoals euthanasie is de NIPT ook een ethisch vraagstuk, waarom kan hier geen inspiratie uit gehaald worden?

Kind en Gezin: Vanuit mijn ervaring is een protocol iets wat stap voor stap uitgewerkt wordt, en waar later ook nog aanpassingen in worden gemaakt. Zie bijvoorbeeld de protocollen bij het neonataal screenen voor gehoor en zicht.

Organisatie voor mensen met een beperking: Screenings hebben een impact, het is normaal dat ouders bij het maken van een keuze door een zwaar traject gaan. Beperkingen worden door de samenleving nu als zwaarder ervaren dan tien jaar geleden. De verklaring hiervoor is dat mensen meer en meer moeten voldoen aan de norm.

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INITIATIEF 3: GETUIGENISSEN
Toelichting: zie supplement 5, p.4

Organisatie voor mensen met een beperking: Een project van ons vertrekt vanuit het idee van de maakbare mens. Als deel van dat project stellen we mensen met een beperking systematisch de vraag: “zijn jullie gelukkig?”. Elke ouder wil een gezond en een gelukkig kind, maar de medische wereld gaat ervan uit dat een beperking gelijk is aan niet gezond zijn, als iets dat genezen moet worden en dat niet gelukkig maakt. Dit proberen we te weerleggen. Als mensen met een beperking niet gelukkig zijn, dan wordt dit niet veroorzaakt door hun beperking, maar wel door de structuur van de maatschappij, door de manier waarop de maatschappij omgaat met hun beperking. In deze context zou het goed zijn om mensen met het syndroom van Down zelf aan het woord te laten, ook al is dat niet makkelijk.

Student biomedische wetenschappen & brus van een jongen met het syndroom van Down: Ik wil de nadruk leggen op de nood aan een goede opleiding voor artsen en paramedici. Ik schrik soms van de verouderde en vaak gewoon incorrecte informatie die wij als student meekrijgen over het syndroom van Down.

Professor in de wijsbegeerte: Aan de getuigenissen kan schriftelijke informatie toegevoegd worden over onder andere ethische aspecten (waarden, existentiele aspecten). Je moet opletten met het contrast dat gecreeerd kan worden tussen het medische, wat als objectieve informatie wordt gezien, en de getuigenissen, die dan als subjectief worden gezien. Volledig neutraal informeren is een illusie, maar als je verschillende standpunten en perspectieven naast elkaar zou leggen kan je door de diversiteit aan beelden in zekere zin de neutraliteit toch bewaren.

Kinderarts: Deze getuigenissen mogen niet meteen na de diagnose getoond worden omdat ouders op dat moment een traumatische ervaring beleven. De arts moet echt wel als uitgangspunt genomen worden bij counseling. Zij kunnen concreet staven wat mensen met het syndroom van Down bijvoorbeeld gemiddeld kunnen op achttienjarige leeftijd. Zo gaat het in Nederland, en ik denk dat dit een goede manier is om de beperkingen en mogelijkheden van iemand met down bij ouders te introduceren. Toch moeten er ook niet enkel dokters aan het woord komen. Als ouders aan het woord komen, is een video wel een goed idee. Een video is afstandelijker, en dus beter. Ook het concept van contactouders dat Downsyndroom Vlaanderen hanteert, is het vermelden waard.

Ouder van kind met Downsyndroom & voormalig contactouder: Getuigenissen in de vorm van videofragmenten kunnen misschien toch een beter alternatief zijn dan wat we met de contactouders doen. Postnataal werkt het contactoudermodel prima, maar de verantwoordelijkheid die je als contactouder draagt bij een prenataal bezoek is erg zwaar, en directiviteit is onmogelijk te vermijden in zo’n context. De afstand die gecreeerd wordt met videofragmenten lijkt mij in die zin wel positief.

Mensenrechtenorganisatie voor mensen met een beperking: De contactpersonen krijgen inderdaad een grote verantwoordelijkheid. Daar moet voorzichtig mee worden omgesprongen. Als er een netwerk van getuigenissen komt, dan moet ervoor gezorgd worden dat dit kwalitatief is en erin wordt geinvesteerd. Ervaringsdeskundigen moeten wel degelijk meer worden betrokken.

Student geneeskunde: Praktisch gezien vraag ik mij af wie de selectie van getuigenissen zou doen? En hoe beslis je welke getuigenissen aan bod komen? Geen enkele getuigenis kan een volledig beeld schetsen, hoe zou je daarmee omgaan?

Organisatie voor mensen met een beperking: Het is moeilijk om een volledig beeld te geven. Stel dat ik al een volledig beeld zou kunnen geven van een kind, een gezond kind, dan zou niemand vermoedelijk nog kinderen willen, omdat dit ook het beeld inhoudt van alles wat kan mislopen, niet van de droombeelden.

Vroedvrouw (zelfstandige): Om terug te gaan naar het aspect van counseling denk ik dat continuiteit heel belangrijk is. Elke zorgverlener is betrokken, maar door versnippering van de zorg komen mensen telkens bij iemand anders terecht. Elke zorgverlener is zo slechts een stukje van het verhaal. Het is belangrijk dat ouders bij eenzelfde persoon een aanspreekpunt vinden doorheen hun traject. Het counselen zou door dezelfde persoon gedaan moeten worden.

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Organisatie voor mensen met een beperking: Ouders worden te weinig ondersteund en begeleid bij de keuzes die ze moeten maken, niet enkel in het geval van Down. De begeleiding moet doorgaan, ook wanneer ouders kiezen voor een kind met een beperking.

Bio-ethicus: Getuigenissen zijn per definitie subjectief. Het idee van niet-directieve counseling is een illusie. De basisvraag 'wil je een NIPT of niet' kan zelfs vanuit institutioneel perspectief al als directief worden gezien. Het is vermoedelijk weinig zinvol om te vertrekken vanuit het idee dat er geen directiviteit mag zijn. Als je eerlijk bent over het feit dat een getuigenis directief is, dan zie ik geen probleem met het gebruik ervan.

Vroedvrouw (thuiszorg): Ik wilde ook nog even benadrukken dat er ook mensen zijn die heel tevreden zijn over de counseling die ze krijgen. Er zijn ook heel mooie verhalen.

INITIATIEF 4: VRAAGTEKEN/VARIA
Toelichting: zie supplement 5, p.8

Mensenrechtenorganisatie voor mensen met een beperking: Er is weinig evolutie in de blik van de maatschappij op mensen met het syndroom van Down. In een ideale wereld zouden mensen in hun dagdagelijkse leven al zo vaak in contact komen met mensen met een beperking, met het syndroom van Down, dat je op het moment van screening niet meer zou moeten uitleggen wat het syndroom van Down is. Dan zou je niet meer moeten investeren in getuigenissen.

Student geneeskunde: Als zorgverleners niet altijd beseffen dat ze een steek laten vallen, hoe kan je de communicatie tussen arts en patient dan verbeteren? Ik denk dat het belangrijk is om feedbackmomenten in te lassen, dit is nog altijd de beste manier om dingen te verbeteren.

Wetenschappelijk medewerker: Hoe laat je health professionals reflecteren over de vraag of ze al dan niet op een effectieve manier counselen? Artsen moeten tegenwoordig alles kunnen, ik vraag mij af waar de beperkingen hier zitten. Wat kunnen we vragen van dokters?

Psychiater: Artsen moeten een persoon zijn, menselijk zijn. Studenten die voor arts kiezen moeten dit bewust doen. Als arts sta je op de frontlinie van leed. Een niet-discriminerende attitude van artsen is ontoereikend. Ouders zullen altijd een 'droomkind' in gedachten hebben. Wanneer dan blijkt dat hun kind hiervan zal afwijken, is dit ook een kind, namelijk hun 'droomkind', verliezen. Dit is ook een soort van rouw, want hun kind zal niet zijn zoals ze verwachtten en ze zullen dus ook moeten leren accepteren en apprecieren wat ze wel krijgen als ze besluiten het kind te houden.

Ouder van een kind met Downsyndroom: We hebben ooit geprobeerd een studiedag voor artsen te organiseren over het leven met het syndroom van Down. Dit was heel moeilijk. Er is een verdeling onder de artsen. Op zo'n studiedag zouden enkel artsen aanwezig zijn die je bijscholing niet meer nodig hebben. Hoe krijg je de ongeinteresseerden geinteresseerd? Studiedagen voor zorgverleners zijn in elk geval belangrijk, maar zij die al veel weten, zullen komen, terwijl zij die het nodig hebben afwezig zullen blijven.

AFSLUITENDE POLL

Uit discussies tijdens deze samenkomst blijkt dat er een gezamenlijke nood is aan een uniform beleid, ondersteund door de politiek. Bovendien wordt er verder onderzoek verwacht naar de norm en het existentiele aspect rond personen met een beperking in deze maatschappij.

Om het stakeholderoverleg af te sluiten, kregen alle aanwezigen de mogelijkheid een poll in te vullen. Deze poll gaat na welke initiatieven de stakeholders het liefst zo snel mogelijk uitgewerkt zien in de toekomst. Dat levert enkele kwantitatieve resultaten op over het initiatief dat het belangrijkste is volgens deze kleine groep van belanghebbenden. Hierbij kregen ze de mogelijkheid een ander dan de drie voorgestelde initiatieven, omschreven tijdens de presentatie als het vraagteken, voor te stellen en opmerkingen achter te laten als feedback. De stakeholders werden niet beperkt tot slechts een initiatief te verkiezen. Figuur 1 stelt deze poll voor.

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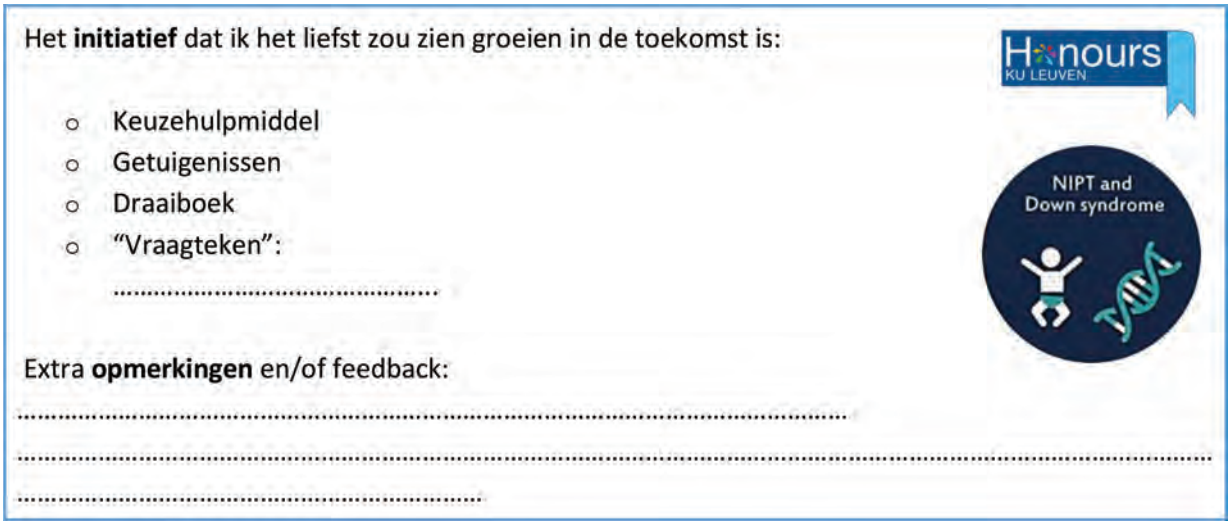

Figuur 1: Voorbeeld van de poll die de aanwezigheden kregen om in te vullen op het einde van het s takeholderoverleg.

Uit de resultaten van deze poll van 30 stakeholders bleek dat het draaiboek als initiatief 54% van de stemmen vertegenwoordigt en het keuzehulpmiddel een percentage van 38. Tabel 1 geeft de stemmen per initiatief weer in absolute cijfers. Negen stakeholders hebben meer dan een initiatief verkozen en hiervan heeft 44% een lichte voorkeur voor het draaiboek. Een stakeholder vulde het vraagteken in met een voorstel tot filosofische gesprekken voor professionals met als doel reflectie en luistervaardigheid te stimuleren.

Initiatief	Aanal voorkeuren
Keuzehulpmiddel	15
Getuigenissen	1
Draaiboek	21
Vraagteken	2

Tabel 1: A summary of the amount of preferences for each initiative per initiative presented at the stakeholder meeting.

Van de 30 ingevulde bevragingen hebben 24 stakeholders een opmerking neergeschreven. Hiervan hebben zeven aanwezigen hun emailadres opgegeven om verdere informatie te ontvangen en/of voor een toekomstige samenwerking. Herhaalde feedback duidt op de nood aan correct, duidelijk en eenvoudig taalgebruik in de verschillende tools, aangepast aan elk type stakeholder en rekening houdend met verschillende culturen. Er wordt verwacht ook meer dan enkel het syndroom van Down te onderzoeken en duidelijk te belichten 'wat in het geval van een positieve NIPT'. Zowel pre- als postcounseling moeten besproken worden. Het draaiboek moet zich bovendien niet enkel richten op directe zorgverleners, ook toekomstige artsen moeten betrokken worden. Als laatste benadrukten enkele aanwezige stakeholders dat het keuzehulpmiddel als aanvullend middel voor counseling moet worden gezien en niet als alternatief. Dat moet duidelijk toegelicht worden bij het gebruik van de tool.

In het algemeen kunnen we besluiten dat er een grote nood ondervonden is naar complementaire middelen als hulpverlening voor counseling. Velen zien dit echter als een enorme uitdaging die in de toekomst enkel groter zal worden zonder ondersteuning van de overheid.

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Supplement 7b: Reconstruction of the Main Insights (English)

Stakeholder Meeting May 8, 2019
Initiatives to stimulate sustainable choices in prenatal screening

This is a reconstruction of the main insights and reflections shared during the stakeholder meeting on the 8th of May 2019. The report was compiled based on the notes of Laura Barilla, Zoe Claesen and Job Meijer; and a poll completed by the stakeholders involved. The reconstruction follows the structure of the meeting and outlines the comments of the stakeholders per proposed initiative (see supplement 5). The stakeholders are anonymized and therefore not mentioned by name but by function or organization.

INITIATIVE 1: DECISION AID
Context see supplement 5, p.2

Bioethicist: It is not self-evident, but still necessary to ensure that everyone is offered the same care and guidance in prenatal screening. How can we ensure that future parents will receive the best support possible? Further standardization and protocolizing of healthcare can help. The government has to assume responsibility for this: they should focus on the development of plans and decision aids, as was the case with screening for breast and colon cancer, and neonatal screening. In the context of prenatal screening, this is much less the case: it was left to the professional field to make arrangements for NIPT. There is certainly room for growth in the developments of a protocol. Now clearly delineated instructions for doctor-patient communication about NIPT are lacking, which can lead to careless and ill-considered decisions. One could say that people are at risk of falling into a sort of 'screening trap'.

Politician: If we want anything to change, counseling in prenatal screening must be included in the coalition agreement. Doctors should also communicate more often to their patients that, in addition to the right to know, they also have the *right not to know*. This last right is only barely discussed with patients. As a result, prenatal tests are often taken without the patient's genuine approval. This can lead to ill-considered decisions in the event of unexpected results. Healthcare providers should take this more into account. The number of prenatal tests that are taken continues to increase, but the patient does not have enough information to accept or reject the test.

Gynecologist: I would like to raise four considerations. (1) The problem with NIPT in Belgium arose because the test was introduced too quickly, without any guidance for the content or form of counseling. (2) Future parents are often not sufficiently informed about the difference between commercial and noncommercial tests. Such commercial tests should be prohibited by law. (3) Clinical biologists rather than gynecologists seem to be the ones who force choices on parents. (4) When we talk about counseling today, it must be said that it occurs quite superficially before the tests are carried out. After taking the test, counseling is usually non-existent.

Human rights organization for people with disabilities: The social context in which a child with Down syndrome is born has hardly changed in the last 25 years. Having a child with Down syndrome is still seen as an accident or a tragedy. Moreover, people with Down syndrome are not treated as full-fledged members of our society. In addition, there is clearly still no political awareness of (the quality of) counseling in NIPT.

Pediatrician: I would like to make three considerations. (1) I would like to support the development of a decision aid. After all, it is difficult to counsel in a non-directive way without a clear guide at our disposal. The directivity will inevitably find expression, for example, in your posture, in the information you do or do not provide and on which information you lay emphasis, consciously or unconsciously. Healthcare providers need support in counseling, precisely for this reason. When you create a decision aid, it is also important to make one for the health care providers as well as one for the parents. (2) Studies in Canada, for example, show that about 30% of pregnant women who go through the NIPT do not know what the test entails. A decision aid can help address this problem, make parents aware of the right not to know, and help them make an unbiased decision about knowing or not knowing based on their own values and

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norms. (3) I would also like to stress that it's a good thing that the NIPT is reimbursed, although the reimbursement came through too quickly. This meant that there was insufficient attention for streamlining the counseling. Everyone, regardless of financial or social class, should have equally easy access to the NIPT.

Midwife: Our research in Ghent shows similar figures: 30–40% of pregnant women do not know exactly what the prenatal tests entail. A decision aid could therefore certainly be an added value. But it is important that such a tool should be offered without obligations, and more importantly, that it is offered supplementary to counseling and not as a replacement thereof.

Kind en Gezin ('Child and Family'; a Flemish agency that works actively in the 'Public Health, Welfare and Family' policy area): The basic principle of any screening is that you should screen only if you know what you want to do with the result. That is why screening must be linked to good counseling. For Kind en Gezin it is also important that everyone, regardless of social class, has equal access to NIPT.

Gynecologist: The counseling practice should not be oversimplified either: counseling should be adapted to religion and various cultural backgrounds. Patients should understand what is being communicated to them. Hence, a decision aid should be sufficiently flexible to serve the entire population and to respond to these differences.

Medical student: The way in which the decision aid is currently presented, gives the impression that it would focus mainly on the highly educated part of society. It might not be so easy to create a decisionmaking tool that is accessible to all layers of the population.

Psychiatrist: The choice parents have to make in prenatal screening may also lead to choices about existence and the absence of existence, which makes it an existential choice. You cannot make such a choice alone. We should not get trapped into mere pragmatism. We must also ask the broader existential questions, such as 'what is regret?' and 'how do people make choices?'.

Human rights organization for people with disabilities: In the discussion about whether the use of such a decision-making tool is mandatory, we should not forget the rights of the unborn child. The unborn child has a right to a well-considered choice.

Organization for people with disabilities: A crucial question here is: what is the norm? The standard of what people should be like, determines the obstacles that people with disabilities face. Society reduces people with a disability to their impairment, that is, to what they cannot do, the point where they differ from the norm. And on the basis of that, they are not considered as full members, as people of society.

Parent of a child with Down syndrome: It is up to the parents themselves to decide whether the child stays or not, not the test. Counseling is also needed after the choice has been made either to process the termination of pregnancy, or to support parents who chose to keep their child in practical matters like education. It's about whether my child is/remains welcome in society.

INITIATIVE 2: PROTOCOL

Context see supplement 5, p.6

Midwife: The challenge of good counseling lies mainly with the peripheral gynecologists. A protocol can certainly be an added value, provided it is constructed in the right way.

Pediatrician: The willingness of the doctors to follow a protocol is probably insufficient at the moment. This can be remedied by giving a kind of scenario or outline to the patient instead of the doctor, as we do with the 'Downpas'. This is a health booklet designed for children and adults with Down syndrome. In this way, the doctor is obliged to pay attention to the content that the parents bring to the doctor's office.

Midwife (self-employed): The first line of healthcare is too frequently forgotten, although they have more time for more extensive prenatal consultation. Midwives can provide understandable counseling tailored to pregnant women.

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When pregnant women end up going to hospitals for their check-ups, they often do not encounter midwives before the twelfth week of pregnancy. The fact that pregnant women in Flanders are typically not referred to the midwife in early pregnancy, I believe, probably has to do with competition. Women are immediately referred to the second line, because there is little cooperation between independent midwives and hospitals. Better agreements between first and second line are desirable.

Politician: An optimal division of roles is indeed very important. Good agreements have been made in the post-natal context after shortening the period of stay in hospitals after giving birth. In this area, the first and second lines are now well coordinated. In the prenatal context on the contrary, there is still a long way to go. We are currently experimenting with this in Leuven. The division of roles must be good and clear—also to prevent overconsumption of care. Patients need to know where they stand and to whom they can turn throughout their pregnancy.

Gynecologist: However, we should not forget that in the first line there are not enough people with the qualified knowledge for genetic counseling. We need to work on this. Moreover, counseling is not lacking in all situations. A protocol should focus on both pre-test counseling and post-test counseling. The distinction between commercial and non-commercial testing should also be addressed. Soon we are moving towards genome-wide screening, this should also be taken into account. If not, the previously made protocol will become irrelevant.

Genetic counselor: Counseling is not self-evident at all. It requires specific training which assesses biomedical knowledge, psychological knowledge, social knowledge, ethical knowledge, legal knowledge and much more. The complexity of post-counseling should certainly not be underestimated.

Medical student: From the perspective of a medical student, I think that a protocol would be very useful for future doctors. The practical aspects of dealing with NIPT in relation to patients is not extensively discussed in class: it is not always clear how and what information is best communicated to patients about NIPT/prenatal tests.

Gynecologist: We still face major challenges in mapping out the additional findings of NIPT. The law is being surpassed by additional findings from NIPT, which makes it not always easy or possible to provide appropriate counseling. A broader protocol can help in this respect. However, we can only do this when we know what we want to know via NIPT, and what we don't want to know.

Human rights organization for people with disabilities: For euthanasia, for example, there is a protocol. How did it gain support? Just like euthanasia, NIPT is also an ethical issue, why can't we draw inspiration from the developments of other protocols?

Kind en Gezin: From my experience, a protocol is something that is worked out step by step, in which adjustments can be made later on. See for example the protocols for neonatal screening for hearing and sight.

Organization for people with a disability: Screening has an impact; it is normal for parents to go through a difficult process when making a choice. Disabilities are now perceived as more daunting by society than they were ten years ago. The explanation for this is that more and more people have to comply with the norm.

INITIATIVE 3: TESTIMONIALS

Context see supplement 5, p.4

Organization for people with disabilities: One of our projects is based on the idea of "the makeable human being". As part of that project, we systematically ask people with disabilities: "Are you happy?". Every parent wants a healthy and a happy child, but the medical world assumes that a disability is equal to not being healthy, as something that needs to be cured and does not make happy. This is what we are trying to refute. If people with a disability are not happy, this is not caused by their disability, but by the structure of society and by the way in which society deals with their disability. In this context, it would be good to let people with Down syndrome speak for themselves, even if that is not easy.

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Student biomedical sciences & sibling of a boy with Down syndrome: I want to emphasize the need for a good education for doctors and paramedics. I am sometimes shocked by the outdated and often simply incorrect information that we, as a student, receive about Down syndrome.

Professor of philosophy: Written information on, among other things, ethical aspects (values, existential aspects) can be added to the testimonials. You have to pay attention to the contrast that can be created between the medical, which is seen as objective information, and the testimonials, which are seen as purely subjective. Completely neutral information is an illusion, but if you could put different points of view and perspectives side by side you could in a way preserve neutrality through the diversity of images.

Pediatrician: These testimonials should not be shown immediately after the diagnosis because parents go through a traumatic experience at that moment. Doctors should really be the starting point for counseling. They can provide concrete evidence of what people with Down syndrome, for example, can do on average at the age of eighteen. This is the way things are done in the Netherlands, and I think this is a good way to introduce the limitations and possibilities of someone with Down to their parents. However, it should not be only left to doctors to talk about this, but also for instance parents of children with Down syndrome When parents share their experience, a video is a good idea because it creates a degree of distance. The concept of 'contact parents' that *Downsyndroom Vlaanderen* [a volunteer organization by and for parents of children with Down syndrome] uses is also worth mentioning.

Parent of a child with Down syndrome & former 'contact parent': Testimonials in video format may be a better alternative than the concept of contact parents. This works perfectly well postnatally, but the sense of responsibility you bear as a contact parent during a prenatal visit is very heavy, and directivity is impossible to avoid in such a context. In that sense, the distance that is created through the medium of video fragments seems positive to me.

Human rights organization for people with disabilities: The 'contact parents' will indeed have a great responsibility. This must be handled with care. If there will be a network of testimonies, the quality must be ensured and more funds need to flow to these kinds of initiatives. Experts by experience need to be more involved.

Medical student: In practical terms, I wonder who would do the selection of testimonials? And how do you decide which testimonials will be discussed? No testimonial can give a complete picture, how would you deal with it?

Organization for people with disabilities: It is difficult to give a complete picture. Imagine I already could give a complete picture of a healthy child, then no one would probably want children anymore. That's because it would be the picture of everything that can go wrong, not of the fantasies people have.

Midwife (self-employed): To go back to the aspect of counseling, I think that continuity is very important. Every care provider is involved, but because of the fragmentation of health care, people always end up with someone else. In this way, every care provider is just a piece of the story. It is important for parents to find a point of contact with the same person throughout their journey. Counseling should be done by the same person.

Organization for people with disabilities: Parents are insufficiently supported and guided in the choices they have to make, not only in the case of Down syndrome. Guidance and support must continue, also when parents choose to have a child with a disability.

Bioethicist: Testimonials are by definition subjective. The idea of non-directive counseling is an illusion. The basic question 'do you want a NIPT or not?' can even be seen as form of directivity from an institutional perspective. It probably makes little sense to start from the idea that there should be no directivity. If you are honest about the fact that a testimony is directive, then I see no problem with its use.

Midwife (homecare): I also wanted to emphasize that there are people who are very satisfied with the counseling they receive. There are also some very nice and positive stories.

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INITIATIVE X : QUESTION MARK/MISCELLANEOUS

Context see supplement 5, p.8

Human rights organization for people with disabilities: There is little positive development in society's view of people with Down syndrome. In an ideal world, people would encounter people with a disability, with Down syndrome, with sufficient regularity in their daily lives that, at the time of prenatal screening, you would no longer have to explain what Down syndrome is. Then you won't have to invest in testimonials anymore.

Medical student: If healthcare providers do not always realize that they inappropriately communicate about NIPT or disability, how could we improve the communication between doctor and patient? I think it's important to include feedback opportunities, this is still one of the best ways to improve things.

Scientific assistant: How do you get health professionals to reflect on whether or not they are counseling effectively? Nowadays, doctors have to be able to do everything, I wonder where the limitations are. What can we expect of doctors?

Psychiatrist: Doctors must be a person, a human. Students who choose to study medicine should do so consciously. As a doctor, you are on the front line of suffering. As a doctor, a non-discriminatory attitude is insufficient. Parents will always have a 'dream child' in mind. If it turns out that their child will deviate from this, this also means they are losing a child, namely their 'dream child'. With this a kind of mourning arises, because their child will not be as they expected, and they will have to learn to accept and appreciate what they get if they decide to keep the child.

Parent of a child with Down syndrome: We once tried to organize a seminar for doctors about living with Down syndrome. This was very difficult. There is a division among the doctors. Only doctors who no longer need your further training would be present at such a seminar. The question is: How do you get the uninterested interested? In any case, seminars for healthcare providers are important, but those who already know a lot will come, while those who need it will remain absent.

FINAL POLL IN CONCLUSION OF THE STAKEHOLDER MEETING

Discussions during this meeting show that there is a common need for a uniform policy, supported by politics. In addition, further research is expected into the norm and the existential aspect of persons with disabilities in this society.

To conclude the stakeholder meeting, all attendees were given the opportunity to fill in a poll. This poll examines which initiatives stakeholders prefer to see developed as soon as possible in the future. This provides some quantitative results about the initiative that is valued most important according to this group of stakeholders. They were given the opportunity to present a different initiative than the three proposed initiatives, described as 'the question mark' during the presentation, and to leave comments as feedback. Stakeholders were not limited to preferring just one initiative. Figure 1 presents this poll.

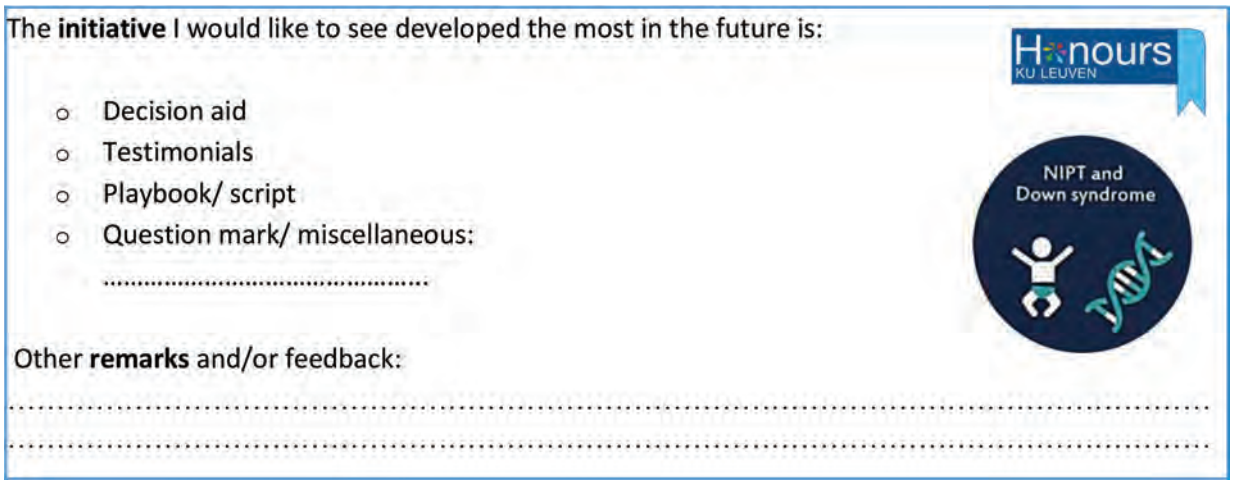

Figure 1. Example of the poll the stakeholders received to fill in at the end of the stakeholder meeting.

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The results of this poll of 30 stakeholders showed that the protocol initiative represents 54% preference votes and the decision aid gain a 38% support. Table 1 shows the votes per initiative in absolute figures. Nine stakeholders chose more than one initiative, 44% of which had a slight preference for the protocol. One stakeholder filled in the question mark with a proposal for philosophical discussions for professionals in order to stimulate reflection and listening skills.

Initiative	Number of preferences
Decision aid	15
Testimonials	1
Protocol	21
Question mark/miscellaneous	2

Of the 30 completed questionnaires, 24 stakeholders wrote a comment. Of those who commented, seven provided their email addresses in order to receive further information and/or for a future collaboration. Recurrent feedback indicates the need for correct, clear and simple language in the different tools, adapted to each type of target and taking into account different cultures. It is also expected to examine more than just Down syndrome and to highlight clearly where the choices lie and 'What to do in case of a positive NIPT?'. Both pre- and post-counseling need to be discussed. The protocol should not only focus on established healthcare providers, but also on future doctors. Finally, several stakeholders emphasized that the decision aid should be seen as an additional tool for counseling and not as an alternative.

In general, we can conclude that there is a great need for complementary resources to assist genetic counseling. Many stakeholders see this as an enormous challenge that will only increase without governmental support.

(Translation based on Deepl)

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Supplement 8: Presentation Held at Transdisciplinary Insights Symposium (English) (May 8, 2019)

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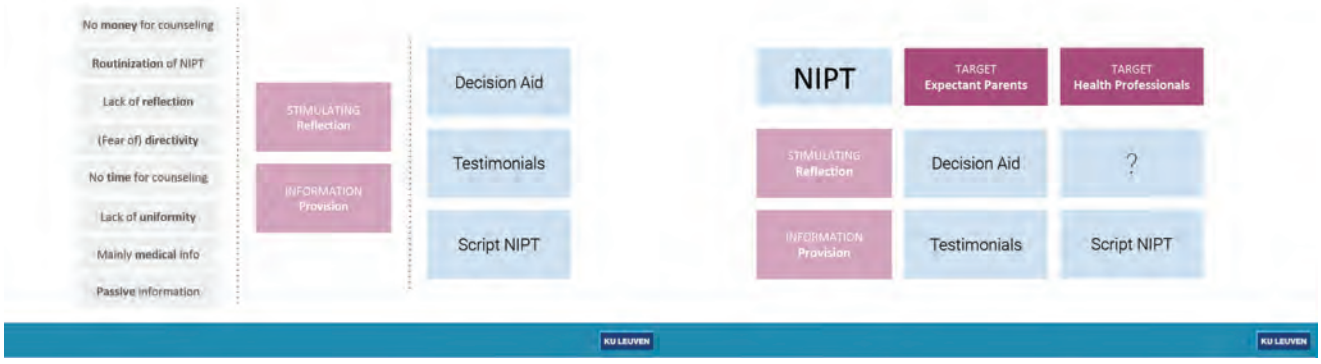

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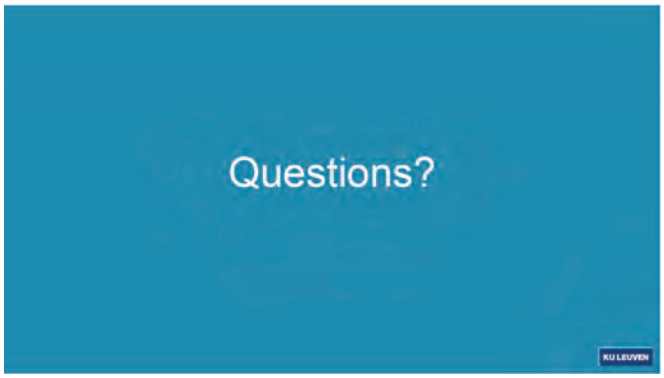

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Supplement 9: Recording Presentation

Counseling in prenatal screening for Down syndrome—Transdisciplinary Insights Honours Programme Symposium, May 8, 2019 – recording presentation here.

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Proposing a Case Study Combining Transdisciplinary and Data-Centered Methods for Understanding Complex Problems in an Educational Context

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Abstract

In this opinion piece we argue for combining data-centered hackathons with transdisciplinarity to better understand wicked problems such as food insecurity. Hackathons represent unique opportunities for answering previously identified and consequently well-defined questions in the context of high-dimensional data. However, the possibilities for providing participants with extensive and potentially quintessential background knowledge and for enabling them to develop a shared understanding of the explicit and implicit meanings of variables associated with the respective problem are limited. Thus, the inherently difficult step of deriving realistic strategic implications from provided or otherwise available data is further aggravated. In the context of this evident void, a format combining transdisciplinary and data-driven approaches could represent a promising approach. Thereby, quantitative and preferably unbiased and qualitative, concept-centered analyses could be paralleled, which would enable the synergistic and incremental understanding of both the relationships between model variables and the meaning of those variables themselves. Furthermore, transdisciplinary approaches are fundamentally stakeholder-focused. The aforementioned approach not only could thus support the development of strategic recommendations concerning the chosen problem, but also facilitates stakeholder engagement, which is central to ensuring that proposed strategies are realistic, implementable, and accepted. Food insecurity represents a prime example of a complex, multidimensional problem of extreme urgency. Besides the availability of a myriad of data relating to several aspects of food insecurity, including data on transport networks, food policy decisions, and climate change, grasping the phenomenon of food insecurity in its entirety remains challenging. Given its relevance and

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complexity and the amount of related data available, food insecurity represents an ideal challenge for exploring the feasibility of combining data-driven and transdisciplinary approaches. Therefore, during the 2018–2019 academic year, a group of students organized a hackathon around food insecurity and drew inspiration from that hackathon to write a challenge document to be taken up during the 'Transdisciplinary Insights' Honours Programme of the 2019–2020 academic year.

Key words

Data, Collaboration, Complexity, Qualitative, Quantitative, Transdisciplinary, Hackathon

1. Introduction

It is estimated that by 2020 1.7 MB of data will be produced every second for every person on earth [1]. Furthermore, international efforts are underway to develop supercomputers with a peak performance capability of up to 300 teraflops (1 teraflop equals 10^{12} floating point operations per second) [2]. Provided that ethical and legal boundaries are collectively agreed upon and respected, the availability and processability of such a vast amount of data are likely to greatly expand humanity's potential for understanding complex systems. Simultaneously, it has been argued that "asking the right question" is the hardest task related to data science [3]. A hybrid approach combining transdisciplinary and data-driven approaches might be suitable for addressing this essential challenge. Therefore, in this opinion piece, transdisciplinary and data-driven approaches will first be introduced independently as possible methodologies for understanding complex problems. Secondly, the potential benefits of combining the two approaches will be discussed in general and in the context of academic education, specifically at KU Leuven. Finally, we will introduce a case study concerning the problem of food insecurity, leveraging the aforementioned insights.

2. Data science approaches for quantitative research

Recently, Cao (2017) provided the following as one possible definition of data science:

> "From the disciplinary perspective, data science is a new interdisciplinary field that synthesizes and builds on statistics, informatics, computing, communication, management, and sociology to study data and its environments […]." ([4], p. 8)

Data science projects are designed to generate data products which are broad in nature but ultimately deliver insights, knowledge, and decision [4]. In order to be able to deliver these values, data scientists not only need to have a thorough understanding of the technical aspects of their work, they also need to develop a profound understanding of the domain and context from which the data originate [4]. In GitHub's "Development Workflows for Data Scientists" (2017) [5], a general data science workflow is detailed as encompassing the generation of an interesting question or hypothesis, data acquisition, data exploration, data modelling and communication and visualization of the results (see Figure 1).

Despite data science relying heavily on statistics, informatics, and computing, both the generation of a question or hypothesis and the interpretation and communication of the results are likely to be primarily dependent on the context of the data analyzed. According to Cao (2017a, 2017b), systems representing data science problems are characterized by several types of complexities [4; 6]. Behavior complexity, for example, is encountered upon bridging the gap between the data world and the physical world constituted by behavioral objects and subjects. In this context, the author remarks on the lack of systematic research into the comprehension and management of complex behaviors [6]. Domain complexity, on the other hand, concerns constituting aspects of a specific domain and includes qualitative and expert domain knowledge, interactions with and involvement of domain experts, and cross-domain interactions. Finally, social and environmental complexities refer, amongst others, to the social and environmental contexts and issues shaping a data science problem.

Recently, hackathons have become increasingly popular for rendering data science more accessible and for addressing problems in the context of such complex environmental and social systems. Hackathons are a heterogeneous phenomenon, certain forms of which may be regarded as primarily data-focused [7]. The duration of a hackathon is usually limited, ranging from a day to a week, and the format unites teams of computer programmers, data scientists,

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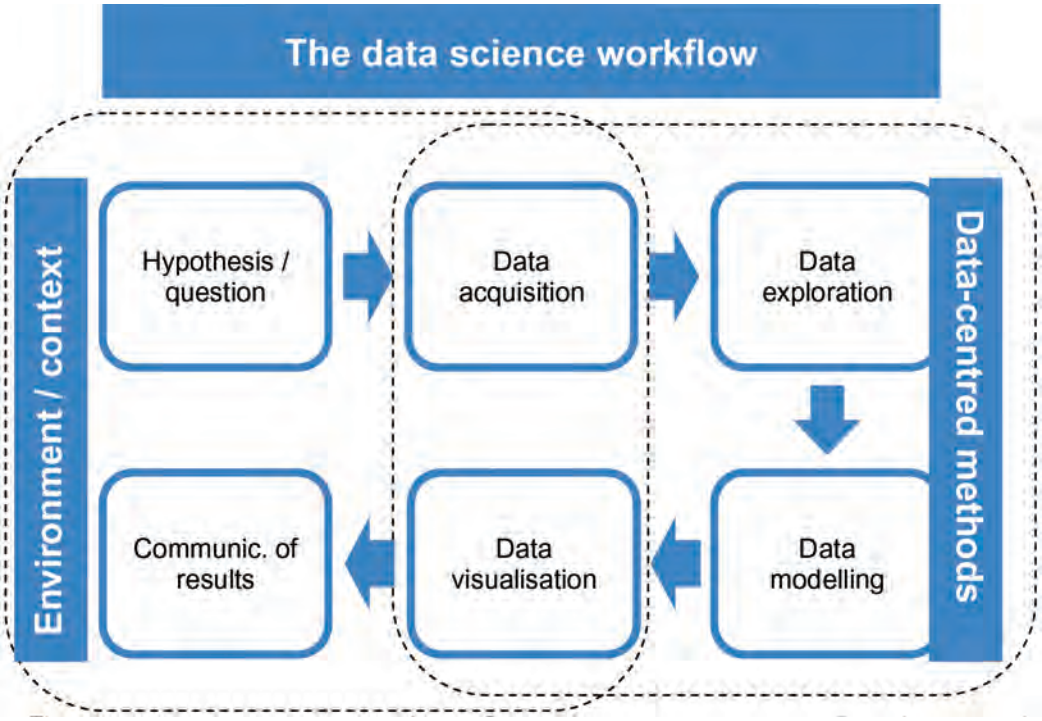

Figure 1. The data science workflow according to Byrne (2017) with adaptations. Both the generation of an interesting question or hypothesis and the communication of the results require the establishment of a thorough understanding of the respective context. A seamless integration of the data science workflow with its external environment might enable data scientists to address meaningful problems in a sustainable manner.

and project managers behind a shared, data-driven goal [7]. According to a classification by Briscoe and Mulligan (2014) [8], hackathons may be either tech-centric or focus-centric, with the former type aiming at rapid software development using a particular technology or creating a particular application, and the latter type seeking to use software development for addressing a specific social or business problem. Focus-centric hackathons may thus be subdivided into socially oriented, demographic-specific and company internal hackathons. In the context discussed herein, socially oriented hackathons, during which a problem of social relevance is addressed, are of particular interest. A myriad of initiatives exists in Belgium and beyond which utilize the compact format of hackathons for generating insights into or (partial) solutions for socially relevant challenges, including Hack Belgium,[1] data for better health,[2] and HackDuke.[3]

3. Transdisciplinary approaches for qualitative research

Over the last seventy years the world has seen significant socioeconomic changes, such as an increase in world population, urban density, energy use, transportation, consumption, and production, all of which have dramatically affected global systems. Human interaction across the planet has created complex and/or wicked problems that require a non-linear approach for their understanding. According to Rittel and Webber (1973), wicked problems are unique and ill-defined (i.e. lack a definitive formulation and stopping rule), attempts to solve wicked problems dynamically change the underlying system itself, and, although the quality of any solution to a wicked problem cannot be generally assessed or categorized as “true” or “false”, planners are ultimately responsible for the consequences of their actions [9]. In short, wicked problems represent social or cultural concerns that are difficult to frame and explain and impossible to solve due to their interconnection with other issues. Inequality, migration, global climate change, and obesity are some examples of wicked problems that require to be addressed collaboratively and cooperatively.

Universities play an essential role in the development of scientific approaches for addressing different problems. Usually, higher education institutions are structured based on disciplines, and the degree of collaboration and cooperation between them determines the type of research, ranging from mono-disciplinary to

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transdisciplinary. The League of European Research Universities (LERU) proposes a spectrum of degrees of collaboration between disciplines [10] (see Figure 2). According to this framework, disciplinary research is a specific unit of knowledge with its own methods of research where researchers belong to the same discipline. Multidisciplinary research is characterized by the juxtaposition of perspectives of researchers from a similar perspective where there is a low level of interaction among them. Interdisciplinary research is characterized by the integration of disciplines, tools, and methods for solving specific problems, with a high level of cooperation and interdependence between disciplines. Transdisciplinary research involves the highest degree of collaboration between disciplines, but also includes interactions with other actors or stakeholders for solving societal challenges.

Transdisciplinarity is a relatively new concept. Only recently has it received heightened attention from scholars as a way to address complex problems of the Anthropocene and, consequently, over the last 20 years the number of publications on transdisciplinarity has increased sharply and was four times higher in 2018 than in 2010 [11].

Although no exclusive definition of transdisciplinary research exists, Pohl and Hirsch Hadorn have provided the following attempt to delineate the concept [12]:

> "Transdisciplinary research is needed when knowledge about a societally relevant problem field is uncertain, when the concrete nature of problems is disputed, and when there is a great deal at stake for those concerned by problems and involved in dealing with them. Transdisciplinary research deals with problem fields in such a way that it can: (a) grasp the complexity of problems, (b) take into account the diversity of life-world and scientific perceptions of problems, (c) link abstract and case-specific knowledge, and (d) develop knowledge and practices that promote what is perceived to be the common good. (Pohl and Hirsch Hadorn, 2007)"

In spite of the ambiguity about the exact meaning of transdisciplinarity several common elements are present in the majority of definitions. For example, transdisciplinary research is considered to deal with societal problems, to require a high level of collaboration between disciplines, to be problem-solving oriented, and to involve and/or engage stakeholders. According to Pohl and Hirsch Hadorn (2007) [13], transdisciplinary research is required where a societally relevant problem is ill-defined, its concrete nature is not universally agreed upon, and its impact on those affected by or involved with the problem is substantial. In short, wicked problems demand transdisciplinary research.

One of the purposes of transdisciplinary research is aligning the knowledge production in academia with the knowledge required for providing solutions to societal challenges. Therefore, transdisciplinary research is concerned with the realms of both science and practice. The former is characterized by the rigor of academic and scientific understanding, while the latter is defined through its relevance and practicality for society. Through its involvement with both realms, transdisciplinary research acts as a catalyst for the exchange between science and practice by promoting the collaboration between researchers and stakeholders in the process of framing and analyzing the problem and exploring the impact on both science and society [14].

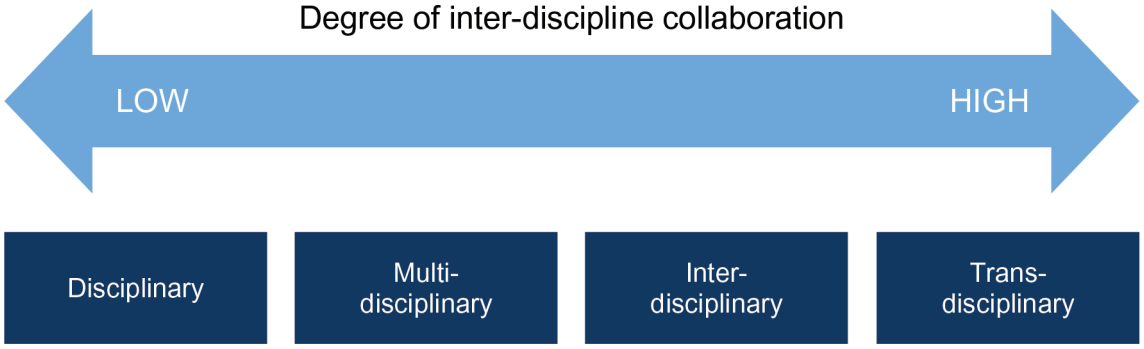

Figure 2. Degrees of collaboration between disciplines, adapted from LERU (2016). Transdisciplinary approaches not only are characterized by a higher degree of collaboration between different disciplines than interdisciplinary approaches, but furthermore specifically attach importance to stakeholder engagement. Thereby, the former is inherently integrative and allows researchers to continuously align their activities with a dynamically evolving context.

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A variety of methods and tools exist for transdisciplinary research. Pohl, Krütli and Stauffacher (2017) [14] propose an approach encompassing ten reflective steps as a structure supporting the transdisciplinary research process and providing reflective tools that promote the interaction between scientists and stakeholders, the understanding of the problem, and its impact on science and society. These ten reflective steps are grouped into three stages. The first stage helps scientists and stakeholders formulate the research question and understand the societal problem, and the knowledge required for attempting to solve it. The second stage is concerned with analyzing the problem and identifying and involving disciplines and stakeholders required for the research project and for achieving the desired societal impact. The last stage concerns reflecting on the previous stages with the goal of identifying the potential impact for the research project.

Based on the phases of co-producing knowledge proposed by the Swiss Academy of Sciences [15], we suggest transdisciplinary research to generally encompass the following phases:

1. Initialization: project idea, potential contributors and procedure
2. Conceptualization: shared understanding of problem, (societal) context, and project goals
3. Research: co-production and integration of knowledge
4. Transformation and evaluation: generation of societal impact and evaluation

In summary, transdisciplinary approaches promote a depth of understanding for, as well as the ability to identify, skills required to succeed in addressing the world's most pressing problems.

4. Transdisciplinary methods and data science: a match made in heaven?

In the context of addressing social and environmental challenges in a data-driven manner, IBM's four Vs of big data are particularly informative [16]. According to IBM, data can be characterized by their volume, variety, veracity, and velocity, which refers to the amount of data available, the different forms of data, the reliability of the available data, and the immediacy of data transfer and analysis, respectively. In the context of wicked problems, one may assume that the variety of data far exceeds their veracity, velocity, and volume [17], which requires data scientists to develop a thorough understanding of the associated variables and the complexity of the underlying system prior to performing data analyses.

Correspondingly, previous authors have identified several limitations of hackathons for good. In their working paper, "Digital Innovation: The Hackathon Phenomenon", Briscoe and Mulligan (2014) [8] argue, for example, that the effectiveness of hackathons might be negatively impacted by a lack of institutional memory, which the authors define as a "collective set of facts, concepts, experiences and know-how held by a group of people" (p.11). Based on their experience with organizing a hackathon for good, Linnell et al. (2014) [18] identified the need for a strong collaboration between the organizers of such an event and a client-centered organization, such as an NGO, as the single most important lesson learned. In the absence of this factor, it would be difficult to ensure that solutions were both useful for the clients and sustainably implemented, according to the authors. Similarly, in the 2014 report "Big Data in Action for Development" [19] published by the World Bank, the authors argue that having a well-defined question constitutes a crucial step in the data science process and advocate for specifying the desired insights in advance in collaboration with stakeholders. This could be particularly relevant in the context of hackathons, during which opportunities to provide participants with extensive information regarding the complex systems their analysis is based on are limited due to their brevity.

Data science has previously been argued to be inherently transdisciplinary due to the need to combine insights from different disciplines and to take into account diverse stakeholders to understand the problems to be addressed [6]. Yet, systematic insights into exactly how this should be achieved methodologically appear to be lacking. Based on the study of literature and our personal experiences with hackathons (see Supplementary Material), we are of the opinion that purely data-centered types of events in general and socially-oriented hackathons in particular have several limitations in the context of wicked problems, which could potentially be overcome by explicitly combining transdisciplinary and data-centered methods in a systematic long-term manner. Furthermore, we strongly advocate for the integration of such a combined

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approach into the university curriculum. Thereby, data science students would be introduced to a ready-to-use toolbox of transdisciplinary methods, while students of other disciplines could familiarize themselves with the data science workflow. In particular, we would like to suggest a hybrid approach, which integrates the data science workflow with transdisciplinary methods, thereby facilitating the team's understanding of the problem and the engagement of relevant stakeholders (see Figure 3). The transdisciplinary toolbox developed by the Swiss Academy of Sciences (SCNAT) [15] offers a range of tools which might be informative in this context. These include the give-and-take matrix, which facilitates the integration of subprojects, the three types of knowledge tool, the focus of which is to generate knowledge about the current system, the desired system and the required transformation process, and the research marketplace, which may be used to foster exchange between subprojects.

Finally, we would like to emphasize that an important aspect of this hackathon is its focus on interdisciplinarity: teams are composed of participants with different backgrounds, ranging from computer scientists to economists and psychological scientists. This permits the teams to cover the subject with broader perspectives and varying inputs, leading to a solution that covers more ground while having a more accurate impact: an interdisciplinary solution. Interdisciplinary problem solving is a method that allows teams to address complex problems more rationally, practically, and morally than using traditional disciplinary methods.

In summary, acquiring data does not necessarily constitute a challenge, but developing reasonable research questions and translating data into valuable output does. Combining transdisciplinary with data-centered methods may result in a powerful tool which could be used to solve large scale and urgent problems. This explicitly includes the presence of other fields of expertise for solving a humanitarian problem. Social and political scientists, as well as economic and psychological practitioners, will be required to solve problems confined by ethical, behavioral and monetary boundaries.

5. Integrating transdisciplinary and data-driven approaches into the university curriculum

In the following, actions undertaken by the KU Leuven with regard to the aforementioned insights will be discussed by way of example.

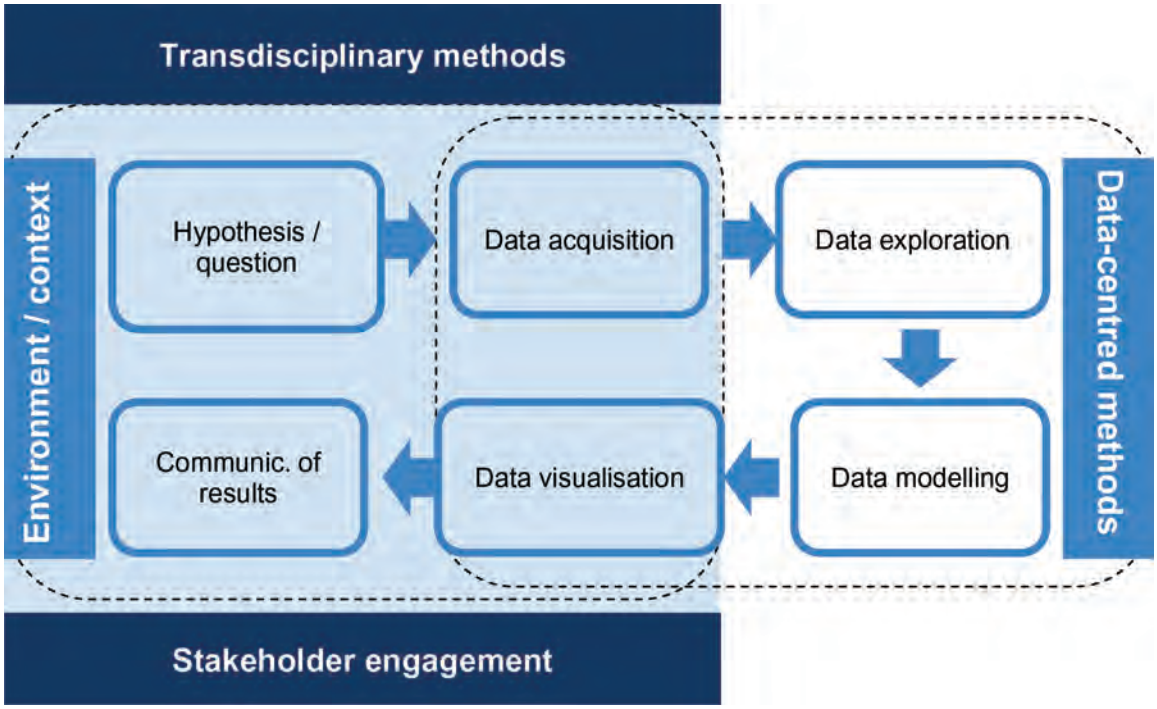

Figure 3. Proposed hybrid workflow combining transdisciplinary and data-centered methods. The data science workflow is represented according to Byrne (2017). Transdisciplinary methods will inform the generation of a hypothesis and facilitate continuous stakeholder engagement, thereby ensuring that the results obtained using data-centered methods are meaningful and can be sustainably transformed into solutions.

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In its vision and policy planning for 2014 to 2017 [20], the KU Leuven Office of Education argued for better implementation of multi-disciplinarity by offering a space for dialogue between research groups, taking advantage of the experience of students following a nonstandard track (i.e. lateral entrants), and designing a framework for permanent education in both disciplinary and interdisciplinary topics.

KU Leuven's Institute for the Future [21] recently introduced its "Transdisciplinary Insights" (TDI) Honours Programme [22]. The aim of this program is to bring together students from a wide variety of backgrounds to work together on a topical, concrete, and multifaceted challenge. The latter can be submitted and overseen by academic staff, industry, organizations or other NGOs, or by the students themselves. A suitable challenge requires the contribution of at least one person trained in each academic discipline (biomedical sciences, science and technology, humanities, and social sciences). An academic team provides lectures and workshops that introduce the participants to the problem and a framework of transdisciplinary methods [23].

Given the aforementioned advantages of integrating transdisciplinary and data-driven approaches and the current educational policy of KU Leuven, we would like to argue for an educational offer explicitly combining the two approaches at this university. We exemplify this with the case study below.

6. Case study: tackling the problem of food insecurity

In October 2018, Emergent Leuven VZW,[4] a Leuven-based organization which introduces students in Leuven to complex, contemporary challenges and is accessible to people of all nationalities, organized a hackathon.[5] The event was conceptually supported by KU Leuven's Transdisciplinary Insights Honours Programme and addressed several aspects of the complex and urgent problem of food insecurity. A total of 123 attendees from seven different faculties worked in teams of four or fewer, with teams composed of different backgrounds (Table 1). Due to these different profiles, teams were assumed to be able to analyze large amounts of data in the most ethical, economical, and socially valuable way.

Faculty Name	Number of Attendees
Faculty of Science	19
Faculty of Engineering	59
Faculty of Medicine	1
Faculty of Law	1
Faculty of Economics and Business	32
Faculty of Social Sciences	9
Faculty of Arts	2
Total	123

Table 1. Number of attendees per faculty at the 2018 hackathon.

Several insights obtained through literature research and as a result of the aforementioned event were further presented at the KU Leuven Symposium, Facing the Future, in May 2019 (see Supplementary Material: Presentation). These include:

- Large amounts of varied data are publicly available in the context of pressing social and environmental issues such as food insecurity
- Data science problems are tightly intertwined with their external context
- Consequently, students in data science might benefit from training with regard to problem framing and students in other disciplines might benefit from training with regard to computer science and data analysis
- Hackathons offer limited opportunities for allowing participants to develop a shared understanding of the problem at hand and for engaging relevant stakeholders
- Addressing social and environmental problems in a data-driven manner might require the continuous alignment between data requirements, data availability, and data interpretation

Given the aforementioned limitations of a hackathon-type exclusively data-driven approach toward a complex problem such as food insecurity, the authors of this opinion piece then suggested including "Understanding and addressing local and global determinants of food insecurity" as a challenge for the "Transdisciplinary Insights" Honours Programme. For this purpose they wrote a challenge document (see Supplementary Material: Challenge document) based on the experience during the hackathon. This challenge

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was indeed offered to the students in the 2019–2020 academic year [22] and could involve further collaborations with Emergent Leuven VZW.

We strongly advocate for implementing challenges that are formulated based on experiences of hackathons in the form of a follow-up hybrid approach in which a team of students will develop a shared understanding of the problem and engage relevant stakeholders using transdisciplinary methodologies in parallel to performing data analyses. A similar idea has recently been published in an article on CGIAR's (Consultative Group for International Agricultural Research) Platform for Big Data and Agriculture, in which the authors suggest agroecosystem sustainability challenges to constitute "wicked problems", which require a shared understanding among the members of data science-focused teams addressing them [17]. By following such an approach, strategies and recommendations derived by the team of students would be based on both a qualitative and a quantitative understanding of the problem and their applicability in a real-world setting would have been assessed by experienced stakeholders. Furthermore, students would be provided with the opportunity to familiarize themselves with key concepts in data science and transdisciplinary methodologies. Finally, we would like to emphasize that an important aspect of this hackathon is its focus on interdisciplinarity: teams are composed of participants with different backgrounds, ranging from computer scientists to economists and psychological scientists. This permits the teams to cover the subject with broader perspectives and varying inputs, leading to a solution that covers more ground while having a more accurate impact: an interdisciplinary solution. Interdisciplinary problem solving is a method that allows teams to address complex problems more rationally, practically, and morally than using traditional disciplinary methods. We are convinced that such an approach would ideally complement the educational infrastructure present at KU Leuven and in the city of Leuven and might serve as a proof-of-concept, which could subsequently be implemented at other universities.

Conclusion

In this opinion piece, we argue for combining transdisciplinarity and data science, and for integrating such an approach into the university curriculum.

In our opinion, the socioeconomic and environmental problems of the Anthropocene demand a combination of transdisciplinary and data-driven approaches. Both transdisciplinarity and data science are likely to mutually benefit from adopting methods inherent in the respective other realm. Integrating such a combined approach into the university curriculum will equip students with the mindset required to understand and address the world's most urgent and challenging problems.

We tested this approach in a case study involving the Transdisciplinary Insights Honours Programme at KU Leuven and Emergent Leuven VZW, through the organization of a hackathon, and the production of a challenge document to be taken up by a transdisciplinary team in 2019–2020. This partial implementation has already commenced, and we anticipate it will provide important insights into the feasibility of combining transdisciplinary and data-driven methods at the university level for understanding food insecurity. We hope that the experience of the new team, together with our experience during the hackathon, can be used to suggest a framework on how such an integration can lead to a better understanding of wicked problems.

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Note from the authors

We would like to point out that the authors of this paper are affiliated with either Emergent Leuven VZW, the "Transdisciplinary Insights" Honours Programme at KU

Leuven, or both, all of which are discussed in this manuscript.

Notes

1 www.hackbelgium.be (retrieved June 29, 2019).
2 www.dataforbetterhealth.be/hackathons (retrieved June 29, 2019).
3 www.hackduke.org (retrieved June 29, 2019).
4 Emergent Leuven VZW. URL: emergentleuven.be (retrieved June 29, 2019).
5 This event was financially supported by Cronos Leuven, AE – Architects for Business & ICT and McKinsey & Company. However, the views presented herein are those of the authors and do not necessarily reflect those of the aforementioned organizations or any of their members.

Supplementary Material

1) Challenge document: "Understanding and addressing local and global determinants of food insecurity".
2) Presentation: "Transdisciplinarity and Hackathons" at the Symposium: KU Leuven Facing the Future, May 2019.

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Supplement 1: Original Challenge Document

Challenge: Food Insecurity

Name of the Challenge

Understanding and addressing local and global determinants of food insecurity

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

Food constitutes a central aspect of the daily life of every individual. While the quantity, quality and nutritional value of the food can be a matter of choice, this is not necessarily the case. After a decade of steady improvement, 2017 has been the third year in a row to witness an increase in world **hunger** as measured by the number of undernourished people globally [1]. The situation is particularly grim on the African continent, where more than one in five people is considered undernourished with the prevalence of undernourishment exceeding 30% in Eastern Africa [1]. On the other hand, both child and adult **obesity** is at a record high, especially in North America [1]. In 2017, more than 35 million children and more than 650 million adults worldwide were obese [1]. Seemingly contradictory, undernourishment and obesity frequently co-exist and disproportionately affect the poor [1].

Food insecurity has been defined by the Food and Agricultural Organization (FAO) on the basis of four pillars, those being 1) the availability of food of sufficient quantity and quality, 2) an individual's access to this food, 3) the adequate utilization of food in the form of a healthy diet and 4) food stability referring to the permanence of access to food of sufficient quantity and quality [2; 3]. Thus, the problem of food security is also closely related to the problem of food safety, i.e. the safety of food from contaminations and infections [4].

Food production, food distribution and food insecurity are both causes and consequences of other well-known global phenomena, with which they are intricately intertwined. In particular, **climate change** directly or indirectly affects all four pillars of food insecurity [1; 3], while food production and food distribution can again contribute to climate change [5]. The agricultural sector provides **employment** for 40% of the global population making it the largest employer in the world and constitutes an essential source of income particularly for poor households [6]. Furthermore, food insecurity is an important driver behind **global migration** [7] and correlates with deficits in **academic performance** and **social skills** in children [8]. Even given moderate estimates, the global population is expected to grow to nearly 10 billion people by 2050 [9], which will further exacerbate the problem of food insecurity.

Despite the enormous relevance of food insecurity on an individual, regional and global level, its numerous facets render it highly difficult to comprehend in its economic, social and environmental context. In this regard, a recent paper highlighted the importance of exploring innovations in **data science** and their potential benefits to improving food security [10]. Data science approaches not only yield the opportunity to substantially improve our understanding of the determinants of food security and their interdependencies, but could also play an important role in improving particular aspects of the food system [11].

In October 2018, the feasibility of a data-driven approach to understanding food insecurity has been assessed in the context of a **hackathon** organized by the student organization **Emergent** [12]. Following workshops on data analysis, data visualisation, case studies, team work and public speaking, participating teams of students could choose 1 of 3 different aspects of food insecurity:

- Food policy analysis: impact of food and agricultural policy on food insecurity for countries in Central Africa
- Land use analysis: impact of different types of land use on food insecurity
- Food security pillar analysis: role of food availability, utilization, access and stability for food insecurity

Within 5 hours, the students were asked to develop a research question, analyse self-chosen publicly available datasets, summarize and visualise their results and derive a strategy with regard to the respective aspect of food insecurity. Afterwards, the teams presented their results in front of a jury in the form of elevator pitches and the winning teams of this round were given the opportunity to re-do their pitches in front of an audience consisting of all participating teams to determine the ultimate winner.

While this hackathon demonstrated the potential of a data-driven approach to the problem of food insecurity, it had substantial limitations. First of all, a complex problem such as food insecurity demands a profound understanding of all associated variables for the correct interpretation of the results. Thus, students should be given the opportunity to familiarize themselves with the problem of food insecurity on a **conceptual level** prior to performing data analysis. Furthermore, students appeared to struggle with the **contextualization** of the results obtained, i.e. with drawing accurate and logical connections between different phenomena, which could be a result of the aforementioned lack of background knowledge on the topic. Thus, it is evident that a comprehensive data-driven approach to the problem of food insecurity will require a transdisciplinary team of students with a shared, **collectively developed understanding** of the challenge.

Would you like to add some objectives to that challenge?

The main objective of this challenge could be to unravel, understand and visualise both known and potentially novel connections between the different aspects of food insecurity and external factors, such as the environment and the social, political and economic context. This approach could result in a **dynamic model of the different causes and consequences of food insecurity** and could be performed both globally or – preferably – locally, e.g. by focusing on a particular region or a specific country. Alternatively, the **possibility of improving particular aspects relevant to food security using data science** (e.g. food production, food distribution, food safety, …), could be explored.

Ultimately, the insights generated using a combination of data science and transdisciplinary methodologies could be used to design a **novel approach** to alleviate the problem of food insecurity in the region or country under study.

Furthermore, this challenge could serve as a **proof of concept** for addressing wicked problems using a combined approach merging transdisciplinary methodologies with data science. Thereby, it could demonstrate the added value of training students of different disciplines in the fundamental aspects of data science to enable them to address a complex problem both qualitatively and quantitatively.

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

Given its universal relevance and urgency, tackling the problem of food insecurity must be considered an essential challenge for humanity in the years to come. This is reflected in the Sustainable Development Goals of the United Nations, specifically in Goal 2 (zero hunger) [13], and in the diverse challenges identified by the FAO with respect to this problem, ranging from improving agricultural productivity and ending hunger and malnutrition to addressing climate change and the prevention of transboundary threats to the food system [14]. The necessity to address food insecurity using a **transdisciplinary approach** has been highlighted previously [11]. The problem of food insecurity is firmly embedded in a network of complex global and mutually reinforcing challenges, thus stakeholders and experts from very different backgrounds will have to come together to develop a mutual understanding of the associated challenges and work towards a (partial) solution.

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Supplement 2: Presentation

Presentation: “Transdisciplinarity and Hackathons” at the Symposium: KU Leuven Facing the Future, May 2019, Available here.

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Student Team Sustainability Research Projects as an Approach to Education for Sustainability at the University Level

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Abstract

At this moment about 7.6 billion people inhabit the earth (Worldpopulation clock 2018). A sustainability revolution is necessary (WCED 1987, UNCED 1992, Rockström 2009) to avoid this huge population in striving for a luxury life depleting the resources of the planet. There are also important social issues that need to be resolved (Raworth 2017). It has been argued that even a real cultural shift is needed (Kagan 2010).

This revolution can be started in education (UN 2003). The decade of education for sustainable development

(UNESCO 2014a) ran from 2005 till 2014. It is being carried further in the Global Action Program (UNESCO 2014b). At the University of Leuven, the 'Science and Sustainability' course is a stand-alone elective course of 6 credits that specifically aims to provide master's students in the natural sciences with education for (the benefit of) sustainability action (Ceulemans & Severijns 2018a and 2018b). Last year (2016–2017), the course ran for the first time and insight was gained in the competences that master's level students hold for sustainability. Based on this experience, stronger emphasis was placed in the second year (2017–2018) on providing, and making students use, tools to approach sustainability issues. Specific attention was directed toward allowing students to get acquainted with systems thinking and deal with inter- and transdisciplinary issues by approaching problems from a multi-stakeholder point of view. The sustainability reports the student teams compiled therefore necessarily included a representation of the system map they compiled to get a grip on the sustainability issue. Also a stakeholder map needed to be drawn.

Near the end of the course it became apparent that students had difficulty in deviating from the Western interpretation of sustainability, where ecological criteria strongly dominate and ecological responsible behavior is pretended to be adequate to drive the transformation for true sustainability. However, it is in the socio-political and socio-cultural dimensions that the value-laden component of sustainability is really found. Several team-tailored feedback and discussion sessions were therefore organized to make students at least consider a slightly broader view on sustainability.

Three student reports of projects that were carried out within this framework are presented in the appendices to this abstract. Students were asked to focus in their reports specifically on the broader sustainability related issues. Technical and exact-scientific information related to their project topic was preferably included in an addendum. Sustainability dimensions on which a focus was laid (e.g. Social, Cultural, Politics, Economics, Communications) varied among the projects, being largely dependent on the topic addressed and in part also on the major stakeholders.

Key words

Education, sustainability, socio-cultural dimension, socio-political dimension, university, projects

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Student Team Sustainability Research Projects as an Approach to Education for Sustainability at the University Level

1. Biofuels in aviation: solution or a myth? – A European perspective

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Summary

The impact of the aviation industry on global carbon emission is important as it represents by itself 2% of global CO_2 emissions, but concrete actions to make the industry more sustainable do not yet result in a visible effect. Indeed, despite the recent advances in technology concerning bio jet fuels, investors are hesitant. This is mostly due to inconsistent policy from the EU. The airline companies at the same time are trying to undermine most EU policies that enforce change, fearing it will affect their prices and create an economic disadvantage. The traveler also has an ethical responsibility and a cultural change to look at transportation differently might be needed.

Introduction

Aviation is a fast-growing industry (1). Revenue Passenger Kilometers (RPK[1]) values show that people have never traveled as much by plane as they do right now (2). In December 2017, IATA proudly announced that the global RPK values had increased by 7.6% compared to 2016 levels. Expressed in number of passengers carried, this comes down to a record total of 4.1 billion passengers transported by air in 2017 (3), an increase by a factor of four compared to 1990 levels. And the aviation industry is expected to grow even further. Predictions show an annual growth rate of 3.6% for the future, meaning the number of air passengers will double over the next 20 years. The biggest driver of this growth is expected to be the Asia-Pacific region, whereas over the past decades the aviation market has been mostly dominated by Europe and the United States (4).

This growth has outpaced efficiency gains, resulting in a worldwide consumption of 200 million tons of kerosene per year, so that the aviation industry is now responsible for 2% of the total global human greenhouse gas emissions (5, 6). With an expected continuous growth rate of 3.6% per year (4), energy use and associated greenhouse gas emissions will continue to increase as well (7). If the fuel consumption and greenhouse gas emissions in other sectors were to grow at the same rate as in the aviation industry, CO_2 emissions worldwide would be multiplied by a factor of six by 2050. Taking the expected efficiency gains into account, it is predicted that fuel consumption would 'only' triple by 2050 (8).

[1] Revenue passenger kilometers (RPK) is an airline metric that indicates the number of kilometers travelled by paying passengers. One RPK amounts to the transportation of one passenger over the distance of one km.

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This is in sharp contrast to the ambitious target of the aviation industry to reduce CO_2 emissions. The International Air Transport Association (IATA) announced in 2009 that it is committed to achieving carbon neutral growth from 2020 onwards, and a 50% reduction in carbon emissions over 2005 levels by 2050 (9). IATA is determined to achieve these goals by improved technology, more efficient aircraft operations, and infrastructure improvement. In order to achieve these goals, IATA identifies sustainable aviation fuels as one of the key elements because they produce 80% less CO_2 compared to conventional jet fuels over the total lifecycle (9). Biofuels can be produced from plants, or from different types of waste (e.g. from agriculture, industry or domestic) if this has a biological origin. Renewable biofuels generally involve contemporary carbon fixation, as occurs in plants or microalgae via photosynthesis.

The use of sustainable aviation fuels sounds promising so far. However, some caveats have to be made. First of all, the use of sustainable aviation fuels does not directly imply a zero-net emission. The production of the feedstock can have an environmental impact as well, and this should not be ignored. Second, sustainable aviation fuels need to meet criteria such as a high energy density and strict safety standards. Next, sustainable aviation fuels are at present produced on only a small scale. In order to make large-scale production feasible technological improvements are required. And, finally, the production of sustainable aviation fuels comes at a high cost, making them currently not competitive with fossil fuels (10). Nevertheless, apart from these obstacles, the use of sustainable aviation fuels is technically viable. The first test flight on sustainable aviation fuels has taken place. In November 2017, the number of flights running on a sustainable aviation fuel blend reached 100,000. However, this is only a small fraction of the total number, as worldwide about 100,000 flights take place every day (11)! To facilitate the use of sustainable aviation fuels, the European Commission suggests an appropriate set of supporting policies (8). The importance of policy is also acknowledged in a feasibility study of biofuels in Australia (12).

Today, almost 10 years after IATA announced its targets for carbon emission reductions, sustainable aviation fuels are available on only a small scale and can be used only in blends with fossil fuels. In terms of logistics, the use of sustainable aviation fuels is not even mentioned by airports, such as e.g. in the 2017 Sustainability Report of Brussels Airport, the national airport of Belgium (13). A possible explanation is the lack of policy and incentives from European Union (EU) policy makers. According to the European Commission (EC), one of the criteria for successfully implementing sustainable aviation fuels is an appropriate set of supporting policies, and up until today no strict legislation regarding the use of sustainable aviation fuels has yet been defined (8).

This paper investigates the current situation regarding sustainable aviation fuels and the problems encountered by stakeholders when it comes to implementing sustainable aviation fuels. In view of the time constraints related to the fact that this research was performed as part of a master's level course dealing with sustainability, it was decided to focus mainly on the lack of policy and the reasons behind it and on current incentives, and thereby limit the stakeholders to the nearby Brussels Airport and the European Commission. Information was obtained from reports and other documents.

Analysis

Brussels Airport (BA) recently published an environmental report for the year 2017. What is understood by the term sustainability relates more closely to a certain energy (and therefore economic) efficiency. The 62-page report does not mention bio jet fuel even once, while media and public opinion claim that the CO_2 emissions from the aviation industry and the decreasing cost of travelling by airplane are the elephant in the room. It was, however, found that it is not BA but the airline companies themselves that provide the fuel for their aircraft. The companies make deals with fuel suppliers to use their fuel and manage the fuel pumps they install at an airport. Smaller airlines can then pay for the service of using the bigger companies' fuel. There are, however, some airports (in e.g. Sweden, The Netherlands, and Canada) and a number of airline companies (e.g. KLM, Finnair, Air Canada, South African, and Singapore Airlines) that have joined SkyNRG[2] to make sustainable aviation fuels the new

[2] SkyNRG is a Dutch company which makes it its mission to lower the hurdles of supplying airlines with sustainable aviation fuels and

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global standard (14). Apart from that, the Air Transport Action Group (ATAG) has issued statements that future carbon-neutral growth of the aviation sector lies in the usage of low-carbon emission fuel with bio-based components (15).

The European Commission (EC) has shown initiative to encourage the use of bio jet fuel in the aviation industry through the European Advanced Biofuels Flightpath Directive (16) and the European Trading Scheme (ETS) for carbon pricing, but taking far-reaching decisions was hampered by the fact that not everyone was convinced of the environmental benefit that would potentially be gained by the use of bio jet fuel. The energy think tank 'Insight_E' which is informing the European Commission recently argued that also considering indirect land use effects might show a strong reduction in environmental effectiveness of biofuels (17). The effectiveness of the carbon pricing trading scheme is also a subject of debate due to the huge drop in price of the carbon stocks (17). The lack of a strong unidirectional policy from the EC has created uncertainty on the European biofuel market, and because of this investors are more hesitant to support biofuel development (17).

Fortunately, there are many projects taking place which are not per se regulated by policy makers or by large companies. Even if those companies at present do not (yet) have the potential to reach the capacities needed, being pioneers they do serve as a level arm for further development and activities in this sector. One of these is the bio-chemical company Proviron, situated in Ostend, Belgium. This company produces prime microalgae which have the potential to produce bio jet fuel. The production of bio jet fuel from microalgae can be seen as a chance to counter the large emissions of the current fossil fuel usage within the aviation industry. Many advantages and disadvantages can be found for the use of these wild algae to produce the fuel of the future, such as the energy conversion from sunlight to oil, without much external effort, but at the same time land and water use can be factors that determine the efficiency of such microalgae plants (7). The benefit that microalgae have in comparison to first- or second-generation bio fuels is that they can be grown in areas that are otherwise unsuitable for anything else. They do not require the use of fertile soils that could otherwise be used for agriculture, but at the moment the systems are very vulnerable to collapse by disease or pollution. Not to forget the fact that the microalgae actually use CO_2 to grow, and thus extract CO_2 from the atmosphere.

There are certain observations that can be made as well regarding the economic situation within the industry. In 2012 the aviation industry made a profit of 7.6 billion US dollar(18). As stated before by IATA, the aviation sector is constantly growing with projections being made until 2031. By that year, there will be a demand for 28,500 new-build passenger aircraft as well as freighters. This demand will mostly arise from Asia, South America, and Africa; however, the mostly mature markets of North America and Europe will continue growing as well (19). An interesting observation is that this growth in the aviation industry is seen as a durable solution for the current economic woes. Alexandre de Juniac, CEO at IATA, states that the enforcement of policies that hold back this growth in the aviation sector could raise barriers for trade rather than making it easier. Slower growth of the industry would result in a 'mere' 5.8 billion passengers by 2035 instead of the projected 7.2 billion (20). This easily shows that the current priorities at organizations such as IATA, which represents 235 airlines comprising 83% of total air traffic, lie in economic development rather than sustainable development as a whole.

The importance of transdisciplinarity can easily be understood by the above analysis, highlighting the importance of policy making and politics, economics, and the environmental challenge of finding a fuel source that could be considered a sustainable alternative to fossil fuels. The systems map (Fig. 1) highlights this transdisciplinarity even more. Note that also playing an important role in this are research centers such as e.g. the Joint Research Center of the European Commission in Karlsruhe, the University of Wageningen's Food & Biobased Research Center (The Netherlands), the Biofuel Research Center at Edinburgh Napier University (UK), the Department of

aims at making such fuels the new global standard. An important observation is that its mission focuses on the supply of sustainable aviation without the complications of deforestation or displacement of food crops. So far, the company has had a rather impressive track record and SAF flight map with recent development in the sustainable aviation fuel sector. To find out more about the mission and statements of the company one is advised to visit their website, http://skynrg.com/.

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Energy BioEnergy Science Center in Oak Ridge (USA), the Biofuels Research Laboratory at Cornell University (USA), and many others.

Systems map

The systems map focusses on two concepts that have been discussed thoroughly in this report so far, i.e. sustainable aviation fuels and fossil fuels. It is easily understood that sustainable aviation fuels and fossil fuels are non-complementary and the usage of one will have a negative impact on the other. A factor that is of major importance in this research project is the environmental impact. The usage of fossil fuels has a negative impact on the environment, whereas the usage of sustainable aviation fuels has a positive impact in relation to the emissions caused by fossil fuels. From the point of view of the environment, its degradation has a negative indirect influence on (i.e. serves as an incentive to reduce) fossil fuel use, and a positive indirect influence on the usage of sustainable aviation fuels. Other elements which are related to both types of fuel are availability and price. The left side of the map was more thoroughly investigated in the present project than the right side (this could however be an interesting research topic in the future). First of all, the incentive element of the map has to be defined. In this project incentives ranging from policy makers and NGOs to research and investment were considered. The latter two fall under the innovations element, whereas the former two constitute the feasibility element (Fig. 1). Both elements have an impact on the availability of sustainable aviation fuels and on their price. Increasing incentives stimulate the innovations, which in turn positively affect the availability of sustainable aviation fuels, and in turn could potentially lower the price. Policy making and lobbying by NGO groups however stimulate the feasibility and availability, while lowering the price for these sustainable aviation fuels as well. It has to be said that this is a rather simplistic view of such a complex system as the aviation industry and many elements were omitted due to a lack of time to generate a more thorough analysis of the industry.

From this restricted systems map it was nevertheless possible to distinguish three stakeholders that we wished to include in our research. The first obvious stakeholder is the European Commission, which falls under the element of incentives and has the power to push policies through to make sustainable aviation fuel usage a norm and stimulate producers as well as consumers of bio jet fuels. Linked to the producer side of the sustainable aviation fuels, the company Proviron was identified as a potential supplier of bio jet fuels from microalgae. Lastly, to close the triangle of producer, policy maker and consumer, Brussels Airport

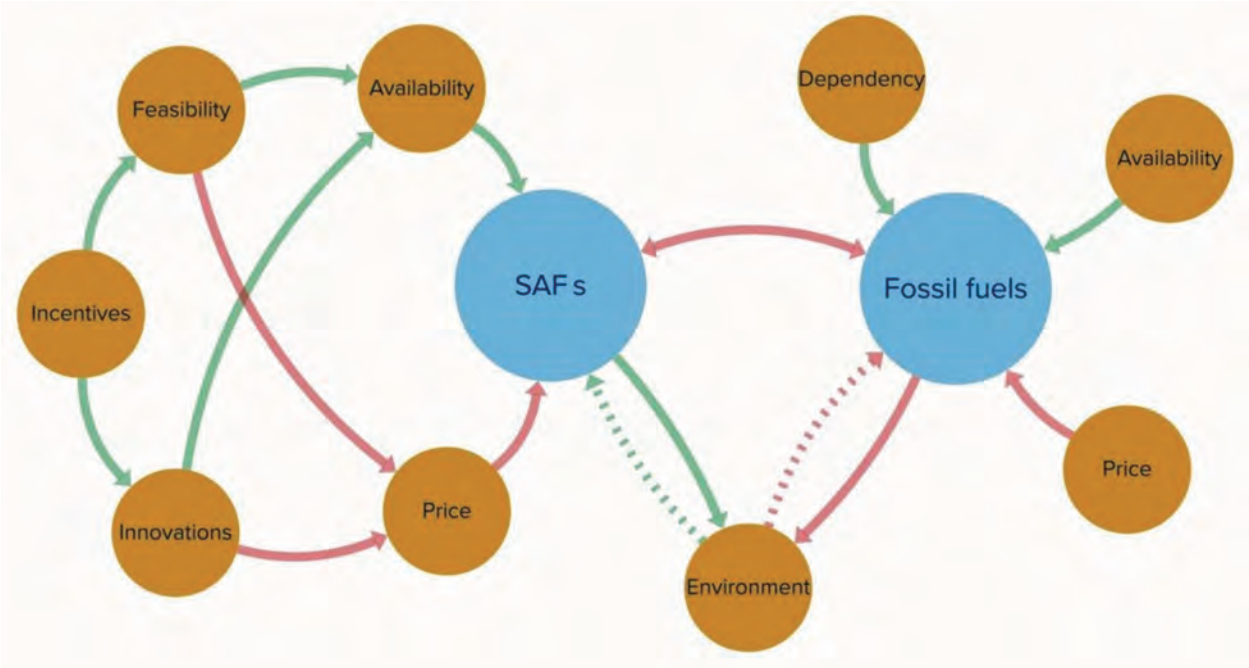

Figure 1. Systems map of the aviation industry. The elements in this systems map are restricted to the ones that are discussed here and were considered in the course of the project. SAF: Sustainable Aviation Fuel. See text for a discussion.

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was identified as the consumer end of sustainable aviation fuel.

Discussion

From the above it seems like the implementation of biofuels could potentially solve the problem of CO_2 emissions caused by air travel. In 2016, 1,500 passenger flights (note that there are worldwide daily about 100,000 flights) were completed with the use of a bio jet fuels blend, and this showed that switching to bio jet fuels could potentially reduce the CO_2 emissions from aviation by 80% (21). Several examples exist of airlines implementing the use of bio jet fuel blends in their aviation fuels inside and outside of the EU (5). Unfortunately, these examples are only a minority of all flights taking place every day. Is the potential of sustainable aviation fuels really as promising as it looks, or are other factors still to be taken into consideration? What are the prospects of EU regulation and policy concerning these sustainable aviation fuels in the future? Are there other ways the aviation industry could become more sustainable and does the traveler himself not carry part of the responsibility?

When looking at the policy concerning sustainable aviation fuels in the EU, matters do not seem to be going very well. The airline companies strongly oppose any change to the current system and go to great lengths to minimize the impact of any policy that could potentially affect their operating costs. They even went as far as to involve foreign governments to pressurize the EC to temporarily exclude all long-distance flights going to or coming from outside of the EU from the European Flightpath Directive. This greatly reduced the impact of the Directive, thus also minimizing the environmental gain. Competition amongst airlines is currently so strong that even a few euros can make the consumer buy his/her tickets from another airline. The lobbying one might expect from many airline companies in combination with discord within the EC forces one to believe that a positive breakthrough concerning sustainable aviation fuels in the near future will not be coming from policy makers or from the airlines themselves.

The question must also be asked whether sustainable aviation fuels could completely replace the demand for fossil jet fuel. First of all, it has to be understood that the current demand for fossil fuels by the aviation industry is very large. In this case, bio jet fuels cannot simply be a solution to the high demand for fuels in aviation, as many other problems will arise regarding land use for cultivation of the crops that produce the sustainable aviation fuels. This is particularly problematic when cultivation of biofuels crops results in loss of tropical rainforest area, as is the case with palm oil cultivation in Indonesia. On the other hand, it must be said that the reduction in CO_2 emissions is limited by the low ratio of energy returned on energy invested for biofuels. Relatively large quantities of fossil carbon are needed to produce the biofuels, either in the form of energy inputs during sowing, harvesting, and processing of the crops, or in the form of energy needed to produce fertilizer or pesticides needed for cultivation. It is also worth mentioning that a complete change-over to bio jet fuel could potentially give airline companies an excuse to fly even more but still claim to be ‘green’, something that has already happened before (rebound effect). This does not, however, fit within a true definition of sustainability and could potentially mislead travelers into believing that flying with low emissions is truly possible.

Finally, like with many sustainable problems, the broad public appears to be looking at policy makers, the industry, or even scientific research to make a change. However, as was explained, it does not seem very likely that these will be able to effectively reduce emissions in the near future and lead us back into the safe operating space of CO_2 emissions. So maybe an attitude change by travelers would not require a huge effort by the individual, yet could bring about a big change and appears to be a more ethical approach to the general problematic. At the end of the day, we are still flying multiple times a year, and mostly within Europe. Many alternatives for medium- to long-distance traveling within the European Union exist, ranging from buses to trains. Current issues with these are accessibility, time, and price, and addressing these will require a new way of looking at traveling in general. So, finally, the problem translates into a change in culture as a whole, which in itself becomes an even more complex problematic. A system where polluting activities will cost more thanks to an integrated environmental cost could be an option, but one may wonder how many people are willing to pay more for their travel in order to preserve the environment? It should also not be forgotten that emissions caused by air travel for further than 1,500 km account for 80% of the total CO_2 emissions from aviation. This means that the impact of finding an alternative for short-distance

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flights would, on a global scale, be able to address only the remaining 20% of CO_2 emissions from aviation.

There are many things concerning the topic of sustainable aviation fuels that still need further research. The perspective of the airline companies would be a valuable asset to try and clarify the discord between them and the EC, although this might prove hard to achieve. It would also be interesting to put the current system of sustainable aviation fuels to the test to see if it can fit within a true definition of sustainability. Maybe an analysis of what is needed to stimulate the use of alternative modes of transportation would be interesting, and this potentially even combined with a study of public opinion or awareness of the problem.

Conclusion

Coming back to the initial question, i.e. whether biofuels are the solution for sustainable aviation, the answer from the analysis presented here is simply 'no'. The regulation of such sustainable aviation fuels could have an initial positive impact but is pushing the problem to another sector, which in turn becomes the new aviation fuel market with its own CO_2 emissions. Indeed, as was mentioned above, relatively large quantities of fossil carbon are needed to produce the biofuels, either in the form of energy inputs during sowing, harvesting, and processing of the crops, or in the form of energy needed to produce fertilizer or pesticides needed for cultivation. A more viable solution to the problem can be put in the hands of the traveler by not flying over short distances. This however does not solve the larger problem at all but could eventually buy more time for more promising potential solutions to arise.

Finally, this report should not be considered as reporting on research that is fully completed, but rather as the first part of a larger research project that could be furthered by other teams as the complexity of the entire aviation-related industry is easily overlooked. There are many focuses that can be made on different parts of the systems map in Fig. 1 which would further highlight the need for transdisciplinarity. The issue of mobility in the EU and the need for certain alternatives could even prove to be a project that could generate concrete results for the student population in our continent, for example promoting train or bus travel or even pushing for more support from the EU towards European mobility by these means of transport.

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(Note that for some references we had to rely on company-based reports, which cannot necessarily be considered to be independent and objective sources).

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Student Team Sustainability Research Projects as an Approach to Education for Sustainability at the University Level

2. A case for thorium power plants in Belgium? Analysis of the viewpoint of two political parties

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Summary

The long-term Belgian energy policy considers a nuclear phase-out. In view of shifting towards a sustainable national energy policy, it would be useful to not rule out nuclear technologies in advance, but instead incorporate the assessment of possible alternatives to the classic uranium-based nuclear power. More precisely, thorium has positive benefits for future energy applications. This paper identifies the major key actors in this debate and the different interactions between individual nodes of the framework. Focus is put on the political and social aspects of the topic. Results show that even key actors do not necessarily reach consensus on the sustainability framework. This, together with the polarization of society as regards nuclear power, emphasizes the complexity of the debate, which can be tackled only through transdisciplinary, independent research and an open debate.

Introduction

In 2016, Belgium produced a total of 79.82Twh of electricity. Nuclear energy makes up about 52% of this, while 29% is produced by fossil fuels, about 7% by biomass, and only 12% comes from renewable sources, such as solar, wind, and hydro energy. Belgium has a total net import of 6.18 TWh (12). The different governments in Belgium recently accepted a policy that resolutely opts for sustainable energy and a nuclear phase-out in 2025 (1). To compensate for the loss of electricity from nuclear production and prevent a blackout, in April 2019 the Belgian government passed a law allowing the support of companies that consider investments to construct a number of new gas-powered power stations (2). Yet, regarding the EU Climate Action 2020, every member state should reduce its greenhouse gas emissions by 20% compared to those of 1990, make 20% of energy production renewable, and make a 20% increase in energy efficiency (3). According to a report of the European Commission, Belgium will miss the mark for renewable energy by 3.5% (4). The planned gas-powered plants are questionable if one is thinking in terms of sustainable energy. It is therefore interesting to consider other possibilities for the production of electricity which may not be renewable, but at least will not directly contribute to carbon dioxide emissions, such as e.g. thorium-based nuclear power plants. In addition thorium-based nuclear power has several advantages compared to uranium-based nuclear power, such as e.g. the greater abundance and safety (see the Appendix). Nevertheless, there are disadvantages or shortcomings as well, related to technology, politics, economics, and social acceptance of nuclear power plants. These shortcomings are important to evaluate, especially in terms of sustainability. The aim of this report is to discuss the energy policy and the role of society in a setting of sustainability to ask whether politicians' arguments are in line with sustainable politics and to investigate if we can propose a sustainable electricity plan for the future.

The research reported here was carried out within a sustainability framework. Sustainability frameworks differ from person to person and between organizations and parties. Nevertheless, to discuss sustainability a

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framework is needed. The framework used here does not pretend to be the one and only possible framework for sustainability, but it is necessary to define the limits of the report and the framework used here. The first important element is planetary boundaries, which define the limits within which humanity can live (5). When those limits are surpassed, instability of the earth's systems may occur. One pillar of sustainability is the ecological or environmental one, the other two important pillars being the social and economic ones. The social pillar takes fairness and equity into account. An acceptable solution cannot benefit some people while strongly harming the interests, livelihoods, and quality of life of others. It should even reduce the gap between rich and poor. The economic pillar is also incorporated. The economy cannot be harmed to benefit the other parts of sustainability. This does not mean, however, that economic growth is an absolute necessity. Overall sustainability means that the needs of the current generations can be fulfilled without harming the possibilities and opportunities of future generations (5).

The research team consisted of three geographers and a geologist, meaning that the inter/transdisciplinarity in the team was limited. It was attempted to improve this by interviewing several persons in different political parties. Note, however, that since only two parties responded to our request, one party being a member of the present political majority and the other being an opposition party, one can wonder whether the discussions with these two parties are representative of the contemporary political discussion. It can further also be questioned whether the contemporary political discussion really is the reflection of public opinion on the topic, and whether the members of the political parties that were interviewed can be considered real experts on the matter. Apart from political parties, a few professors from the faculty of social sciences were also contacted and provided us with some relevant scientific publications (e.g. 6).

Different sources of information were used to gather the necessary data. The largest amount of information came from different articles, books, and other literature. Yet the most important source of information came from the interviews with the political parties. This offered a unique insight into the decision-making process in the country.

Analysis

1. System and stakeholder map

Determining the future electricity mix is a complex sustainability problem, e.g. when considering whether thorium nuclear power could have a place in this mix. This complexity mainly originates in the vast number of partners or stakeholders that are involved and the processes that are impacted. One would think this would result in a complex and diverse approach to the subject. Yet, as this would result in complicated and possibly ambiguous results, a lot of effort was put into trying to simplify and delineate the subject as well as possible. Systems thinking was used for this.

Systems thinking is extremely relevant to apply in complex sustainability problems. It is the skill to examine the (inter) connections and relationships between objects/stakeholders and events, and the objects and events themselves. Having done so, it is possible to predict how changes in one component of the system will lead to changes in another (7). To visualize the system a concept map was created (Fig. 1).

Great effort was put into the mapping of the different stakeholders involved in the problem, thereby using the so-called salience model of stakeholders (19). These stakeholders are shown in the system map, which also shows the connections between them. Society definitively is an important stakeholder because of the power and legitimacy manifest in democratic elections. This stakeholder consumes energy and therefore an adequate energy supply is needed. If society does not want the energy to be produced by conventional techniques, there will be great urgency to find alternative techniques. The legislature is an important stakeholder as well. Politicians are elected to represent the population. They have the power and legitimacy to govern. The urgency can depend on ideology or the political party to which one belongs, or even on what society wants. Subsequently, the scientific community is a stakeholder with no power, but usually with a lot of urgency and legitimacy, i.e. when considering climate change and the United Nations Climate Change Conferences.

The integrated system and stakeholders map shows interrelations between different elements of the system and the stakeholders, while indicating also the aspects linking them. Where relevant it illustrates whether a relation that is shown has an enforcing (plus sign) or

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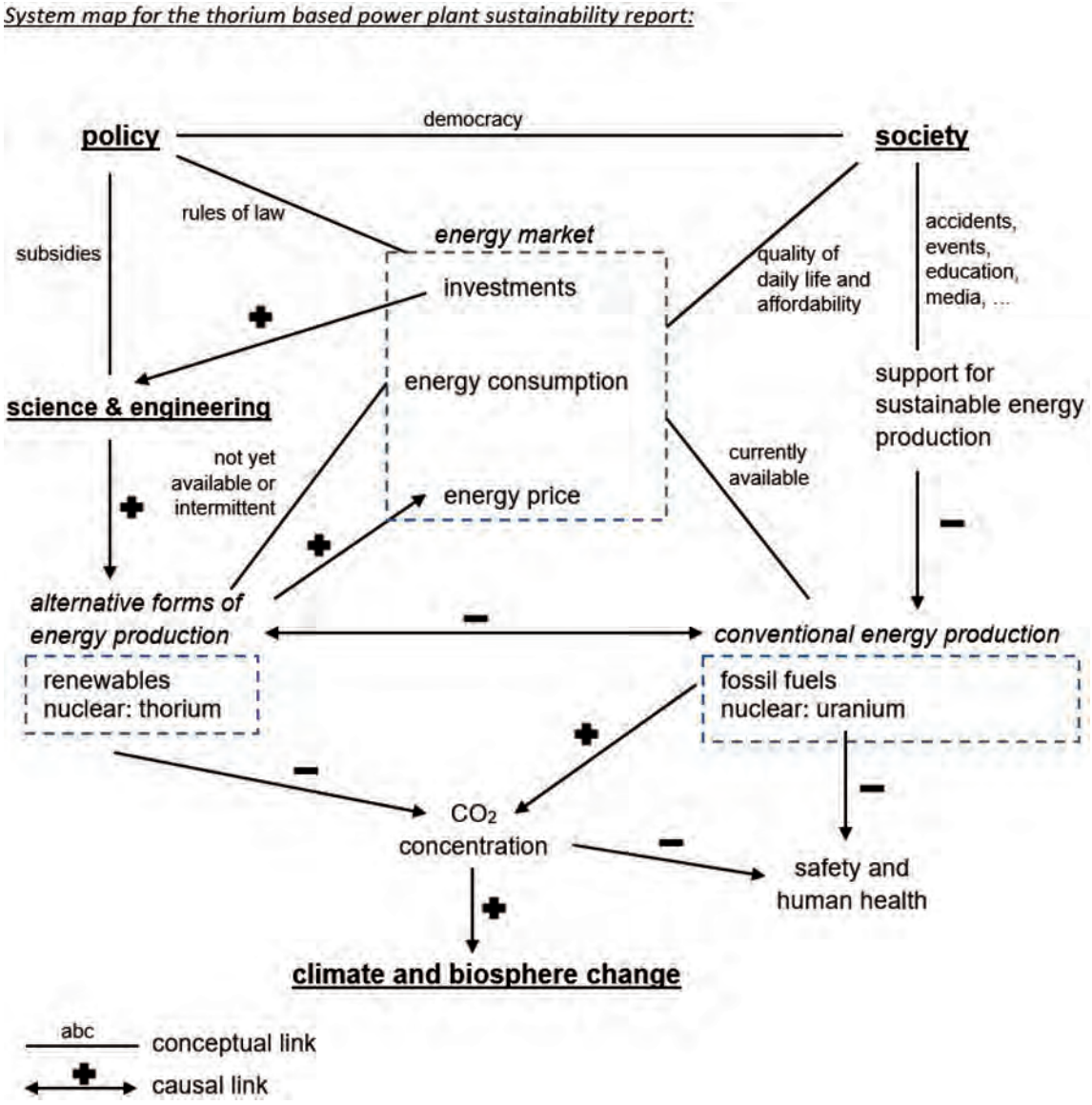

Figure 1. Integrated system and stakeholder map for addressing the potential role of thorium-based nuclear power plants in a sustainable electricity mix, with identification of the stakeholders and the connections between them. A distinction was made between conceptual links and causal links. The conceptual links are based on non-causal relations and can be described using categories, objects, goals, principles, … The causal links are increasing or decreasing causal relations, i.e. if one or both elements changes, this will affect the other element as well. Dotted-lined boxes list components of the element listed on top of the box (e.g. investments, energy consumption, and energy price are different components of the energy market that we distinguish here). (More details are given in the text).

rather a reducing (minus sign) influence (causal links/ relations). Thus, e.g. (see figure 1) support for sustainable energy production leads to a reduction in conventional energy production, while conventional energy production has a negative effect on safety and human health, and it and alternative forms of energy production are mutually exclusive, alternative forms of energy production lead to higher energy prices, and science and engineering have a positive effect on alternative forms of energy production.

Due to the complexity of the system, a leverage point was necessary in order to get a good insight into the system. It was therefore decided to focus in this report on the political aspects, without ignoring other parts, but an entry point is needed to say something about the complex system. Thus, the system map (figure 1) does not have the ambition to be complete, but rather focuses on those aspects that have a relation with and can be influenced by politics and policy making, as this is the focus of this project.

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Considering longer timescales, i.e. several decades, thorium could be a sustainable part of the Belgian electricity mix, since it could meet all three subparts of sustainability. Ecologically, the CO_2 emissions are significantly lower compared to those of fossil fuels. Compared to uranium-based nuclear energy, several orders of magnitude less nuclear waste is produced. The fuel is further harder to use for manufacturing nuclear bombs and is much safer in terms of reactor stability. For more details the reader is referred to the appendix.

2. Opinions of political parties

In Belgium there are a rather large number of political parties. There are three traditional parties, i.e. Christian democrats (Cd&V, center to leftish), socialists (SpA, left-wing), and liberals (Open Vld, center to right-wing), as well as the ecologist party (Groen, left-wing). These four parties each have a (fully independent) sister party in the other (Flemish, respectively Walloon (French-speaking) part of the country). On the Flemish side there are in addition two right-wing parties, a democratic one (NVA) and an extremist one (Vlaams Belang). On the Walloon side there is a rather extreme left-wing party. Originally only the ecologist parties were opposed to nuclear energy. They were soon followed by the socialist parties. Other parties were in general in favor. In 2003 the government (then including the socialist, the ecologist, and the liberal parties) decided that Belgium was to phase out all nuclear power plants by 2025. Following the nuclear accident in Fukushima (Japan) in 2011 the Belgian population became strongly polarized about the issue of nuclear energy. The Christian democrat and the liberal parties then joined the parties that were already opposing nuclear energy, although it would not be surprising if they were to change their opinion again if the electricity supply were at stake when shutting down all nuclear power plants. The more extreme right-wing parties (NVA and Vlaams Belang) are openly in favor of nuclear energy.

Representing the policy making stakeholders in our project were the liberal party ('Open VLD') and the green party ('Groen'). A politician from the Christian democratic party was also contacted for an interview, but unfortunately no positive answer was received. In general, Open Vld supports the renouncing of nuclear energy. It substantiates this view with a few very clear arguments. "The classical argument: nuclear energy in its current state produces waste" (8). Another argument against nuclear energy, according to Open Vld, is that "nuclear energy is not compatible with intermittent energy sources". However, Open Vld keeps an open mind towards innovative new technologies for producing electricity and does not rule out the option of thorium-based nuclear energy. Open Vld knows the advantages of thorium and can even provide some interesting arguments: "Thorium is a raw material that is 'geostrategically' far less delicate compared to uranium" (8).

Compared to renewables such as wind and solar energy, thorium-based electricity is less clean, but it could be used together with them in an energy mix, serving as baseload for example. Groen counters this (9) by referring to a study carried out by Energyville (10). This states that in a scenario where Belgium renounces nuclear energy and puts more effort into renewable energy and energy efficiency the country will produce less CO_2 compared to a situation where two nuclear power plants are kept in operation (10). It is to be noted though that this particular scenario assumes the import of about 30% of electricity from neighboring countries, thereby attributing the related possible CO_2 emissions to those countries …

In order to make thorium-based electricity an economically feasible option more research is needed. Thorium is at the moment too expensive to consider, if even technically possible, certainly for a country as small as Belgium. This is the biggest issue for Open Vld in considering the possibility of implementing thorium-based electricity in Belgium. Research in countries like India and China could also benefit the global energy market, but at the moment too little is communicated to consider its economic feasibility.

The social component of thorium power is mainly limited by the social acceptance of a nuclear power source. Contemporary public opinion in Belgium is against nuclear power. Clear communication about the difference between thorium- and uranium-based nuclear power will be needed in order to change public opinion if thorium-based electricity were to be considered. Even a political party like Groen seems to have a hard time distinguishing between the two. They use similar arguments against thorium to those they use against uranium. They say that the supply of thorium is indeed greater compared to uranium, but still remains limited. They further argue that thorium-based nuclear energy indeed produces less waste, but that "even in

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small amounts, this waste can be dangerous". They even use fear due to uranium-based nuclear disasters also for the case of thorium: "Nuclear disasters and the risks connected to nuclear energy can hardly be associated with emotionality." (11). How small the risk is does not matter to them as "the risk will always exist". Of course, a 100% no-risk scenario is impossible for any technology. Open Vld wants to change public opinion by using a 'cool-down' period, thus allowing the negative connotation to fade from public memory and then building public opinion from scratch. Considering the timescale needed to meet the other two sustainability criteria, they consider there is enough time for this to change. The two political parties further state they are open for a discussion about this. Groen also stresses they are open for a debate on alternative nuclear energy if it is performed with transparency and if all important factors are included. Those factors are: price, uncertainties, risks, time perspective, already deployed means, insurance/liability, problems on power, and complementarity with renewable energy sources. The importance of fundamental research is also recognized, but the implementation greatly differs. Although Open Vld recognizes the possible advantages of thorium, it aims for investments in research and development for the broad realm of possible new electricity production technologies. It would be a pity, it considers, if Belgium were to focus mainly on a single technology which could, in the end, prove to be not very effective. The mere fact that China and India are heavily investing in research on thorium is due to their energy race and their steeply increasing need for electricity in the coming decades. According to Open Vld, an open mind should be kept towards the possibility of buying thorium technology and applying it here. This will, however, also be bought with tax money. "The nuclear sector should accept that a total nuclear rejection is necessary at this moment, and they should invest their means in intensive research." (8). Groen argues that all the means that have been put into research on nuclear energy should instead be put into energy efficiency, renewable energy, and the development of a flexible, low carbon, and democratic energy system. If nuclear power plants are to be renounced, Belgium should invest in extra conventional energy sources like natural gas. Groen states: "The least amount of CO_2 emission will be produced when we decrease our energy consumption and get all our electricity from solar and wind energy." They also claim following statement: "Sustainability is not only a matter of reducing CO_2 emissions. Storing long-lived nuclear waste and mining uranium is not sustainable at all."

Discussion

It is clear that there is a variety of possibilities for thorium-based power, but there are also a lot of problems and obstacles that limit the possibilities in the short term. At the moment the most important limitation is technical feasibility. One should keep in mind that, when starting to take measures to make thorium energy socially acceptable or start planning the implementation of thorium-based power into the electricity network, the technology might be commercially available only in about 15 years from now. As this timescale is longer than the horizon over which most political decisions are usually made, thorium energy was not considered in the inter-federal '*Energiepact'* (2050). One can wonder whether this long period is reasonable, also in view of the fast technological developments in the electricity production sector. Clearly, fundamental research, political will, and communication with the public would be necessary in order to make thorium a part of a sustainable electricity mix.

Overall, the politicians assess all three aspects of sustainability to be equally important but some nuances can be found in their reasoning. Groen claims that realizing the three aspects together is essential. The economic goals should be realized within the borders of our planet and in a socially responsible way. A distribution of burdens and profits should be made, thereby keeping social justice in mind. Open Vld thinks more within an economic framework. From its point of view, internalization of external costs is the best way to link the ecological and social aspect to the economic one. According to Open Vld, prosperity should be measured not only by GDP, but also by sustainability and even SDGs.

When talking about nuclear energy, Groen always refers to the currently existing nuclear power plants. When the alternative, thorium-based nuclear energy is mentioned they say that they know about the new technology. However, Groen dismisses this option very readily by claiming that the progress in this new technology is not yet advanced enough. Also, when mentioning that thorium shows some clear advantages over uranium, Groen still sees those two as almost equally dangerous and wants to have a no-risk policy.

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In our opinion, that is impossible. Groen refers to a document from Energyville claiming that dismantling all nuclear power plants and partly replacing them with natural gas plants will lead to a decrease in CO_2 emissions. What it fails to mention is that in this given circumstance Belgium will have to increase its electricity imports from 14.4% to 28.4%. The question is whether the CO_2 emissions of those countries are taken into account. Another point worth mentioning is that those calculations were based on the best economic solution, so the question arises whether the ecological counterpart of sustainability is viable. This is a direct contrast with the views of the party.

Open VLD seems to have less problem with the idea of thorium nuclear power. Its idea of sustainable energy is based on economics. When all costs are internalized, it considers the three pillars of sustainability will become one and the question of sustainability will be resolved on its own. Attached to this is also the idea of circular economy, an idea that is less relevant in this context but is a concept that was strongly emphasized.

The most striking thing about the interview of Open VLD was the solution for the social acceptance of thorium energy. A cool-down phase was proposed. This could probably be an effective way but might be ethically questionable. It could also cause important knowledge concerning nuclear practices to be lost.

Overall, Open VLD made a more informed and nuanced impression. It has to be mentioned that this can be strongly influenced by the way our questions were answered. Due to the face to face contact, Open VLD had the opportunity to add to and comment on statements and directly react to considerations and remarks. It was Groen's own choice to answer the questions in writing, although it is a topic that plays a major role in their program. But at least they answered, in contrast to other parties that also have a strong opinion on the topic of energy and nuclear power but did not cooperate in this research.

Conclusion

Currently, the Belgian energy policy consists of closing all nuclear reactors, while reevaluating annually whether this course is to be maintained. This policy considers a shorter time period compared to that for which thorium reactors can be considered feasible. This way, thorium-based nuclear power plants can be considered as one of the many possible long-term solutions to the energy problem that still need a lot of research and development to be efficiently employable in a sufficiently large scale, like nuclear fusion, renewables, or hydrogen. It could be part of a long-term solution, fitting into a broader sustainable energy system, but for short time scales it has limited potential.

The long time span and the complexity of the system make it very hard for this both in time and in possibilities rather limited, research project to make strong recommendations considering the need for implementation of thorium power in the Belgian energy system. This project focused deliberately only on the policy aspects while (indirectly) the risk perception of society was taken into account as well. Clearly, there are a lot more stakeholders than those that could be considered in the scope of this research. All of them need to be considered in order to have a chance to arrive at a sustainable solution.

Considering sustainability, an important obstacle was encountered, most likely a problem for any sustainability issue. It concerns the framework of sustainability. All stakeholders have a different view on sustainability, even if they say otherwise. The first thing that needs to be done is to reach a consensus on what sustainability is, also considering unspoken association and seemingly self-evident issues. Only then can a real discussion about sustainability be started. This first step is already a very difficult one. Inter- and probably even transdisciplinarity in the teams handling the sustainability topic could help in offering an open view of the framework. In addition, using other possible scenarios, such as e.g. foresight scenarios (18), might be of interest as well.

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Appendix – Technical information on thorium-based nuclear power

Thorium is rather abundant, making the available amount sustainable on a human timescale (13). It is also found in association with other rare earth minerals, meaning that it will be mined anyway. The local effect of the extra mining of Thorium will be limited as existing

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infrastructure can be used (14). Furthermore, thorium is – unlike uranium- insoluble, limiting the danger of polluting water bodies and river courses in the proximity of mines (15). It has to be noted that the figures for thorium resources are estimations based on association with other rare earth minerals, as thorium is not a primary exploration target (15). The biggest challenge in exploiting thorium on a large scale is its purification. Thorium is separated from the other associated minerals with the use of acid and alkaline solutions. This process is not yet optimized, as thorium is not exploited on a large scale, leaving room for improvement (15).

Five major advantages of thorium-based nuclear reactors are:

– Thorium has been mined already, but is hardly used;
– The waste of thorium nuclear energy has far less potential for nuclear proliferation.;
– Less waste is produced which, moreover, has a radioactive half-life sufficiently small that it has to be stored for only about 300 years;
– Thorium-based power plants provide the ability to process the long-lived waste of uranium-based nuclear power plants;
– Higher safety (15)

Thorium-232 is fertile and has to absorb a neutron to become Thorium-233, which decays to Uranium-233. Uranium-233 can be used as reactor fuel. The fission process needs a fissile element to supply the neutrons required to keep the process going (14, 15). However, "breeding" is possible, limiting the need for input materials to a regular input of Thorium-232 (14–16). So far, several reactor types have been able to use thorium as a fuel, among which is a Liquid Fluoride Thorium Reactor (LFTR), which avoids structural damage to the fuel rods and in principle enables the total burn-up of the fuel.

Thorium reactors, especially LFTR, are somewhat more efficient than traditional uranium plants (16). Furthermore, they produce fewer, less long-living nuclear waste that is less suitable for producing a nuclear bomb (14, 17). The liquid promotes the inherent stability of the reactor, by solidifying when cooled down (17).

Nevertheless, a facility for preparing the fuel and for reprocessing used fuel is needed. Provided the required very high safety standards that are typically applied in nuclear industry are followed, this should not constitute any major burden for society. Note that this fuel processing facility can also be used to separate fission isotopes of interest for medical usage, such as e.g. ^{99}Mo/^{99}Tc that is used in Computer Tomography scanners.

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Student Team Sustainability Research Projects as an Approach to Education for Sustainability at the University Level

3. A sustainability comparison of fishery techniques

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Summary

Scientific research shows that the electric trawling technique is a more sustainable technique for the catching of plaice compared to the classical trawling technique. Even though electro trawling has its limitations with respect to sustainability, this technique is less damaging to the marine ecosystem. In January 2018, the European Parliament voted on a ban on the electric trawling technique based on the limited scientific evidence supporting the sustainability of the technique. Bloom Association also urges a ban not just on the electric trawling method but also on the classical trawling method, labeling them both as dangerous to the marine environment. For both the EU and Bloom, socio-economic factors also play an important role in the argumentation in favor of the ban. Continued discussion among the stakeholders and subsequent compromises are suggested for reaching a lasting solution to the problem of selecting the most sustainable flatfish fishing technique.

Introduction

On January 16, 2018, the European Parliament voted on an amendment proposing an EU-wide ban on the use of electro trawling, a relatively new, efficient, and (ecologically) promising technique in flatfish and brown shrimp fishery. This decision was somewhat controversial, given the possible eco-friendliness of electro trawling (also called pulse fishing, electrofishing, or electric pulse fishing). This project focuses on the comparison of classical beam trawling and electro trawling in flatfish (specifically plaice) fishery. This comparison will mainly address the ecological side of the issue, but the social and economic pillars also need to be discussed concisely.

The first step in the comparison consists of identifying the stakeholders and determining their relationship to each other in a systems map. All stakeholders were subdivided according to urgency, legitimacy, and power. This information can consequently be used to perform a stakeholder analysis and flow sheet providing an overview of all inputs and outputs at each stage of the flatfish fishery and food industry. This is the life cycle inventory (LCI) and can be used to determine the impact of both fishery techniques. We also performed a literature study, mainly providing information on the ecological side of the story. To get a better view on the socio-economic part of the comparison, several stakeholders were interviewed. The most important goal of this was to see what their values and ideas are and how they relate to each other.

Before starting the sustainability comparison between classical beam trawling and electro trawling, we would list below the important criteria for 'sustainable trawling':

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- Sustainable trawling minimizes damage to the marine ecosystem and non-target species, thus avoiding the loss of resilience of the ecosystem and preserving it for future generations.
- Sustainable trawling respects quotas, which are such that the flatfish population does not decrease but instead increases back to its natural size, thereby preserving this valuable resource for future generations.
- Sustainable trawling should be possible for all fishermen, from those using small-scale and traditional fishing methods to industrial fishery. Regulations (e.g. organizing and dividing the sea areas for different sizes of fishery industries) and efficient controls could achieve this.

The student team that performed this project consisted of master's students in chemistry, biology, geology, mathematics, and statistics. During this project, the team not only learned a lot about fishing techniques and their ecological, political, and economic aspects, but also learned about how to collaborate efficiently in an interdisciplinary team. Experience was also gained on how to use the different backgrounds and expertise of the team members in such a way as to enrich discussions and gain a deeper understanding of this complex problem. In addition, it was realized that open, continuous discussion with a number of people with different backgrounds is indeed needed to gain a better understanding of situations as complex as the ones encountered in sustainability issues.

Analysis

1. Value prioritization, systems map, and stakeholder analysis

During this project it was decided to take the ecological and socio-economic factors as our prioritized values. Since the original motivation for the development of electro trawling was the reduction of damage to the marine ecosystem, the ecological pillar was an obvious choice. Besides, as scientists, the authors were most intrigued by the ecological aspect of the problem. Apart from the marine environment, a strong concern was also felt for the well-being of the fishermen and human beings in general. It was therefore decided to consider the socio-economic aspect as the second prioritized value. However, apart from the ecological and socio-economic aspects, many other values are related to this problem and different stakeholders might prioritize different values. In order to get a broad overview of all related stakeholders and their prioritized values a systems map was developed, shown in Figure 1. The systems map represents a nested model, with the social, legal, and economic factors contained within the ecological framework. Notice that fishery industries exceed the ecological boundary, which represents the overexploitation of marine resources.

For the marine environment as a stakeholder, it is important to bring catch rates back to a level where a constant fish population can be maintained and the resilience of the system is preserved. The environment is primarily peopled by NGOs, and to a certain extent by the consumer through its public opinion.

The fishery and food industries focus on two main values: (i) they want to make a profit from which they can live comfortably, (ii) they do not want the fish to go extinct because of overexploitation, so they follow the quota imposed by governments. These two values provide a trade-off. On the one hand, fishermen want to catch as much as possible for socio-economic benefits in the short term. On the other hand, they do not want to overexploit the resource stocks in the long term. As regards electro trawling their views are divided. The Dutch industrial fisheries are in favor, because of the environmental and economic benefits. Besides, a large part of the Dutch fleet has already switched to electro trawling. The traditional small-scale fisheries (mostly in Belgium) do not like electro trawling because of the high investments that have to be made in order to switch to this technique and because of the unfair competition with the industrial fisheries using electro trawling. The government (the European Union in this case) has to take the opinions of all stakeholders into account in order to make fair decisions. Consumers are of special importance to the government because it is they who give the government legitimacy through the elections. The most important values for the government as a stakeholder are (i) keeping the citizens' support and (ii) providing legislation that ensures the continuation of society as we know it. The socio-economic values are therefore often the most important factors for decision-making.

The NGOs and consumers act as the ecological, economic, and social soundboard of earth and all its residents. Their values vary: NGOs primarily support ecological preservation but are also concerned by

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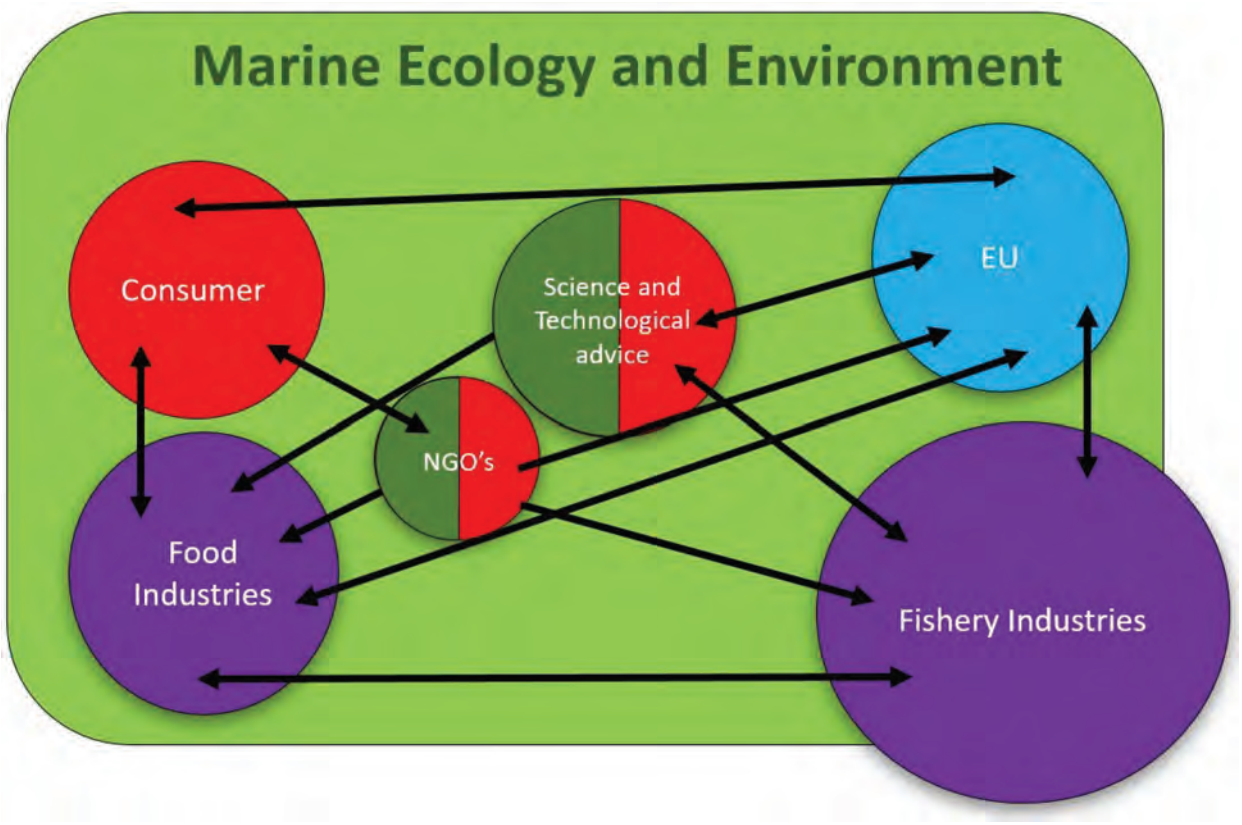

Figure 1. Systems map showing the most important stakeholders. The different interests of all stakeholders are represented by different colors: green = ecologic; red = social; purple = economic; blue = governmental.

social issues. NGOs can influence the opinion of the consumer as well as the government. The consumer primarily sees the socio-economic issues. Consumers are responsible for the demand side in economic activities and also here. In general, people do not want to reduce their fish consumption but are open to changes that can preserve the marine ecology. For example, a significant number of people are willing to pay more for fish that has been caught sustainably. Indeed, in research on this issue performed in eight European countries (i.e. Finland, France, Germany, Ireland, Italy, Poland, Spain, and UK) three clusters were found: On an average of all countries, the percentage of participants in the cluster with no 'willingness to pay' (WTP) was 47%, but 44% were in the 'medium WTP' cluster, and 9% in the 'High WTP' cluster (26).

Technological support and knowledge provided by science are important aspects that should be considered by all stakeholders. Further, not only are the prioritized values different for all stakeholders, but also the means by which these values are reached. The stakeholders can therefore be distributed (using the so-called salience model of stakeholders of Mitchell et al. (1)) according to urgency, legitimacy, and power, as is shown in the figure below (Fig. 2). A more detailed discussion of the stakeholders in this sustainable fishery project is found in Appendix 1.

It was attempted to interview three of these stakeholders: a spokesperson from the EU, a scientific expert in electro trawling, and a representative of an NGO with a strong opinion on electro trawling. Unfortunately, we could not reach a spokesperson from the EU. The results of these interviews will be discussed in a later section.

2. Life cycle inventory

Although this project focuses on sustainability at the fishing stage, the processing and consumption of captured fish are equally important with regard to sustainability. We therefore developed a stakeholders' flow sheet including all different stages from sea to plate (Fig. 3). Based on this flow sheet, we constructed a life cycle inventory (LCI) showing the main inputs and outputs at every stage (see Appendix 2). These can be used as key points to make the whole process more sustainable. It has to be noted that technological

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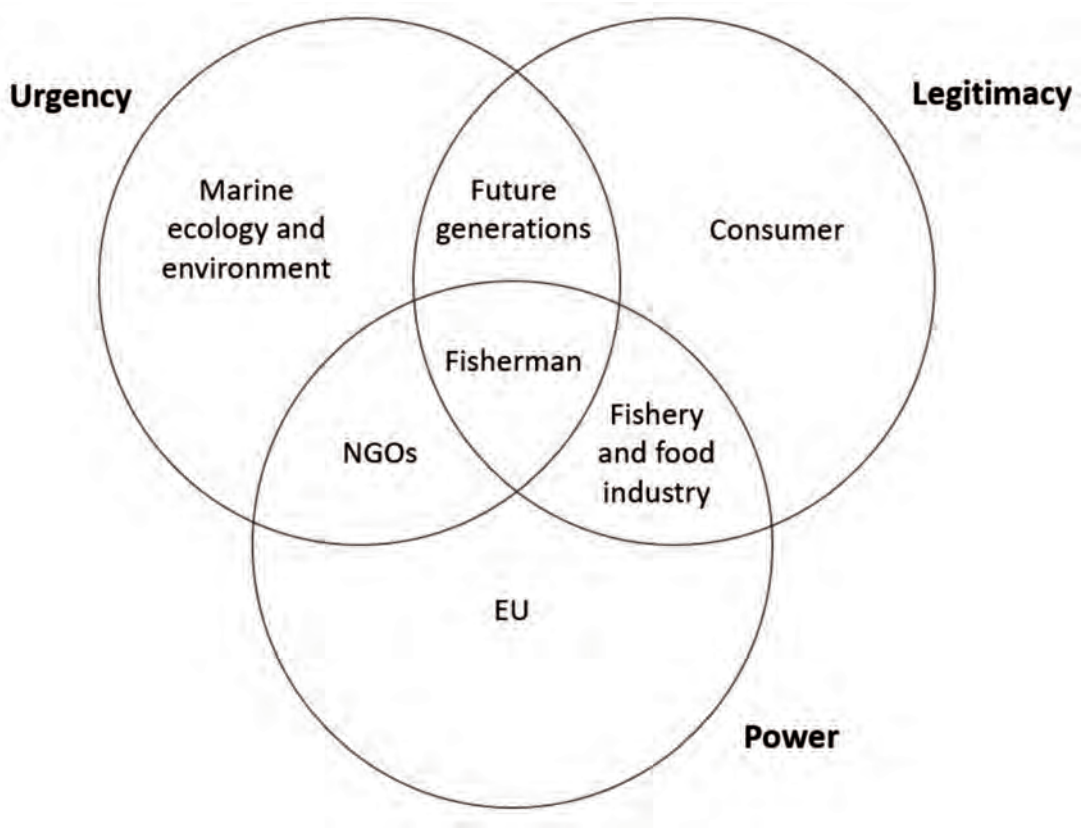

Figure 2. Distribution of the stakeholders according to urgency, legitimacy, and power.

Figure 3. Stakeholders' flow sheet from sea to plate.

support as well as technical and legal advice are needed in every stage of the flow sheet.

3. Literature study

In order to gain more information about the problem at hand, we performed a literature study. The full literature study with references to the documents used can be found in Appendix 3. It focuses mainly on the ecological aspect of this project. Based on the information gathered we made a comparison between the two techniques, using five parameters that are most frequently linked to advantages and disadvantages of both techniques. The main results of this study are summarized in Table 1. In the following paragraphs we briefly discuss the most important findings from classic

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beam trawling and electric pulse trawling with regard to the marine ecosystem.

Beam trawling uses a beam attached to the opening of the net to keep it from closing in the water. This beam allows the attachment of tickler chains to startle flatfish up from the seabed and into the nets. The net and tickler chains are dragged across the seabed and thereby cause damage to the seafloor, its inhabitants, corals, and sponges. Due to the lack of selectivity of the net, non-target species can end up as bycatch. In addition, the resistance of the net against the seabed leads to high fuel consumption and the emission of combustion gases. In the case of electro trawling, the tickler chains used for classical beam trawling are replaced by electrodes that emit electric pulses. These pulses cause brief convulsions in the muscles of the fish residing in the seabed, causing them to rise up and get caught in the net. Because in this case only the surface part of the seabed is touched and no deep intrusion into it occurs, it is mainly flatfish that are caught and only a small fraction of other fish species.

Electro trawling has several advantages compared to classical beam trawling. It does not disturb the seabed to the same extent and therefore fewer creatures living on and in the seabed end up as bycatch. The ships also use less fuel because the pulse trawl is lighter and has less drag resistance. This results in fewer CO_2 emissions and lower costs for fishermen. Also, the fish that are caught are of better quality because they have suffered less direct damage. However, electro trawling might have some disadvantages as well. The electric pulse can induce vertebral fractures in roundfish. This occurs in approximately 2% of the whiting and 9% of the cod. The electric pulses might also affect benthic invertebrates. However, it is believed that the electric pulse does not affect the mortality of benthic species. At last, it is hypothesized that the electric pulses might induce chemical reactions which release pollutants that are bound to sediment particles. Since 2009, EU member states have been allowed to use electro trawling in the southern part of the North Sea with up to 5% of their fleet. The Dutch intensively use and investigate electro trawling. Despite the fact that electric pulse trawling has disadvantages as well (see Table 1), it might be a sustainable alternative to the classical beam trawling.

Interviews with stakeholders

Apart from the ecological aspect, it is also important to have other insights into the topic. We therefore decided to interview three stakeholders: a spokesperson from the EU, a representative from the NGO BLOOM, and professor Rijnsdorp from Wageningen University who is well-known in the electro trawling field. Unfortunately, we could not reach a spokesperson from the EU. The interviews with the BLOOM representative and with professor Rijnsdorp were finally done as phone calls.

Professor Rijnsdorp is investigating the effects of electro trawling on the marine ecosystem and is a profound supporter of this technique. He considers the European Parliament has taken a political decision based on emotions and not on scientific evidence. The NGO BLOOM aims to preserve all marine resources for future generations. It claims that electro trawling is destructive of the seabed ecosystem and that it is not selective. It also states that electro trawling is too effective and literally empties the oceans. However, it admits that classical beam trawling is a destructive

	Conventional trawling	**Electro trawling**
Seabed disturbance	High	Low
Direct injuries to fish	High	Medium (vertebral fractures)
By-catch	High (only depends on type of nets)	Low (depends on pulse voltage and frequency and type of nets)
Fuel consumption & CO_2 emissions	High	Low
Risk of damage to spawning grounds	Yes	Potentially

Table 1. Comparison between the ecological effects of electro trawling and conventional trawling.

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technique 'as well'. Since we could not reach an EU spokesperson, we decided to analyze an EU document that includes all written explanations of the vote on January 16, 2018.[25] Based on these explanations, we feel that the European Parliament voted against electro trawling because of a suspicious attitude toward pulse fishing. Arguments that are often encountered are that electro trawling is devastating for marine ecology and that it is unethical to electrocute fish. Additionally, it is often argued that there are too many unknowns related to this technique.

Discussion

Firstly, background information was gathered on the ecological, political, and economic aspects of trawling and pulse fishing, as well as on the concept of a Life Cycle Assessment (LCA). It showed, however, that comparing the two fishing techniques by using an LCA would be too specific and a too strictly exact-scientific approach, as a broader view of the problem was in fact aimed at.

While gathering background information, it was soon noticed that, even with different scientific backgrounds being present in the research team, there was still a lack of insight into several areas, such as the economic, political, and social sciences, which was deemed necessary to get to a more complete understanding of the problem and the views of the different stakeholders. Furthermore, difficulties regarding the large amount of information available and the very specific – not so general – nature of this information were experienced.

Based on the analysis presented above, it is not straightforward to come up with a perfect solution. During the process of gathering information and writing the report, we noticed that both fishery techniques have advantages and disadvantages, summarized in Table 1. The value that was concentrated on first was ecology. The technique of electro trawling seems very promising ecologically. With traditional beam trawling, the seabed is disturbed on such a large scale that ecosystems are seriously harmed and take a long time to recover. Yet, these ecosystems are important to keep fish stocks healthy. It is true that electro trawling will also carry risks for the ecosystems of seas and oceans, but hitherto there has been no clear evidence that electro trawling would reduce the resilience of certain species. Besides, bycatch is reduced by using electro trawling instead of bottom trawling. Either way, there are still challenges for all stakeholders in this process.

For fishery industries, it will be key that fish quotas are still respected. Electro trawling may be more efficient, and as a consequence quotas may be reached faster. Fishermen will have to spread their fishing efforts in both time and space, and in such a way that the quotas are not exceeded, since most of the positive effects of the technique will vanish if they are not respected. They will also have to make large investments in new gear, and this should maybe be funded by the government. At this moment, there are already large subsidies going to the fishery industry. Larger companies get bigger shares; small-scale fisheries get smaller shares. It might be desirable to work out an arrangement that makes sure the small-scale fisheries get their fair share of both the subsidies and the fishing quota.

Another stakeholder is the consumer, although the majority of the people may not care too much about how the fish is caught, and certainly not about the debate between beam trawling and electro trawling. Certainly, consumers can be critical, but this criticism focuses on aspects of fishery other than this one. For example, the differences between aquaculture and wild catch are much greater and could really divide opinion. From the scientific point of view the electro trawling technique seems to be preferred. It is motivating to see that advances in a field are actually appreciated if it is proven that a new method works and that apparently no large risks are involved. From a scientific perspective, it is then disappointing to see that, after so much time and work has been invested in a technique, it is now banned, even though there seem to be clear ecological benefits. This might be a challenge for NGOs gathering objective information on both techniques, i.e. if they indeed found that electro trawling is to be preferred, to then try to convince governmental instances that new technological advances like this one are worth a shot, and that it may not be a bad decision to invest money in it.

Also important is the socio-economic aspect. The team conducting this research has no expertise in this and we had to make an extra effort to understand it. An issue that was considered in some detail is the future of the fishermen themselves. If electro trawling were to be made completely legal for the whole catching quota, it is possible that the quota could be caught using fewer fishermen to do the job. In the first instance, this seems

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to be a huge problem because a lot of fishermen would lose their jobs. On the other hand, it is possible that some of them would not mind stopping fishing if they had the chance. Early retirement could be a more attractive solution for them. However, we did not find hard evidence that electro trawling is in fact more effective than beam trawling, so this problem might not be too big. Electro trawling might even be less efficient than beam trawling, but instead be more selective. This means that the share of the target species in the total catch will be higher. Nevertheless, some countries argue that electro trawling would deplete fish stocks faster. This is a bit confusing, since quotas still have to be respected, and bycatch and the share of immature fish caught are limited.

In conclusion, the technique of electro trawling seems to be more advantageous than traditional beam trawling for the reasons summed up above and in Table 1, and discussed more thoroughly in Appendix 3. However, more expertise from other sectors is still required. There are certainly things that were overlooked in this limited study. An economist and a social expert could help with the socio-economic part of this project, as the team lacks sufficient background in these matters. Cooperation with economists, social experts, and maybe even lawyers could pave the way to an integrated solution for the problem of sustainable fisheries.

Conclusion

Sustainable fishery is about finding fishery techniques which allow for ecological as well as socio-economic sustainability. It is supposed to minimize the damage to the marine ecosystem, respect quotas, and also give job security to the fishermen. Based on these ecological and socio-economic factors, a direct comparison was made between electric trawling and classical trawling techniques.

Because of the smaller amount of ecological damage done by electric trawling, it is considered to be ecologically the more sustainable fishing technique for flatfish. However, it provides advantages only to large corporations and seems to cause financial disadvantage to small-scale fisheries. This then poses an important socio-economic problem.

Despite the ecological advantage of the electric trawling technique over classical trawling the European Parliament decided to vote for a ban on the former. Criticism of the lack of sufficient scientific evidence for the safety of the technique and socio-economic and politically funded arguments was the motive of the European Parliament in banning electric pulse fishing.

The Bloom association also considers the ban on electric trawling a good solution. In fact, Bloom considers both the electric trawling and the classical trawling methods to be dangerous for the marine ecosystem and states that both should be banned as fishing techniques for plaice.

The big question here is: Is a compromise possible? There are different opinions within the European Parliament itself while, in addition, the many other stakeholders involved do not agree. Reaching a compromise within and between all these bodies might bring an acceptable solution. A possible way of finding a solution might be by further discussions among all parties involved. A solution to this problem has to take into account ecological as well as socio-economic sustainability, thereby including preventing the loss of fishermen's jobs.

Acknowledgments

We would also like to thank Professor Adriaan Rijnsdorp from Wageningen University and Research and Mrs. Laetitia Bisiaux from BLOOM association for their time and for sharing their opinions on this subject.

Appendix

1. Distribution of the stakeholders according to legitimacy, urgency, and power

The distribution of stakeholders according to their power and the role they play in the problem as described in the introduction and analysis can be (more or less) rationalized using the definitions of different types of stakeholder (e.g. dangerous stakeholder, dormant stakeholder, etc.), proposed by Mitchell et al. (1). The types of stakeholders are characterized by three factors, which overlap in a Venn-type diagram (Fig. 2). Each surface in the diagram represents a stakeholder. Urgency can be defined as the degree to which a stakeholder demands immediate action. Legitimacy is defined as the perception that actions of the stakeholder in question are desirable, proper, or appropriate according to society, within the system of norms, values, etc. Power is the relationship within

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which one stakeholder can get another stakeholder to do something that he/she would not otherwise have done.

It should be noted that there is more than one possibility for filling the scheme in Fig. 2. For example, the consumer and the EU (i.e. the government) can be interchanged since it is desirable that the government makes laws to protect the marine ecosystem, while consumers (voters) have the power to change the power balance in the government through elections, and thus can let the new government do something the old government would otherwise not have done. Also, through general opinion and purchasing decisions, the consumer has great influence on the food and fishing industries. However, we argue that the government in fact is the dormant stakeholder (possesses only power) since it directly imposes the rules, thus letting the fishing and food industries do something they would otherwise not have done. The government cannot act until a critical mass in the group of voters/consumers decides that action is needed. The consumer can take action through manifestation, writing, NGOs' actions, and voting, thus appropriately choosing the course of the government. Defining the demanding stakeholder (urgency) is easier. Here, it is clear that the main actor is the marine ecology and the environment itself. It does not have a voice itself, so it is powerless and needs NGOs, which are considered to be 'dangerous stakeholders', since they combine urgency and power. Besides, the latter often lack the legitimacy factor, since there is initially always resistance against the change they want to set in motion. As to the dependent stakeholder, which has both a legitimate and an urgent claim but no power, the 'future generations' were selected here since they are voiceless but are effectively to be taken into account as they are the ones who invoke some the norms and values in the debate: "We have to preserve the resources for our children." Obviously, the food and fishing industries are the dominant stakeholder, since they are able to directly change the course of their actions, having an immediate impact on the matter in question. For example, they can decide to focus on sustainable trawling because they want consumers to have a positive view of them so that they will buy their products more often. Finally, there is the definitive stakeholder, who comes into all of the categories. In this case, we chose the fishermen. They have the power to change the ways of the fishing industries, since they can go on strike or demand change via unions. Generally, we agree that fishermen impose their values and norms on the debate (legitimacy), since they are the experts and most involved stakeholder in this matter (fishing is their job, their life). Finally, fishermen also see that the way the fishing industry organizes the fishing activity has to change if they want to keep their jobs: no fish means no fishermen.

2. Life cycle inventory

Stakeholder	Input	Output
Fishery industries ***Fishermen***	– Energy – Fishing gear – Boat – Fuel – Staff	– Caught fish – Bycatch – Scrap metal – Plastic nets
		– Combustion gasses (CO_2, NO_x, SO_2) – Marine ecology damage – GHGs and nuclear waste – (indirect from energy production)
Logistics *(transport)* *(warehousing)* *(at multiple stages)*	– Energy – Vehicles – Fuel – Buildings – Packaging	– Combustion gasses – Halogenated hydrocarbons (from cooling) – Scrap metal – Plastics – Building waste – GHGs and nuclear waste (indirect from energy production)

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Food industry *(processing)* *(packaging)*	– Energy – Packaging – Machinery – Other ingredients	– Semi-manufactured products/packaged food – Food waste – Waste from packaging – GHGs and nuclear waste (indirect from energy production)
Wholesale	– Energy – Buildings – Vehicles	– Combustion gasses – Waste from building material – Scrap metals – Plastics – GHGs and nuclear waste (indirect from energy production)
Consumer phase	– Energy – Natural gas – Refrigerators, freezers – Kitchen tools – Other ingredients	– Prepared Food – Food waste – Human waste – Packaging waste – GHGs – Halogenated hydrocarbons (from cooling) – GHGs and nuclear waste (indirect from energy production)

3. Literature study

a) North Sea and plaice ecology (Refs. 2, 3)

The North Sea is a marginal sea of the Atlantic Ocean located between Great Britain, Scandinavia, Germany, the Netherlands, Belgium, and France. It has a shallow (<50 m) south-eastern part and a much deeper (50–100 m) central part that is situated to the north of the British coast. the central northern part of the shelf goes down to 200 m. The maximum depth is reached along the Norwegian coast, where the Skagerrak can be up to 500 m deep. Water circulation in the North Sea is mostly represented by a counter-clockwise gyre, driven mainly by the wind. This pattern may sometimes be reversed or split into two gyres in the north and in the south. These currents may have an influence on the transport of larvae and eggs of multiple species in the North Sea. The temperature and salinity of the North Sea are influenced by the North Atlantic Oscillation (NAO), by the movement of water between these two ocean bodies, and by the ocean-atmosphere heat exchange. The temperature of the water varies from 6°C in winter to 17°C in summer, while the salinity of the water is typically about 34–35 g of salt per liter, being lower around freshwater inflows. Like many other regions in the world, the North Sea is also influenced by climate change, and this has already started on the lowest level of the food chain: the plankton community. The plankton community is shifting towards warmer water species, and this is clearly associated with a decline in fish reproduction, especially cod. The zooplankton is of critical importance for the food web in the North Sea, as well as for fishery yields and the sensitivity of the community to further climate change. The next level in the food chain is the larger benthic invertebrates. Their community composition varies with sea depth and sediment type and is also affected by temperature and trawling intensity. Beam trawling used in plaice fishing alters biomass, production, size structure, and diversity of benthic communities, reduces the growth of the benthic invertebrates and increases mortality. This may eventually lead to a food shortage for fish, the next level of the food chain. The dominating pelagic fish species is herring (*Clupea harengus*) and the main flatfish species are the common dab (*Limanda limanda*), plaice (*Pleuronectes platessa*), and sole (*Solea vulgaris*). Due to overexploitation, fish mortality has increased, the mean size of individuals in the community has decreased, and the abundance of smaller species has increased. The major forage fish species is the sandeel (*Ammodytes marinus*) and is an essential component of the diet of piscivorous fish species but also of the puffin, but has declined over the last 25 years. This decline will have serious implications for these piscivorous fish species, but also for birds and marine mammals.

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Although a lot of information is available already on the processes happening in the North Sea, there is still need for further research, especially in the fields of community ecology, temperature preferences of organisms on all food levels, implications of depleted populations, and measures for population fecundity.

The fish species focused on in this project and a popular fish in North Sea fisheries is the European plaice (*Pleuronectes platessa*). It is a common flatfish and occurs on muddy or sandy bottoms from the western Mediterranean and along all European coasts. The upper side of the plaice is dark green to brown with orange spots, making it conspicuous to predators. The side of the plaice that is in contact with the soil is pale white. Both eyes are located on the right side of the body. Another remarkable characteristic of the species is the curved lateral line. Plaice is mostly active at night and is a generalist: it feeds on polychaetes (worms) and bivalve molluscs.

Plaice has a rather complex life cycle with different life stages occurring in different, specific habitats. Spawning happens in deep water from January to June, laid eggs and developed larvae are pelagic and drift with the current. Although they cannot resist these currents, they can change their vertical position in the water column to enter favorable currents until they arrive at a suitable habitat for metamorphosis. Metamorphosis takes place at nursery grounds in estuaries and along sandy coasts. In the first years of their lives, the juveniles spend their time in these nurseries. As they grow older, they move to deeper water. Age at maturity for males is 2–3 years and for females 4–5 years. Adult plaice migrate between feeding areas and spawning grounds and can reach ages up to 30 years. During the whole lifespan, sandy bottoms remain the preferred sediment type for the species.

b) Classical trawling (Ref. 4)

Some information on trawling and its effect on the environment will be given here. Trawling can be divided into two kinds: midwater and bottom trawling. In midwater trawling (also known as pelagic trawling) a large funnel-shaped net is towed by a fishing vessel through a water column far enough from the sea bottom. Bottom trawling on the other hand is a fishing technique where the net is dragged along or close to the sea floor. We will focus on the latter as it is more relevant to our case study regarding fishing for flatfish, which reside on the ocean floor. There are several different trawling methods. Beam trawling is a method where a beam is placed in the opening of the net to keep it from closing. This beam also allows the attachment of several tickler chains to the frame of the net. These tickler chains startle the creatures burrowed in the seabed, causing them to rise so that they can be caught in the net. Another well-known method called otter trawling uses so-called “otter boards”, attached to both sides of the net, to keep the mouth of the net open. These trawling methods can be used for both midwater and bottom trawling.

As the net is towed across the seabed, it causes a large amount of damage to the seafloor and its inhabitants. Trawlers can greatly reduce the textural complexity of the seabed and plow deep furrows in it. A distinction can be drawn between immediate and long-term effects. How large these effects are depend greatly on the amount of contact with the seabed, the depth, the nature of the seabed, and the strength of the currents. In areas where currents are abundant, the effects caused by the displacement of sediment are short-lived compared to places like the deep ocean, where there is very little water movement. Fortunately, in many European Union waters, including the North Sea, bottom trawling is not allowed at a depth below 800 meters (10).

During trawling, macrobenthos, which are bottom dwellers that are visible to the naked eye, are removed. Some of these macrobenthos cannot recover, while other species soon recolonize. In some places such as the Wadden Sea and the Kattegat, there has been a noticeable increase in some populations, while at the same time a reduction has occurred in others (6). Whether this is a result of trawling alone is difficult to determine, as natural fluctuations and other changes such as pollution can also influence the growth or decline of the populations. Some field studies suggest that the abundance of macrobenthic species (epifaunal and infaunal) is reduced by trawling, and that large species are generally more vulnerable than smaller ones (8). This causes a greater prevalence of small infaunal species in the trawled communities. The increase in the production of smaller infauna, however, seems rather small in relation to the losses in overall community production, caused by the reduction in the population of larger fish. Small meiofaunal species, marine creatures smaller than macrofauna and bigger than

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microfauna, seem to be relatively unaffected by trawling, and this might be because they are resuspended by the trawl rather than crushed, or because they have fast generation times (5). Bottom trawling also causes the destruction of many deep-sea corals and sponges, which are the habitat of a large amount of marine life. Between 1997 and 1999 the destruction was of the order of one million pounds of corals and sponges in Alaskan waters alone (7).

Another major ecological threat is the amount of "bycatch". "Bycatch" is a term used for the marine species that are unintentionally caught while fishing for a specific target species or target size. Because of the lack of selectivity of the trawl net, trawling catches a large number and diversity of non-target species. Many of those fish end up being discarded because they lack commercial value, because of the cost involving in landing fish, or because of the lack of storage on the fishing vessel.

Shrimp trawling has one of the highest discard/catch ratios of the fisheries, which ranges from 3:1 to 15:1. This ratio is of course dependent on the area, season, and target species. Data from the 1980s and early 1990s revealed that commercial bottom trawling contributed about 27 million tons of discards. An analysis by FAO based on data from 1992 to 2002 estimated that the discard rate was 8% of the total catch (9).

When towing a large net across the seabed, the fishing boat experiences a large amount of resistance from the ground. Therefore, a large amount of fuel is needed to move the trawler forward. When looking at the data concerning the fuel combustion of the Swedish cod fishery in 1999(5) one notices that the emissions (HC, NO_X, CO, SO_X and CO) from trawling are much greater than from e.g. gillnet fishing, another method that is often used by Swedish fishermen to fish for cod. The large fuel consumption is not helped by the large fuel subsidies given to fisheries. These subsidies give an economical advantage to trawlers. Their large fuel consumption, on the other hand, makes them very sensitive to fuel price increases. Pair trawling, where the trawl net is towed between two fishing vessels, also seems to give lower emission levels than regular trawling. A big disadvantage of this method, however, is the large amount of bycatch. This disadvantage of pair trawling also resulted in the prohibition of pair trawling for bass by UK vessels in UK territorial waters.

c) Electro trawling as an alternative

Since beam trawling is associated with several disadvantages such as seabed disturbance and high fuel consumption, alternative and 'more sustainable' methods of catching flatfish have been explored since the 1970s (11). Electro trawling, using electrical stimulation to catch fish, is the most recent development in the flatfish fishery. Here, the tickler chains used for classical beam trawling are replaced by electrodes that emit electric pulses. These pulses cause brief convulsions in the muscles of the fish, causing them to rise up from the seabed and get caught in the net.

Currently, the technique is largely banned in Europe. However, since 2009 member states have been able to obtain an exemption to use electro trawling in the southern part of the North Sea for up to 5% of their fleet (12). Within the EU, it is the Dutch who intensively use electro trawling with a total of 84 exemptions in 2014 (11).

Based on scientific literature, electro trawling indeed seems to possess several advantages compared to classical beam trawling. First of all, electro trawling does not disturb the seabed to the same extent as classical beam trawling, and therefore fewer creatures living on the seabed end up as bycatch. The ships also use less fuel because the pulse trawl is lighter and has less drag resistance, resulting in less CO_2 emissions and lower costs for fishermen. Also, the fish that are caught are of a better quality because they have suffered less direct damage (12).

Unfortunately, electro trawling also has detrimental effects on marine organisms and the marine ecosystem. There is evidence that the cramp evoked by the electric pulse induces vertebral fractures and associated haemorrhages in roundfish such as cod and whiting. Based on a comparative fishing experiment, it is estimated that vertebral fractures are induced in 9% of the cod and in 2% of the whiting (13). It is clear that sensitivity to the electric pulse and the incidence of vertebral fractures differ between different fish species. According to De Haan et al., the probability of developing fractures increases with field strength and decreases with frequency and body size(14). The electric pulses also affect benthic invertebrates, which show responses such as closing their shells, withdrawing into their shell or showing a tail flip response. However, some benthic species did not show a visible response, and it is suggested that the electric pulse

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does not affect the mortality of benthic species as compared to a control group (11). Although no studies have yet addressed this question, it is hypothesized that the electric pulses might induce chemical reactions releasing pollutants that are bound to sediment particles.

d) Comparison between conventional trawling and electro trawling Ecological (Refs. 15–19)

Some more explanation is obviously necessary for Table 1. For every parameter, a short discussion and some examples from the literature will be given.

In the case of seabed disturbance, it is clear that electro trawling offers the best advantages. In electro trawling there is often no contact with the seabed. Only in flatfish fishing is a footrope (rope with electrodes on it) still in contact with the bottom. This rope is much lighter than the tickler chains often used in conventional (beam) trawling which penetrate the seabed more intensely, to a depth of 8 cm on average, thereby destroying the local ecology and damaging fish and benthic invertebrates.

The reduced contact with the seabed in the case of electro trawling also has another major advantage: less fuel is consumed due to the smaller friction and because the electro trawling equipment is lighter compared to conventional trawls of a similar size. For conventional trawling, about 2.5 to 4 liters of fuel is needed per kilogram of fish. About 65% of the fuel is used in dragging the trawl over the seabed and 30% of the total fuel is lost to the resistance of the tickler chains on the bottom. Studies have shown that electro trawling consumes up to 50% less fuel.

Another consequence of direct contact with the seabed is possible damage to the sea life which thrives on the bottom. Spawning grounds (e.g. in muddy estuaries) can also get damaged by passing trawlers. In the classical trawling technique using mechanical excitation of the fish, the damage to the life forms is quite obvious. Here, the trawl, or at least the tickler chains, plows through the sediment, often hitting marine life forms that were not the original target. In electro trawling, many studies have been performed on the possible damage to other fish and the benthic invertebrates in the marine environment, but knowledge of the harmful effects on marine organisms is still scarce. The opponents of electro trawling claim this to be the main reason why it should be banned. Of course, they also acknowledge the harmful effects of conventional trawling, and therefore prefer to limit any activity of this type. Other, less damaging ways to catch flatfish such as plaice can be applied as well. One could think of aquaculture as a possibility, but experimental work in the United Kingdom in the 1940s showed that this would not be economically viable due to the expensive feed and the slow growth rate of the plaice. Diseases were also a problem in aquaculture plaice. Although there are not many alternatives, several countries have actually already banned trawl gear entirely (e.g. Belize).

Several investigations of various fish species and invertebrates showed that the damage caused to other organisms by electro fishing is in fact rather limited. Cod has been studied the most. It was concluded that, while 50–70% of adult cod exposed to highly intense electrical fields showed spinal injuries, none of the juvenile cod were affected. In dogfish, a species that relies on electroreceptors for finding its prey, no injuries and no deviating feeding patterns were found. Benthic invertebrates did not show any effects or reactions to electrical pulses that were twice as intense and lasted 8 times longer than those used in conventional electro trawling. Van Marlen et al. (2009) found similar results and concluded that “it is … plausible that the effects of pulse beam trawling, …, are far smaller than the effects of conventional beam trawling”. Besides this conclusion, quite some attention has also been paid to the effect of pre-set parameters, such as the voltage, frequency, and duration of the electric pulses. These can be optimized to get the most efficient catch results of the target species with the least amount of damage to other species, since the excitation/injury thresholds for each species are different. An important side-remark to make is that these studies were all investigating short-term effects. Long-term effects and repeated exposure might be interesting as well in order to estimate the real impact of this kind of fishery.

A last factor to consider is the selectivity of these fishery techniques. Apart from fuel consumption, this is the only technique for which data are available to quantify the respective impacts. The quantification is usually given as mass of bycatch (non-target species or non-saleable target fish that are caught) relative to the total mass of the landing or the total mass of the target species. Through improvement of the nets and new legislation making discarding bycatch illegal (EU

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2013), the annual amount of discards has steadily dropped to pre-1950s levels (less than 10 million tons per year). The question of what to do with the bycatch is important, and still under investigation. Some non-marketable species, such as starfish, still pose a problem.

According to Zeller et al. (2018), active bottom-contact gears (i.e. conventional trawling) are one of the most widespread large-scale types of fishing gear and are known to produce the highest amount of discard of any fishing gear. This is in contrast with electro trawling, which has very high selectivity because the pulses can be fine-tuned in such a way that only the target species is affected. Of course, both in conventional trawling and electro trawling the design of the nets plays a crucial role. (The shape and size of the holes in the nets help to 'select' the right species. Also, industrial fisheries are the main contributor (93%) to discards, while small-scale fishers typically discard very little.)

Socio-economic (Refs. 20–24)

A constant demand for fish in general and for plaice (or flatfish) in particular poses the need for the use of more effective and sustainable methods of fishing in order to meet present and future demands. The two fishing techniques, the classic trawling and the electric pulse techniques, show a variation in the catch efficiency with respect to the type of fish under consideration. This can be seen by the higher catch efficiency of the pulse trawling technique for sole and its lower catch efficiency for plaice and other species.

However; in 2011 the successful implementation of the pulse trawl technique in the Dutch flatfish fishery showed a 21% and 28% reduction in the catch rate per hour for marketable-sized sole and plaice respectively. This was attributed to the lower towing speed and hence the smaller surface area covered per hour of fishing. At the same time, the discarded bycatch catch rate for the pulse trawl was reduced by 67%. Despite the lower catch rate, electro trawling is still more efficient due to high selectivity for a single kind of fish (e.g. plaice). Also, the size selectivity for plaice (only adult species) suggests that the pulse trawl is more selective in catching marketable-sized flatfish. The choice of pulse trawling over classic trawling for catching plaice is thus made mainly for ecological reasons, but other social factors will give reasons for using the classical trawl technique and hence the banning of the pulse trawl technique by the European Union.

The high cost of pulse trawl equipment, as well as the high cost of maintenance, poses a problem for small-scale fishermen who will find it difficult to finance the activity. This might lead to those fishermen losing their jobs. However, the effect of pulse trawling on the jobs market in general is not very certain.

Fuel consumption per kilogram of fish caught should also be taken into consideration. The pulse trawling method uses less fuel, thereby corresponding to a lower fuel consumption per kilogram of fish caught. This leads to a decrease in the emission of CO_2 and also to a decrease in fish prices.

Despite the obvious ecological benefits of the pulse technique over the classical trawling technique, the European Union decided to place a ban on the pulse trawl technique (25). This decision can be seen to have been made for socio-political and economic reasons. In certain countries (France, UK, etc.), only small-scale traditional plaice fisheries exist, which suffer as a result of the Dutch fishery industries, which have a long tradition of fishing for plaice on a grand scale. The decision of these countries to back the prohibition on electro trawling, used by almost half the Dutch fleet, can probably be seen as economic protectionism. However, it also has a legal basis, since the Dutch were allowed to apply electro trawling to only a limited percentage of their fleet (5%) under the cover of scientific research. However, at present, after gaining concessions from the EU Commission over the last few years, their fleet has exceeded the 5% limit and is no longer used just for gathering scientific data, but is applied to the large-scale industrial fishing of flatfish.

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A Systems Map to Elucidate the Factors Influencing Vaccine Coverage

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Abstract

This abstract is a report of the investigations by a transdisciplinary team working on the 'Vaccine Confidence' challenge (Supplement 1). Since their introduction, vaccines have been one of the most successful health interventions in medicine. Prior to vaccination programs against poliomyelitis, more than 350,000 cases of polio were reported annually worldwide, a number that decreased to just 33 reported cases in 2018[1]. Additionally, between 2000 and 2017, the measles vaccination program is estimated to have prevented 21.1 million deaths.[2] However, in 2018 more than 19 million children under one year of age did not receive the recommended WHO vaccines.[3] A recent rise in anti-vaccine or vaccination-hesitant mentalities has led to decreasing vaccine coverage in several Western countries. The WHO identified three C's as main determinants of vaccine hesitancy, namely Complacency, Convenience in accessing vaccines, and Confidence. However, the term 'vaccine hesitancy' tends to be interpreted as a lack of confidence in vaccines and vaccinations for various reasons. Nevertheless, the goal of vaccination is to reach herd immunity by reaching a high vaccination coverage (90–95% vaccinated) to stop the circulation of vaccine preventable diseases. We wanted to give equal attention to the three C's as they are equally important in reaching herd immunity.

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Therefore, we chose to present the problem as a challenge of 'vaccine coverage,' rather than 'vaccine hesitancy' or 'vaccine confidence'. In order to understand the complexity of the problem, we have developed a systems map which relates different global factors that impact an individual's vaccination decision-making, as well as their likelihood of receiving vaccinations (Supplement 2). To create this map we assembled the information for the variables and connections from literature studies of peer-reviewed articles and interviews with stakeholders, kept anonymous, in the field of vaccination or healthcare (Supplements 3 & 4). This approach was selected as it provides a wide perspective that allows academics, governmental authorities, and lawmakers to better assess the various factors that affect vaccine coverage, and how they are related. The work leading to the map was presented to the public at a symposium (Supplement 5). Our map identifies essential factors such as psychology, education, economy, vaccine technology, political and environmental sphere, sources of information, and healthcare in order to understand what governs vaccination coverage. The map emphasizes how various factors and determinants are often interrelated, as opposed to the isolated factors described in previous literature. We identified important discrepancies between developed and developing countries regarding the factors that drive vaccine-related decision-making and availability. The systems map could ultimately serve as a tool to better understand the multifaceted problem of suboptimal vaccination coverage.

Vaccine hesitancy as a threat to vaccination coverage is a complex and wicked problem with many underlying contributing factors, as has been depicted in our systems map on vaccine coverage. Our systems map allows more in-depth insights, not only into which factors are contributing, but also into the relationship between factors. Solving the decrease in vaccination coverage will require different types of solutions which can be developed by using a transdisciplinary approach.

Key words

Vaccines, Herd Immunity, World-Map, Systems Map

Supplements

Supplement 1: Original challenge document submitted to the 'Institute for the Future.'
Supplement 2: Systems map of vaccine coverage using the KUMU software.
Supplement 3: Elements and connections in the systems map exported to excel.
Supplement 4: Reference list accompanying the KUMU map.
Supplement 5: Link to video recording of the presentation held at the Symposium 'KU Leuven Facing the Future,' May 8, 2019, Leuven, Belgium.

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Supplement 1: Original Challenge Submission

The challenge was taken up by a team of master's students, their coach, and stakeholders in the context of the Honours Programme 'Transdisciplinary Insights' (https://rega.kuleuven.be/if/vaccine-hesitancy).

HONOURS PROGRAMME TRANSDISCIPLINARY INSIGHTS KU LEUVEN

ABOUT YOUR CHALLENGE

NAME OF THE CHALLENGE

Understanding the impact of fake news on vaccination confidence and finding ways to reverse the negative consequences.

(Challenge submitted by Prof. Corinne Vandermeulen)

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.

Besides running water and hygiene, vaccines are the best preventive medical invention/intervention that worldwide have impacted morbidity and mortality significantly, and their effect can hardly be overestimated. By using vaccines systematically and globally through organized vaccination programs, about 2–3 million deaths are averted annually (WHO). The advantage of vaccines is not only that they are able to induce individual protection against disease, but a vaccinated person can, for most vaccines, not be infected anymore and will thus stop transmission of the infectious pathogen. This phenomenon made eradication of smallpox possible and the elimination of many vaccine-preventable diseases (e.g. polio, diphtheria, measles, rubella, …) in countries with high vaccination coverage. By organizing vaccination programs where >90–95% of the population is vaccinated, circulation can be stopped and the most vulnerable children and adults, who cannot be vaccinated or do not respond to vaccination, can also be protected. This is called herd or community immunity.

Despite the overwhelming scientific evidence of the positive effect of vaccination and of herd immunity, over the last decade vaccine hesitancy has been increasing. The three Cs that define vaccine hesitancy are Convenience, Complacency, and Confidence. Where Convenience is defined by access to vaccines, Complacency and Confidence are related to knowledge about and trust in vaccines, vaccinators, governments who organize vaccination programs, and vaccine manufacturers.

The current generation of new parents is not familiar anymore with the severity and complications of vaccine-preventable infectious diseases, and parents are increasingly focused on (alleged) side effects of vaccines. This phenomenon has led to lower confidence in the effects of vaccination and increased complacency. An increasing proportion of parents are doubting and delaying vaccination or even refusing to have their child vaccinated. Even though it is the individual choice of parents not to immunize their child, that should be placed in a broader societal context. Especially over the internet and through social networks fake news on vaccines is spreading with lightning speed. Shares, likes, and tweets of emotional witnesses of alleged side effects of vaccines are spread more easily than solid scientific evidence, helped by internet bots and trolls. Parents also tend to click more on negative news when looking for information on vaccines on the internet. Additionally, search engines have features which are more advantageous for negative vaccine messages as inputs of searches are already pre-populated by search strings that are used more often. As such the anti-vaccine movement is helped by technology and is increasing vaccine hesitancy in parents. As a result more parents refuse to have their children vaccinated or delay essential vaccination to a later, mostly undefined, age.

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Unfortunately, this hesitancy has led to a decrease in vaccination coverage in different countries and has given rise to new epidemics of vaccine-preventable diseases which we thought were eliminated, such as measles. This means that unprotected and often vulnerable children get ill and suffer again from complications of infectious diseases which had almost disappeared.

Even though many initiatives have already been taken to identify factors which influence vaccine hesitancy (e.g. vaccine confidence project), and many initiatives are taken to increase vaccine confidence, especially new ways on how to tackle this issue would be most welcome. It is important that this high wave of vaccine hesitancy is somehow stopped before our countries are flooded again with vaccine-preventable diseases.

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

The interdisciplinary group will be asked to think about ways to increase confidence in vaccines and reduce complacency. This will be done by case studies of vaccines which have suffered from fake news (e.g. measles, HPV) in different countries. Through conversations with specialists of different disciplines (health psychology, sociology, communication, …) and its own literature search, the group should suggest new steps on how to address vaccine hesitancy.

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.

WHO and experts around the world recognize that loss of vaccine confidence is a growing challenge for vaccination programs and undermines the efforts that have been made in the past to eliminate some of the more serious infectious diseases. Vaccine hesitancy can be present in all countries, but underlying mechanisms can be different as vaccine hesitancy is also the result of a broader societal context and should be looked at in the historical, political, and socio-cultural context in which vaccination takes place. (Dubé et al., Vaccine 2014) By bringing together people from different disciplines (health psychology, sociology, informatics, medicine, communication, new technologies, …), insights on vaccine hesitancy from other perspectives might help to find new ways to address this growing problem.

Could you indicate from which disciplines you want a researcher to address this challenge? You need to pick at least one from each domain.

Domain of Humanities and Social Sciences:

- Arts
- Canon Law
- Economics and Business
- Law
- Philosophy
- Psychology and Educational Sciences
- Social Sciences
- Theology and Religious Studies
- Other: _____

Domain of Science, Engineering and Technology:

- Architecture
- Bioscience Engineering
- Engineering Science
- Engineering Technology

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- Sciences
- Other: IT, network specialists

Domain of Biomedicine:

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

Can we contact you to get further details of your challenge?

Yes: corinne.vandermeulen@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 Not-for-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 for 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.*

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Footnote: If your challenge involves a confidential agreement or if it requires corporate considerations, please contact: jorgericardo.novablanco@kuleuven.be

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 the name(s) of stakeholders willing to get involved in this research and, if you have them, some contact details for each one?

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 the name(s) of stakeholders willing to get involved in this research and, if you have them, some contact details for each one?

- Heidi Larson, Vaccine confidence project, London School of Hygiene and Tropical Medicine
- Robb Butler, WHO Europe
- Matthew Snape and Andrew Pollard, Oxford Vaccine Group

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:

Word cloud of the challenge.

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Supplement 2: Systems Map of Vaccine Coverage using the Kumu Software

Available at: https://embed.kumu.io/05b50ce938a9b9028afc41c6533f4ea7

The following introductory text accompanies the map:

Vaccine Hesitancy and Vaccine Coverage

The idea of finding a solution to vaccine hesitancy and increasing vaccine coverage appears simple when first considered. However, after considerable research one would learn about the countless influences and factors that can have an impact on vaccine coverage in different populations. As researchers, we were able to illustrate the interconnected nature of elements impacting vaccine coverage, which helped clarify our initial confusion surrounding vaccine hesitancy. Ultimately, the goal of the project became to distill the complexity of the problem into an easily navigable map, and in this way our work can serve to inform the reader of the situation's complexity. We believe that before any solution can be found, one must first understand the subtleties of the problem they intend to solve.

When navigating this map, one might explore a single factor affecting vaccine coverage and soon find it affecting or being affected by several others. As the Greek historian, Thucydides, says, 'The worst thing is to rush into action before the consequences have been properly debated.' It is our hope that with this uniquely different approach we may provide a suitable place and insight for others to develop solutions to increase vaccine coverage themselves.

To understand this map:

- The legend includes the subdisciplines, such as individual and social psychology, which are uniquely involved in this wicked problem.
- Green arrows connecting the elements represent a positive relationship. For example, when there is an increase in 'vaccine confidence' there will also be an increase in 'vaccine coverage'.
- Red arrows connecting the elements represent a negative relationship. For example, when there is an increase in 'belief in delaying vaccinations' there will also be a subsequent decrease in 'adherence to vaccination programs'.
- The map is fluidly structured from bottom to top. Societal/herd factors situated near the bottom of the map influence individual decision making, culminating in the final vaccination decision at the apex of the map.

These connections do not imply direct causality, and may vary from region to region.

To read sources and information about the relationships between elements click on the connecting line. The information included in this map was compiled from various sources including an in-depth literature study of peer-reviewed articles, several interviews with (anonymous) stakeholders in the field of vaccination or healthcare. In some cases, logical reasoning steps are made in place of a direct literature citation, e.g. an increase in Vaccine Coverage will lead to a decrease in the Incidence of Vaccine-Preventable Diseases.

This map was compiled by an interdisciplinary team of 5 students:
Ellie Cassandra Clark (Biology/Psychology)
Florian De Rop (Bioscience Engineering)
Iria Anne Jimenez Garcia (Biomedical Science)
Ana Nogal Macho (Bio-informatics)
Ruel Alexander Mannette (Philosophy)
Kaat Ramaekers (Supervisor)
Prof. Corinne Vandermeulen (Supervising Professor)

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The following figure is a screenshot of the map:

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Supplement 3: Elements and Connections in the Systems Map Exported to Excel

Label	Type	Description
Amount of anti-vaccine religious beliefs	Individual Psychology	
Individuals range of Rebelliousness	Individual Psychology	
Trust in primary care physicians	Healthcare and Health	
Access to Vaccines	Healthcare and Health	
Quality of logistics infrastructure	Economics	
Length of Vaccine Tender	Economics	
Availability of alternative methods of vaccination	Vaccine Technology	
Level of Education of Society	Education	
Individual Nation-States Vaccine Budget	Economics	
Desire to be a good parent	Individual Psychology	Shui I, Kennedy A, Wooten K, Schwartz B, Gust D. Factors influencing African-American mothers' concerns about immunization safety: a summary of focus group findings. J Natl Med Assoc 2005; 97:657–66; PMID:15926642
Quality of Vaccination Registry	Healthcare and Health	
Number of vaccinations	Healthcare and Health	
Presence of Vaccine-related Infrastructure	Healthcare and Health	
Number of vaccines per needle	Vaccine Technology	
Vaccine Literacy of Society	Education	
Vaccine Coverage	Goal	
Rural Births	Healthcare and Health	Minor effect
Vaccine Convenience	Core Principles	Vaccination convenience is affected by: 1) Physical availability 2) Affordability/willingness-to-pay 3) Geographical accessibility 4) Ability to understand (language and health literacy) 5) Appeal of immunization services 6) The quality of the service (real and/or perceived) and 7) Degree to which vaccination services are delivered at a time and place and in a cultural context that is convenient and comfortable

Personal vaccination complications	Healthcare and Health	
Hostility of the Climate	Political and Environmental Sphere	
Experience with primary care physicans	Healthcare and Health	
Demand for Vaccines	Healthcare and Health	
Influence of Anti-vaccine Movement	Sources of Information	
Price of Vaccine	Economics	
Concerns for child well-being	Individual Psychology	
Number of shots per visit	Vaccine Technology	
Confidence in Omission Bias	Individual Psychology	The concern of the consequences of doing something, (vaccine side effects), over the concern of not doing something, (vaccination). Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decisionmaking about vaccines for infants: the importance of trust. Pediatrics 2006; 117:1532–41; PMID:16651306; http://dx.doi.org/10.1542/peds.2005–1728 Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, et al. Omission bias and vaccine rejection by parents of healthy children: implications for the influenza A/H1N1 vaccination programme. Vaccine 2010; 28:4181–5; PMID:20412878; http://dx.doi. org/10.1016/j.vaccine.2010.04.012
Confidence in Big Pharma	Sources of Information	
Privatization of Clinics	Economics	
Economic Prosperity	Economics	Per nation/region
Vaccine literacy of Parents	Education	
Vaccine Complacency	Core Principles	Vaccination complacency is affected by: 1) Vaccination is not deemed a necessary preventive action (due to low incidence of vaccine preventable disease 2) other life/health responsibilities that may be seen to be more important at that point in time. 3) Immunization programme success may, paradoxically, result in complacency 4) Individuals weigh risks of vaccination with a particular vaccine against risks of the disease the vaccine prevents that disease is no longer common. 5) Self-efficacy (the self-perceived or real ability of an individual to take action to be vaccinated)

Incidence of vaccine stockouts	Healthcare and Health	
Valuation of Personal Health	Individual Psychology	
Acceptance of vaccination social norms	Social Psychology	
Confidence in Government	Sources of Information	
Level of Education of Parents	Education	
Accuracy of the News	Sources of Information	
Ability to determine validity of vaccine information	Sources of Information	
Vaccine literacy of Healthcare Workers	Education	
Rate of Vaccine Completion	Healthcare and Health	
Degree of belief in Natural Holism	Individual Psychology	Degree of belief in Natural Holism represents the degree in which an individual ascribes to an inviolability of nature, wether philosophical or religious. Lower belief in natural holism represents a predilection to 'natural' products, practices and food while a higher belief represents a conception of natural sanctity (pantheistic) and omnipotence in which only 'natural cures' can work. It can overlap with various other religious and philosophical outlooks.
Adherence to Vaccination Programme	Healthcare and Health	
Local Experience with Pandemics	Healthcare and Health	
Range of Moral Sphere	Individual Psychology	The range of who you consider within your ethical sphere. The lowest is egoism, the mid-range is family or nationality the further extreme is all animal life and the farthest extreme is pantheism. This is meant as purely descriptive and not intended to bias one range over another. If you dont consider certain people within your moral sphere then appeals for their health are irrelevant for the individual.
Degree of Belief in Pseudoscience or Biased science	Sources of Information	
Trust in Health Care Workers	Healthcare and Health	
Susceptibility to conspiracies	Individual Psychology	
Localized Clinical Costs	Economics	
Quality of information on the internet	Sources of Information	

Influence of High profile Individuals	Social Psychology	
Quality of vaccine storage	Vaccine Technology	
Vaccine Confidence	Core Principles	Confidence is defined as trust in: (i) the effectiveness and safety of vaccines (ii) the system that delivers them, including the reliability and competence of the health services and health professionals (iii) the motivations of policy-makers who decide on the needed vaccines.
Passive Vaccination	Individual Psychology	"The biggest threat is not that 30% don't vaccinate, but the threat is that people passively vaccinate – they do it because everyone else does it. They don't really understand how it works. This is great if everyone vaccinates, but when you get a rumour, you get a wave effect because people just copy each other. People realise you have to invest in peace time, otherwise you don't get resilience." *Robb Butler (in an interviewed by the students on 29/04/2019)*
Quality of Health Care Infrastructure	Healthcare and Health	
Level of Religiosity	Individual Psychology	Level of religiosity represents the degree in which an individual practices common religious activities, personally ascribes to religious beliefs and operates actively in a religious community or otherwise spiritually associated collective.
Predictability of Vaccine Demand	Healthcare and Health	
Indirect costs of Vaccines	Economics	
Short-term political Goals	Political and Environmental Sphere	**You saw that people vaccinate without thinking, do you think therefore that enhancing literacy is the way to go?** "Yes, we have to put more emphasis on longer term return on investment. We need a long term objective in investing in parents before they become parents, in healthcare workers at the start of their curriculum, and better relationships with the media. All three aspects are important. My children already know a lot about smoking, traffic, reproduction, ... But not immunisation. What politicians want is something that pays off within their tenure. That's something we have to try and get over. Immunisation is the corner stone of primary health care. There is no universal care unless you reach every child. If you have outbreaks and the inability to respond to outbreaks, then vaccine-preventable diseases should be the centre of your program. Medical practitioners have only 40 minutes on vaccinology. There's something wrong with how we're equipping our medical health care workers." *Robb Butler (in an interviewed by the students on 29/04/2019)*

Socio-Economic Status of Individual	Economics	
Health of individual	Healthcare and Health	
Confidence of Alternative Therapies	Alternatives to Vaccination	
Concern about side effects	Individual Psychology	
Incidence of Vaccine-preventable Disease	Healthcare and Health	
Influence of Peer Group	Social Psychology	
Parental Hesitancy	Individual Psychology	
Emergency Migrations	Political and Environmental Sphere	
Belief in delaying vaccinations	Individual Psychology	
Presence of Health Concepts in Media	Social Psychology	
Opportunity Cost for family seeking Vaccination	Economics	
Access to Healthcare	Healthcare and Health	
Wait Time for Vaccination	Economics	
Socio-cultural Morality Scale	Social Psychology	This is ranging from high number on the scale which is extremely tight knit and collectivity focused to a low number on the scale which is extremely individualistic. This is following the psychologists Johnathan Haidt's moral reasoning and its relationship to culture. Below is the paper on disgust and its cultural contingency. Haidt, Jonathan, Paul Rozin, Clark Mccauley, and Sumio Imada. "Body, Psyche, and Culture: The Relationship between Disgust and Morality." Psychology & Developing Societies 9, no. 1 (1997): 107–31.
Stability of Government	Political and Environmental Sphere	

From	To	Type	Description
Access to Healthcare	Health of individual		Logical step. If there is no healthcare available, then the health of individuals would be affected.
Vaccine Confidence	Influence of Anti-vaccine Movement	Opposite	Hussain H, Omer SB, Manganello JA, Kromm EE, Carter TC, Kan L, et al. Immunization safety in US print media, 1995–2005. Pediatrics 2011; 127(Suppl 1):S100–6; PMID:21502237; http://dx.doi.org/10.1542/peds.2010-1722O Kennedy A, Lavail K, Nowak G, Basket M, Landry S. Confidence about vaccines in the United States: understanding parents' perceptions. Health Aff (Millwood) 2011; 30:1151–9; PMID:21653969; http://dx.doi.org/10.1377/hlthaff.2011.0396 Davies P, Chapman S, Leask J. Antivaccination activists on the world wide web. Arch Dis Child 2002; 87:22–5; PMID:12089115; http://dx.doi.org/10.1136/adc.87.1.22 Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Influence of Anti-vaccine Movement	Degree of Belief in Pseudoscience or Biased science		Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Level of Religiosity	Range of Moral Sphere		Kahn, Peter A. "Bioethics, Religion, and Public Policy: Intersections, Interactions, and Solutions." Journal of Religion and Health 55, no. 5 (2016): 1546–560.
Level of Religiosity	Degree of belief in Natural Holism		Increase in religiosity as an increased adherence to religious practices from any of the major world religions or belief systems and coinciding with a belief in the predominance of religious explanations for events in reality. This increase in a religious explanation for events in reality then will coincide with a preconception that nature functions either: seamlessly, along-a preordained plan, or that 'nature' represents a sacred whole that functions properly. This conception of nature as an unadulterated whole that functions holistically outside of human development is natural holism. The connection between the increase in religiosity is that religious explanations regarding nature are more likely tend to be totalizing of nature as it functions rather than viewing nature as ad hoc or fallible.
Hostility of the Climate	Emergency Migrations		Tacoli, C. (2009). Crisis or adaptation? migration and climate change in a context of high mobility. Environment and Urbanization, 21(2), 513–525. doi:10.1177/0956247809342182

Socio-cultural Morality Scale	Concerns for child well-being		Based on the definition of socio-cultural morality scale, someone who scores highly in socio-cultural morality would be collectively focused on a community and would therefore also have an increased concern for child well being, as children are seen as being a part of said community. A decrease in socio-cultural morality would lead to more individualistic beliefs and tendencies, leading also to a decrease in concern for child well-being. Socio-cultural morality scale: This is ranging from high number on the scale which is extremely tight-knit and collectivity focused to a low number on the scale which is extremely individualistic. This is following the psychologists Johnathan Haidt's moral reasoning and its relationship to culture. Below is the paper on disgust and its cultural contingency. Haidt, Jonathan, Paul Rozin, Clark Mccauley, and Sumio Imada. "Body, Psyche, and Culture: The Relationship between Disgust and Morality." Psychology & Developing Societies 9, no. 1 (1997): 107–31.
Concern about side effects	Belief in delaying vaccinations		Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.
Privatization of Clinics	Wait Time for Vaccination	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Parental Hesitancy	Vaccine Confidence	Opposite	Wheeler M, Buttenheim AM. Parental vaccine concerns, information source, and choice of alternative immunization schedules. Hum Vaccin Immunother. 2013 Aug 1;9(8):1782–9.
Valuation of Personal Health	Vaccine Complacency		Logical step. A person who has an interest in their own personal health would be more likely to also be complacent with vaccinations.
Quality of Health Care Infrastructure	Localized Clinical Costs		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Quality of vaccine storage	Incidence of vaccine stockouts	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Amount of anti-vaccine religious beliefs	Degree of Belief in Pseudoscience or Biased science		Julie Milstien, P. David Griffin & J-W. Lee (1995) Damage to immunisation programmes from misinformation on contraceptive vaccines, Reproductive Health Matters, 3:6, 24–28, DOI: 10.1016/0968-8080(95)90155-8

Desire to be a good parent	Range of Moral Sphere	Opposite	Consider that an individual with a small moral sphere is more concerned about the well-being of those closest to them than any other living being or belief. It would logically follow that someone who desires to be a good parent would also be more concerned about the well-being of their child than most other things. Thus, the desire to be a good parent leads to a decrease in their moral-sphere. Based on the definition of moral sphere. Moral sphere: The range of who you consider within your ethical sphere. The lowest is egoism, the mid-range is family or nationality the further extreme is all animal life and the farthest extreme is pantheism. This is meant as purely descriptive and not intended to bias one range over another. If you do not consider certain people within your moral sphere then appeals for their health are irrelevant for the individual.
Economic Prosperity	Quality of logistics infrastructure		Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Degree of Belief in Pseudoscience or Biased science	Vaccine Confidence	Opposite	Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Quality of information on the internet	Vaccine Confidence	Same	As the quality of information on the internet regarding vaccines increases, or becomes more accessible and attractive, it would follow that those who subscribe to the information would become more confident in the safety of vaccines. Brewer NT, Chapman GB, Rothman AJ, Leask J, Kempe A. Increasing Vaccination: Putting Psychological Science Into Action. Psychological Science in the Public Interest. 2017 Dec;18(3):149–207.
Access to Vaccines	Adherence to Vaccination Programme		Direct relationship. It would make sense that if an individual has access to vaccines they would be more likely to adhere to a vaccine program.
Vaccine literacy of Healthcare Workers	Vaccine Literacy of Society		Gust DA, Kennedy A, Shui I, Smith PJ, Nowak G, Pickering LK. Parent attitudes toward immunizations and healthcare providers the role of information. Am J Prev Med 2005; 29:105–12; PMID:16005806; http://dx.doi.org/10.1016/j.amepre.2005.04.010
Acceptance of vaccination social norms	Adherence to Vaccination Programme		Shui I, Kennedy A, Wooten K, Schwartz B, Gust D. Factors influencing African-American mothers' concerns about immunization safety: a summary of focus group findings. J Natl Med Assoc 2005; 97:657–66; PMID:15926642 Liu, Jiming. "A Computational Approach to Characterizing the Impact of Social Influence on Individuals' Vaccination Decision Making." PLoS One 8, no. 4 (2013): E60373.

Desire to be a good parent	Concerns for child well-being	Same	Shui I, Kennedy A, Wooten K, Schwartz B, Gust D. Factors influencing African-American mothers' concerns about immunization safety: a summary of focus group findings. J Natl Med Assoc 2005; 97:657–66; PMID:15926642
Accuracy of the News	Degree of Belief in Pseudoscience or Biased science	Opposite	Articles most likely to be shared contain information that is an easily identifiable 'gist'. Articles of these types tend to be 'click-bait' and are known to misrepresent data. The misrepresented data can be used to reinforce individuals belief in biased or pseudoscience science. Therefore, the accuracy of the news would an effect on the degree of belief in biased or pseudoscience. Brewer NT, Chapman GB, Rothman AJ, Leask J, Kempe A. Increasing Vaccination: Putting Psychological Science Into Action. Psychological Science in the Public Interest. 2017 Dec;18(3):176.
Incidence of Vaccine-preventable Disease	Health of individual	Opposite	MacDonald, N. E., Eskola, J., Liang, X., Chaudhuri, M., Dube, E., Gellin, B., … Schuster, M. (2015). Vaccine hesitancy: Definition, scope and determinants. Vaccine, 33(34), 4161–4164. doi:10.1016/j.vaccine.2015.04.036
Personal vaccination complications	Concern about side effects		Logical step. Complications from vaccines can include health risks, such as developing a fever- which can increase individual concern about the side effects of other vaccinations as well.
Experience with primary care physicans	Trust in primary care physicians	Opposite	Bardenheier BH, Yusuf HR, Rosenthal J, Santoli JM, Shefer AM, Rickert DL, et al. Factors associated with underimmunization at 3 months of age in four medically underserved areas. Public Health Rep 2004; 119:479–85; PMID:15313111; http://dx.doi.org/10.1016/j.phr.2004.07.005
Quality of logistics infrastructure	Incidence of vaccine stockouts	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Desire to be a good parent	Belief in delaying vaccinations		Among vaccine-hesitant parents, it is a common belief that delaying vaccines is healthier for their children as it allows the child's immune system to mature, as opposed to the normal schedule that many feels are too much of a demand on their children. Therefore, these parents are acting in a manner that seeks the best interests of their children and would consider themselves good parents for doing so. Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.
Vaccine Literacy of Society	Passive Vaccination	Opposite	From an interview with a social scientist specializing in public health interventions and social safeguards, former head of national NGO.

Stability of Government	Economic Prosperity		La Porta, R., Lopez-de-Silanes, F., Shleifer, A., & Vishny, R. (1999). The quality of government. Journal of Law, Economics, and Organization, 15(1), 222–279.
Degree of Belief in Pseudoscience or Biased science	Confidence in Big Pharma	Opposite	Based on an interview with a single male in his mid-twenties who is vaccine-hesitant.
Concerns for child well-being	Desire to be a good parent		Logical step. A parent that is concerned for their child's well being is typically intrinsically motivated to be a good parent as well.
Economic Prosperity	Emergency Migrations	Opposite	From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Personal vaccination complications	Parental Hesitancy		Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.
Presence of Vaccine-related Infrastructure	Vaccine Confidence		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Influence of High profile Individuals	Parental Hesitancy	Opposite	Scherer LD, Shaffer VA, Patel N, Zikmund-Fisher BJ. Can the vaccine adverse event reporting system be used to increase vaccine acceptance and trust? Vaccine. 2016;34:2424–9.
Vaccine Coverage	Incidence of Vaccine-preventable Disease	Opposite	Logical step. An increase in vaccine coverage would lead to a decrease in vaccine-preventable diseases among the general population. MacDonald, N. E., Eskola, J., Liang, X., Chaudhuri, M., Dube, E., Gellin, B., … Schuster, M. (2015). Vaccine hesitancy: Definition, scope and determinants. Vaccine, 33(34), 4161–4164. doi:10.1016/j.vaccine.2015.04.036
Quality of Health Care Infrastructure	Price of Vaccine	Opposite	From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Quality of information on the internet	Degree of Belief in Pseudoscience or Biased science	Opposite	The quality of information on the internet is affected by the increasing popularity of vaccine-hesitant websites that provide incorrect or biased science that is often supported by so-called "whistle-blowers" in positions of power- Andrew Wakefield. Therefore, as the quality of the information on the internet changes, for example, decreases in quality, the degree of belief in pseudoscience or biased science would fluctuate in response, in this case, increase. Brewer NT, Chapman GB, Rothman AJ, Leask J, Kempe A. Increasing Vaccination: Putting Psychological Science Into Action. Psychological Science in the Public Interest. 2017 Dec;18(3):157
Number of vaccines per needle	Number of shots per visit	Opposite	Logical Step: if the number of vaccines able to be delivered per needle were to increase the number of shots required per visit to achieve the recommended vaccinations would decrease.

Concerns for child well-being	Concern about side effects		Logical step. A parent who is concerned about their child's well being would also be likely to be concerned about any possible side effects that may arise from a vaccination.
Economic Prosperity	Stability of Government		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Vaccine Convenience	Vaccine Coverage		MacDonald, N. E., Eskola, J., Liang, X., Chaudhuri, M., Dube, E., Gellin, B., … Schuster, M. (2015). Vaccine hesitancy: Definition, scope and determinants. Vaccine, 33(34), 4161–4164. doi:10.1016/j.vaccine.2015.04.036
Trust in Health Care Workers	Influence of Peer Group	Opposite	Bardenheier BH, Yusuf HR, Rosenthal J, Santoli JM, Shefer AM, Rickert DL, et al. Factors associated with underimmunization at 3 months of age in four medically underserved areas. Public Health Rep 2004; 119:479–85; PMID:15313111; http://dx.doi.org/10.1016/j.phr.2004.07.005
Accuracy of the News	Vaccine Confidence		Articles most likely to be shared contain information that is an easily identifiable 'gist'. Articles of these types tend to be 'click-bait' and are known to misrepresent data. The misrepresented data can be used to decrease the individual's confidence in vaccines. Therefore, the accuracy of the news would affect vaccine confidence. Brewer NT, Chapman GB, Rothman AJ, Leask J, Kempe A. Increasing Vaccination: Putting Psychological Science Into Action. Psychological Science in the Public Interest. 2017 Dec;18(3):176.
Quality of Vaccination Registry	Rate of Vaccine Completion		Hill, D. R., Ericsson, C. D., Pearson, R. D., Keystone, J. S., Freedman, D. O., Kozarsky, P. E., … Ryan, E. T. (2006). The practice of travel medicine: Guidelines by the infectious diseases society of america. Clinical Infectious Diseases, 43(12), 1499–1539. doi:10.1086/508782
Influence of Anti-vaccine Movement	Parental Hesitancy		Davies P, Chapman S, Leask J. Antivaccination activists on the world wide web. Arch Dis Child 2002; 87:22–5; PMID:12089115; http://dx.doi.org/10.1136/adc.87.1.22
Indirect costs of Vaccines	Adherence to Vaccination Programme	Opposite	From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Range of Moral Sphere	Vaccine Complacency		Someone with a high moral sphere, who might consider all living beings as being ethically important to them, would also be highly likely to be vaccine complacent in order to prevent vaccine-preventable illnesses and to contribute to herd immunity. Someone with a smaller moral sphere might be less likely to be vaccine complacent as they would be more likely to succumb to concerns about vaccine side effects or may not be personally interested in vaccinating themselves. Based on the definition of the moral sphere.

			Moral sphere: The range of who you consider within your ethical sphere. The lowest is egoism, the mid-range is family or nationality the further extreme is all animal life and the furthest extreme is pantheism. This is meant as purely descriptive and not intended to bias one range over another. If one does not consider certain people within their moral sphere then appeals for the health of other people are irrelevant for the individual.
Individual Nation-States Vaccine Budget	Privatization of Clinics	Opposite	From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Concern about side effects	Confidence in Omission Bias		Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. Pediatrics 2006; 117:1532–41; PMID:16651306; http://dx.doi.org/10.1542/peds.2005-1728 Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, et al. Omission bias and vaccine rejection by parents of healthy children: implications for the influenza A/H1N1 vaccination programme. Vaccine 2010; 28:4181–5; PMID:20412878; http://dx.doi.org/10.1016/j.vaccine.2010.04.012
Quality of logistics infrastructure	Quality of Health Care Infrastructure		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Valuation of Personal Health	Vaccine Complacency		Logical step, someone who highly values their personal health would be more likely to also comply with vaccinations. Thus, when the valuation of their personal health increases, so does their likelihood to also be vaccine complacent.
Length of Vaccine Tender	Price of Vaccine	Opposite	From an interview with a professor of vaccinology at Katholieke Universiteit Leuven.
Stability of Government	Quality of logistics infrastructure		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Predictability of Vaccine Demand	Incidence of vaccine stockouts	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Access to Vaccines	Vaccine Convenience		Logical Step: Insofar as Vaccine convenience is defined by the degree in which vaccines are accessible in a given locale (i.e. convenient when accessible inconvenient when inaccessible) it only follows that the access to vaccines would directly impact this.

Socio-cultural Morality Scale	Acceptance of vaccination social norms		Socio-cultural morality scale: This is ranging from high number on the scale which is extremely tight-knit and collectivity focused to a low number on the scale which is extremely individualistic. This is following the psychologists Johnathan Haidt's moral reasoning and its relationship to culture. Below is the paper on disgust and its cultural contingency. Based on this definition, as an individual's socio-cultural morality scale increases and they become more focused on the collective well being of those surrounding them, it would be logical that these people are more likely to accept the vaccination social norms of those around them. These vaccination social norms would include the population's beliefs towards vaccinations at that point in time, which would generally be positive towards vaccinations but could also be negative. Thus, as an individual becomes more concerned about the well being of the collective, they would also be more likely to adhere to the beliefs about vaccines around them.
Quality of Health Care Infrastructure	Vaccine Convenience		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Price of Vaccine	Access to Vaccines	Opposite	From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Access to Healthcare	Wait Time for Vaccination	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Vaccine Confidence	Confidence in Omission Bias	Opposite	Logical step. If an individual becomes more confident in the efficacy of vaccines, they will be less likely to rely on omission bias. Omission bias occurs when an individual is more likely to avoid a certain action due to the possibility of negative consequences regardless of the possible consequences that would be a result of doing nothing. Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decisionmaking about vaccines for infants: the importance of trust. Pediatrics 2006; 117:1532–41; PMID:16651306; http://dx.doi.org/10.1542/peds.2005-1728 Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, et al. Omission bias and vaccine rejection by parents of healthy children: implications for the influenza A/H1N1 vaccination programme. Vaccine 2010; 28:4181–5; PMID:20412878; http://dx.doi.org/10.1016/j.vaccine.2010.04.012

Socio-Economic Status of Individual	Health of individual	Same	Krieger, N., Williams, D. R., & Moss, N. E. (1997). Measuring social class in us public health research: Concepts, methodologies, and guidelines doi:10.1146/annurev.publhealth.18.1.341 Bloom, D. E., Canning, D., & Sevilla, J. (2004). The effect of health on economic growth: A production function approach. World Development, 32(1), 1–13. doi:10.1016/j.worlddev.2003.07.002
Number of vaccinations	Vaccine Complacency	Opposite	Logical Step: The number of vaccines decreases the prevalence of vaccine preventable diseases in a given population (herd immunity). In addition, a lack vaccine preventable diseases in a given population is a precondition for complacency. (There must be no/limited diseases for a group to not worry about them). Furthermore, Vaccination is the most likely way for this lack to occur. Therefore, Vaccination is the most likely way to achieve the precondition for complacency.
Influence of Anti-vaccine Movement	Confidence in Big Pharma	Opposite	Smith, T. C. Vaccine Rejection and Hesitancy: A Review and Call to Action. Open Forum Infect. Dis. 4, (2017).
Number of vaccinations	Adherence to Vaccination Programme		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa, a global health advisor for European Commission Humanitarian Aid Office, as well as a professor of health economics at Katholieke Universiteit Leuven.
Confidence in Omission Bias	Parental Hesitancy	Same	Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. Pediatrics 2006; 117:1532–41; PMID:16651306; http://dx.doi.org/10.1542/peds.2005-1728 Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, et al. Omission bias and vaccine rejection by parents of healthy children: implications for the influenza A/H1N1 vaccination programme. Vaccine 2010; 28:4181–5; PMID:20412878; http://dx.doi.org/10.1016/j.vaccine.2010.04.012
Amount of anti-vaccine religious beliefs	Vaccine Confidence	Opposite	Those who follow religions that either place restrictions on not receiving vaccines or the beliefs are against them would also be more likely to not be confident in the efficacy of vaccines. Therefore, as the more an individual adheres to religions that deter vaccinations the less likely the individual would be confident in getting vaccines.
Influence of High profile Individuals	Influence of Anti-vaccine Movement		Scherer LD, Shaffer VA, Patel N, Zikmund-Fisher BJ. Can the vaccine adverse event reporting system be used to increase vaccine acceptance and trust? Vaccine. 2016;34:2424–9.

Acceptance of vaccination social norms	Parental Hesitancy		Kennedy A, Lavail K, Nowak G, Basket M, Landry S. Confidence about vaccines in the United States: understanding parents' perceptions. Health Aff (Millwood) 2011; 30:1151–9; PMID:21653969; http://dx.doi.org/10.1377/hlthaff.2011.0396 Liu, Jiming. "A Computational Approach to Characterizing the Impact of Social Influence on Individuals' Vaccination Decision Making." PLoS One 8, no. 4 (2013): E60373.
Emergency Migrations	Economic Prosperity	Opposite	Akanbi, Olusegun Ayodele. International Journal of Social Economics 44, no. 5 (2017): 683–95. Cooper, Richard. "Recent Books on International Relations: Economic, Social, and Environmental: Diaspora, Development, and Democracy: The Domestic Impact of International Migration From India." Foreign Affairs 90, no. 1 (2011): 175.
Vaccine literacy of Parents	Trust in Health Care Workers	Opposite	Opel DJ, Taylor JA, Mangione-Smith R, Solomon C, Zhao C, Catz S, et al. Validity and reliability of a survey to identify vaccine-hesitant parents. Vaccine 2011; 29:6598–605; PMID:21763384; http://dx.doi.org/10.1016/j.vaccine.2011.06.115
Desire to be a good parent	Vaccine Confidence		Shui I, Kennedy A, Wooten K, Schwartz B, Gust D. Factors influencing African-American mothers' concerns about immunization safety: a summary of focus group findings. J Natl Med Assoc 2005; 97:657–66; PMID:15926642
Economic Prosperity	Quality of Vaccination Registry		From an interview with a professor of health economics at Katholieke Universiteit Leuven.
Influence of Anti-vaccine Movement	Acceptance of vaccination social norms	Opposite	Navin, Mark (2013) Disgust, Contamination, and Vaccine Refusal. In: [2013] 3rd Annual Values in Medicine, Science, and Technology Conference (Dallas; 22–24 May 2013) http://philsci-archive.pitt.edu/view/confandvol/confandvol2013avmstcdallas2224may2013.html. URL: http://philsci-archive.pitt.edu/id/eprint/9767 (accessed 2019–02–07).
Access to Healthcare	Access to Vaccines		Logical step. Health infrastructure is required for the ordering and delivery of vaccines.
Confidence of Alternative Therapies	Vaccine Confidence	Opposite	Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Experience with primary care physicans	Trust in Health Care Workers	Opposite	Experiences with primary care physicians had a direct impact on the trust individuals place in health care workers in general. People who had positive experiences were more likely to have trust in health care workers. Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.

Socio-cultural Morality Scale	Individuals range of Rebelliousness	Opposite	Sobo, ELISA J. “THEORIZING (VACCINE) REFUSAL: Through the Looking Glass.” Cultural Anthropology 31, no. 3 (2016): 342–50.
Stability of Government	Emergency Migrations	Opposite	Calderón, Irene Rivera. (2017, May 5). Migration: Causes, Conflict, and Policy Solutions. Retrieved from http://www.saisjournal.org/posts/migration. Ziesemer, Thomas H. W. H. “Developing Countries’ Net-migration: The Impact of Economic Opportunities, Disasters, Conflicts, and Political Instability.” International Economic Journal 25, no. 3 (2011): 373–86.
Rural Births	Predictability of Vaccine Demand	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Presence of Vaccine-related Infrastructure	Quality of Vaccination Registry		Hill, D. R., Ericsson, C. D., Pearson, R. D., Keystone, J. S., Freedman, D. O., Kozarsky, P. E., … Ryan, E. T. (2006). The practice of travel medicine: Guidelines by the infectious diseases society of america. Clinical Infectious Diseases, 43(12), 1499–1539. doi:10.1086/508782
Passive Vaccination	Vaccine Complacency		From an interview with a social scientist specializing in public health interventions and social safeguards, former head of national NGO.
Socio-cultural Morality Scale	Range of Moral Sphere		Socio-cultural Morality Scale being a range from individualist to communal socio-cultural patterns. So seeing communal as high and individualist as low. Range of moral sphere being: a large moral sphere means a larger group of assumed moral actors while a smaller moral sphere entails a smaller group of assumed moral actors. An example: A very large moral sphere including all humans, plants, and animals a very small moral sphere being only a select group of humans worthy as moral actors. (e.g. Aristotle’s specific rational wealthy males). This scale is assumed value-neutral as to which range would be better or worse and is instead meant as an empirical evaluation of the ranges of morals for individuals. It is assumed that these examples are extreme and the exact range of beings people assume are moral agents. This moral sphere can also contain internal hierarchies where ones family or religion may be valued above others but the individual may still consider all of humanity for instance as moral actors. Egoism as the lowest pantheism as the highest.

			Based on these definitions we can see that a social-cultural morality scale that is more individualist would lead to a decrease in range of moral sphere assuming that the range of the moral sphere is impacted by the broader socio-cultural morality scale. We are not assuming that this connection is deterministic and necessarily follows. Rather, that the social pressures of the socio-cultural morality will more often be mimicked in the individuals own moral sphere.
Confidence in Omission Bias	Vaccine Confidence	Opposite	Based on an interview with a single male in his mid-twenties who is vaccine-hesitant.
Belief in delaying vaccinations	Adherence to Vaccination Programme	Opposite	Based on an interview with a single male in his mid-twenties who is vaccine-hesitant.
Economic Prosperity	Socio-Economic Status of Individual		General relation between wealth of society and wealth of the individual Horton, R. (2000). The health and wealth of nations. Science, 287(5456), 1207–1209. doi:10.1126/science.287.5456.1207
Adherence to Vaccination Programme	Vaccine Coverage		Logical step. If more people adhere to vaccination schedules, vaccine coverage then increases as well.
Vaccine Complacency	Vaccine Coverage		MacDonald, N. E., Eskola, J., Liang, X., Chaudhuri, M., Dube, E., Gellin, B., … Schuster, M. (2015). Vaccine hesitancy: Definition, scope and determinants. Vaccine, 33(34), 4161–4164. doi:10.1016/j.vaccine.2015.04.036
Short-term political Goals	Vaccine Literacy of Society		From an interview with a social scientist specializing in public health interventions and social safeguards, former head of national NGO.
Level of Education of Parents	Vaccine literacy of Parents	Opposite	Gust DA, Kennedy A, Shui I, Smith PJ, Nowak G, Pickering LK. Parent attitudes toward immunizations and healthcare providers the role of information. Am J Prev Med 2005; 29:105–12; PMID:16005806; http://dx.doi.org/10.1016/j.amepre.2005.04.010
Incidence of vaccine stockouts	Vaccine Convenience	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Quality of logistics infrastructure	Access to Healthcare		Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Availability of alternative methods of vaccination	Number of shots per visit	Opposite	Based on an interview with a single male in his mid-twenties who is vaccine-hesitant and a professor of health economics at Katholieke Universiteit Leuven.

Localized Clinical Costs	Indirect costs of Vaccines		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Number of shots per visit	Concern about side effects		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Individual Nation-States Vaccine Budget	Length of Vaccine Tender		From an interview with a professor of vaccinology at Katholieke Universiteit Leuven.
Degree of belief in Natural Holism	Confidence of Alternative Therapies		Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Quality of Health Care Infrastructure	Economic Prosperity		Piabuo, S. M. & Tieguhong, J. C. Health expenditure and economic growth - a review of the literature and an analysis between the economic community for central African states (CEMAC) and selected African countries. Health Econ. Rev. 7, (2017).
Individuals range of Rebelliousness	Vaccine Complacency		Sobo, ELISA J. "THEORIZING (VACCINE) REFUSAL: Through the Looking Glass." Cultural Anthropology 31, no. 3 (2016): 342–50.
Degree of Belief in Pseudoscience or Biased science	Influence of Anti-vaccine Movement		Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Incidence of vaccine stockouts	Adherence to Vaccination Programme	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Incidence of vaccine stockouts	Access to Vaccines	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Level of Religiosity	Amount of anti-vaccine religious beliefs		Khan, Muhammad, Umair Ahmad, Akram Salman, Saad Ayub, Maria Aqeel, Talieha Haq, and Noman-ul Saleem. "Muslim Scholars' Knowledge, Attitudes and Perceived Barriers Towards Polio Immunization in Pakistan." Journal of Religion and Health 56, no. 2 (2017): 635–48. Grabenstein, John D. "What the World's Religions Teach, Applied to Vaccines and Immune Globulins." Vaccine 31, no. 16 (2013): 2011–023.

Level of Education of Society	Economic Prosperity		Gylfason, T. (2001). Natural resources, education, and economic development. European Economic Review, 45(4–6), 847–859. doi:10.1016/S0014-2921(01)00127-1
Wait Time for Vaccination	Opportunity Cost for family seeking Vaccination		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Belief in delaying vaccinations	Vaccine Confidence	Opposite	Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.
Opportunity Cost for family seeking Vaccination	Indirect costs of Vaccines		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Degree of belief in Natural Holism	Amount of anti-vaccine religious beliefs		Grabenstein, John D. “What the World’s Religions Teach, Applied to Vaccines and Immune Globulins.” Vaccine 31, no. 16 (2013): 2011–023.
Degree of belief in Natural Holism	Parental Hesitancy	Same	Kata, A. (2010). A postmodern Pandora’s box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Opportunity Cost for family seeking Vaccination	Adherence to Vaccination Programme	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Susceptibility to conspiracies	Confidence in Big Pharma	Opposite	Based on an interview with a single male in his mid-twenties who is vaccine-hesitant.
Level of Education of Parents	Concern about side effects		Opel DJ, Taylor JA, Mangione-Smith R, Solomon C, Zhao C, Catz S, et al. Validity and reliability of a survey to identify vaccine-hesitant parents. Vaccine 2011; 29:6598–605; PMID:21763384; http://dx.doi.org/10.1016/j.vaccine.2011.06.115
Level of Education of Parents	Level of Education of Society		Logical step. If we consider that the parents are individual actors within a society, it would follow that the level of education the parents obtain would have an influence not only on the education of their child but would also contribute to the education level of their society.
Confidence in Big Pharma	Vaccine Confidence		Based on an interview with a single male in his mid-twenties who is vaccine-hesitant.
Economic Prosperity	Access to Healthcare		Krieger, N., Williams, D. R., & Moss, N. E. (1997). Measuring social class in us public health research: Concepts, methodologies, and guidelines doi:10.1146/annurev.publhealth.18.1.341 Retrieved from www.scopus.com

Ability to determine validity of vaccine information	Vaccine literacy of Parents		Gust DA, Kennedy A, Shui I, Smith PJ, Nowak G, Pickering LK. Parent attitudes toward immunizations and healthcare providers the role of information. Am J Prev Med 2005; 29:105–12; PMID:16005806; http://dx.doi.org/10.1016/j.amepre.2005.04.010
Level of Education of Parents	Ability to determine validity of vaccine information		Gust DA, Kennedy A, Shui I, Smith PJ, Nowak G, Pickering LK. Parent attitudes toward immunizations and healthcare providers the role of information. Am J Prev Med 2005; 29:105–12; PMID:16005806; http://dx.doi.org/10.1016/j.amepre.2005.04.010
Access to Health-care	Adherence to Vaccination Pro-gramme		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Confidence in Omission Bias	Parental Hesitancy		Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. Pediatrics 2006; 117:1532–41; PMID:16651306; http://dx.doi.org/10.1542/peds.2005-1728 Brown KF, Kroll JS, Hudson MJ, Ramsay M, Green J, Vincent CA, et al. Omission bias and vaccine rejection by parents of healthy children: implications for the influenza A/H1N1 vaccination programme. Vaccine 2010; 28:4181–5; PMID:20412878; http://dx.doi.org/10.1016/j.vaccine.2010.04.012
Vaccine literacy of Parents	Adherence to Vaccination Pro-gramme	Opposite	Opel DJ, Taylor JA, Mangione-Smith R, Solomon C, Zhao C, Catz S, et al. Validity and reliability of a survey to identify vaccine-hesitant parents. Vaccine 2011; 29:6598–605; PMID:21763384; http://dx.doi.org/10.1016/j.vaccine.2011.06.115
Degree of belief in Natural Holism	Degree of Belief in Pseudoscience or Biased science		"In addition, these parents were not convinced that vaccines worked, stating 'there is no evidence proving vaccine's effectiveness [as a way to prevent disease]' and, 'If immunizations worked, you wouldn't have epidemics.' Rather, relying on natural immunity was a motivation for some parents who believed as this parent wrote that, 'All diseases can be prevented and cured using safe natural means, without resorting to manufactured chemical processes.' Parents also believed that if they used natural methods for boosting the child's immune system, vaccinations were not needed. As stated by several parents, '… I believe [the] body can heal itself' and, 'I know there are other options to prevent disease. I work at a natural health clinic' and, 'I use homeopathic methods to build up my child's immune system (a natural alternative).'"

			Luthy, Karlen E, Renea L Beckstrand, Lynn C Callister, and Spencer Cahoon. “Reasons Parents Exempt Children From Receiving Immunizations.” The Journal of School Nursing 28, no. 2 (2012): 153–60.
Vaccine Confidence	Confidence of Alternative Therapies	Opposite	Kata, A. (2010). A postmodern Pandora’s box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Degree of belief in Natural Holism	Confidence in Omission Bias		Natural holism as conception of nature as an unadulterated whole that functions holistically outside of human development. Omission bias, in this case, being the assumption that avoiding something (vaccines) that has known side affects is inherently safer. This misses the possibility that the results of not doing anything could potentially be worse. So if you assume nature functions ideally or perfectly without human interaction this allows people to more confidently assume that their omission of the dangers potentially associated with side effects of vaccine will therefore be safer. Natural holism provides an increase in confidence for omission bias. (Conclusions drawn based off of an interview with vaccine hesitant individual)
Degree of belief in Natural Holism	Vaccine Confidence	Opposite	Kata, A. (2010). A postmodern Pandora’s box: Anti-vaccination misinformation on the Internet. Vaccine, 28(7), 1709–1716. https://doi.org/10.1016/j.vaccine.2009.12.022
Level of Education of Society	Vaccine Literacy of Society		Van der Heide, I. et al. The relationship between health, education, and health literacy: results from the Dutch Adult Literacy and Life Skills Survey. J. Health Commun. 18 Suppl 1, 172–184 (2013).
Influence of Anti-vaccine Movement	Vaccine Confidence	Opposite	Direct relationship. Vaccine confidence is lowered by increasing influence of the anti-vaccine movement. Brewer NT, Chapman GB, Rothman AJ, Leask J, Kempe A. Increasing Vaccination: Putting Psychological Science Into Action. Psychological Science in the Public Interest. 2017 Dec;18(3):149–207.
Vaccine Confidence	Vaccine Coverage		MacDonald, N. E., Eskola, J., Liang, X., Chaudhuri, M., Dube, E., Gellin, B., … Schuster, M. (2015). Vaccine hesitancy: Definition, scope and determinants. Vaccine, 33(34), 4161–4164. doi:10.1016/j.vaccine.2015.04.036
Rate of Vaccine Completion	Vaccine Coverage		Direct relationship. It would make sense that vaccine completion would lead to an increase in vaccine coverage as well.
Quality of Vaccination Registry	Predictability of Vaccine Demand		Logical Step. While no study inherently states that the quality of vaccine registration impacts the forecasting of vaccine demand. It can be gathered that as this information is key in predicting demand, having a higher quality vaccine registry will improve the accuracy of vaccine demand.

			From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office. Chiu, R., Chang, C. & Chang, Y. A Forecasting Model for Deciding Annual Vaccine Demand. in 2008 Fourth International Conference on Natural Computation 7, 107–111 (2008).
Trust in primary care physicians	Concern about side effects		Gust DA, Woodruff R, Kennedy A, Brown C, Sheedy K, Hibbs B. Parental perceptions surrounding risks and benefits of immunization. Semin Pediatr Infect Dis 2003; 14:207–12; PMID:12913833; http://dx.doi.org/10.1016/S1045-1870(03)00035-9
Trust in Health Care Workers	Vaccine Confidence		Gust DA, Woodruff R, Kennedy A, Brown C, Sheedy K, Hibbs B. Parental perceptions surrounding risks and benefits of immunization. Semin Pediatr Infect Dis 2003; 14:207–12; PMID:12913833; http://dx.doi.org/10.1016/S1045-1870(03)00035-9
Socio-Economic Status of Individual	Concern about side effects		Opel DJ, Taylor JA, Mangione-Smith R, Solomon C, Zhao C, Catz S, et al. Validity and reliability of a survey to identify vaccine-hesitant parents. Vaccine 2011; 29:6598–605; PMID:21763384; http://dx.doi.org/10.1016/j.vaccine.2011.06.115
Vaccine Complacency	Adherence to Vaccination Programme		Logical step. Vaccine complacency leads to an adherence in vaccination programme.
Economic Prosperity	Individual Nation-States Vaccine Budget		Logical step. A nations GDP and goverment structure impacts the way budgets are distributed and therefore how the individual nations vaccine budget.
Incidence of Vaccine-preventable Disease	Economic Prosperity	Opposite	Fonkwo, P. N. (2008). Pricing infectious disease. the economic and health implications of infectious diseases. EMBO Reports, 9(SUPPL. 1), S13-S17. doi:10.1038/embor.2008.110 Ozawa, S. et al. Estimated economic impact of vaccinations in 73 low- and middle-income countries, 2001–2020. Bull. World Health Organ. 95, 629–638 (2017).
Short-term political Goals	Vaccine literacy of Healthcare Workers		From an interview with a social scientist specializing in public health interventions and social safeguards, former head of national NGO.
Confidence in Government	Stability of Government		Government at a glance 2013. OECD 2013
Quality of Vaccination Registry	Demand for Vaccines		From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.

			Chiu, R., Chang, C. & Chang, Y. A Forecasting Model for Deciding Annual Vaccine Demand. in 2008 Fourth International Conference on Natural Computation 7, 107–111 (2008).
Indirect costs of Vaccines	Access to Vaccines	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Emergency Migrations	Predictability of Vaccine Demand	Opposite	From an interview with a professor of operations management and operations research, the logistics coordinator for Southern, Central, Eastern Africa and the Indian Ocean, a researcher of sustainable innovation and customization working on a project in Africa and a global health advisor for European Commission Humanitarian Aid Office.
Belief in delaying vaccinations	Vaccine Complacency		Belief in delaying vaccinations decreases self-efficacy which affects vaccine complacency.
Incidence of vaccine stockouts	Rate of Vaccine Completion	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Local Experience with Pandemics	Incidence of vaccine stockouts	Opposite	Hessel, L. (2009). Pandemic influenza vaccines: Meeting the supply, distribution and deployment challenges. Influenza and Other Respiratory Viruses, 3(4), 165–170. doi:10.1111/j.1750-2659.2009.00085.x
Presence of Health Concepts in Media	Valuation of Personal Health		Hodgetts, Darrin, Bruce Bolam, and Christine Stephens. “Mediation and the Construction of Contemporary Understandings of Health and Lifestyle.” Journal of Health Psychology 10, no. 1 (2005): 123–36.
Number of vaccinations	Concern about side effects	Opposite	Gowda C, Dempsey AF. The rise (and fall?) of parental vaccine hesitancy. Human Vaccines & Immunotherapeutics. 2013 Aug 8;9(8):1755–62.
Degree of belief in Natural Holism	Range of Moral Sphere		Logical Step: If we have defined Natural Holism as a degree in which nature is seen to be valued and interconnected. The highest degree equalling everything in the universe while the lowest degree a monadistic isolationist conception of no interconnectedness. Meanwhile range of moral sphere was defined as high moral sphere being also broadly encompassing while the lowest moral sphere being associated with egoism. Therefore it follows that the higher degree you would consider things interconnected and valuable in themselves the more you would consider them to fall within your moral sphere. Meanwhile the inverse would also be true the less you consider things as interconnected and mutually valuable in themselves the less you would consider within your moral sphere. Further explanation: If ‘A’ considers 1–50 as = to ‘A’ therefore A will value them all at the same level as moral agents.

			If 'B' Considers only 1–10 as equally valuable to itself than only 1–10 could be considered as moral agents. If 'C' considers 1 and not 2–50 as equally valuable to itself only 1 could be a moral agent. These statements are intended as purely descriptive based on the two concepts as have been defined.
Vaccine Literacy of Society	Vaccine Confidence		Johri, M. et al. Association between maternal health literacy and child vaccination in India: a cross-sectional study. J. Epidemiol. Community Health 69, 849–857 (2015). Lee, H. Y. et al. Disparities in Human Papillomavirus Vaccine Literacy and Vaccine Completion Among Asian American Pacific Islander Undergraduates: Implications for Cancer Health Equity. J. Am. Coll. Health J ACH 63, 316–323 (2015).

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Supplement 4: Reference List Accompanying the Kumu Map

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Supplement 5: Video Recording

Link to the video recording of presentation held at the Symposium ‘KU Leuven Facing the Future’, May 8, 2019, Leuven, Belgium: available here.

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Designing Future Perspectives for Dairy Farming in Flanders

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Abstract

This paper provides insight into perspectives for the desirable future of the Flemish dairy industry in twenty years. Globally, the dairy farming sector is facing numerous challenges, from encountering environmental barriers to economic uncertainty, growing consumer awareness and increased availability of technology, bringing both opportunities and threats to the sector.

The dairy industry in Flanders is potentially reaching a threshold where changes in production methods are essential to overcome the aforementioned challenges. With such complex challenges it is essential to include different perspectives. Therefore, we created a transdisciplinary team where all members have different backgrounds, supported by coaches and specialists.

The assumptions on the dairy industry were investigated through literature, stakeholders' interviews, and farm visits. From these insights a system map was

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developed with the intention to develop futures through observing megatrends, trends, and novelties. We imagined the most optimal future around social and planetarian boundaries for some diverse personas, which helped to understand the complexity of future patterns and highlighted topics that needed more in-depth research. Five main topics of the current situation and the desirable futures were discussed: (i) Environmental impact of the dairy sector; (ii) Big and Small farms; (iii) Health and how 'the planetary diet' can be healthier while saving the planet; (iv) Consumer Behavior; and (v) Government Policy. As a result, the future personas are described as motivating why certain perspectives are desirable; perspective from a farmer with a small farm and one with a larger farm. These perspectives could inspire the co-creation of a sustainable future, involving consumers, farmers, as well as industries and policy makers.

Key words

Dairy industry, sustainability, future perspectives, Flanders, wicked problem.

1. Introduction

The dairy industry is facing numerous challenges. Environmental concerns include global warming, water stress, the effect on soil quality, and biodiversity. Socially and economically farmers have a hard time competing with the global markets and suicide numbers are higher than in other occupations (Lunner Kolstrup, Kallioniemi et al. 2013). The dairy industry will have to react to these challenges.

The region of Flanders has its own unique socio-economic and environmental situation. Flanders' soil is exceptionally rich yet may nonetheless be depleted if used improperly. Climate change is predicted to change patterns of rainfall with the potential to bring water stress not only in the form of drought when there is too little water in the summer months, but also a heightened risk of flooding when periods of high precipitation result in too much water. Additionally, farmers must always seek to maintain and improve wastewater treatment procedures and follow Flemish environmental regulations. The small size of Flanders means that the amount of land is limited. Furthermore, the cost of labor is high compared to other countries. These constraints on land and labor will also influence the future change in the farming industry. Flemish culture has the belief that milk is healthy and positive in essence. A well-known Dutch proverb goes *'Melk is goed voor elk'* which means *'Milk is good for all [people]'* in English ("Melk is goed voor elk – Techniek in Nederland," no date, Retrieved July 5, 2019).

This paper reflects the insights and thoughts developed by a team of master's students under the guidance of three coaches. In this paper we will consider parts of the Flemish dairy industry and describe what futures are likely and desirable. The goal of this paper is not to provide a comprehensive overview of the current challenges the diary sector is confronted with. Numerous other papers describe this profoundly and extensively. During this process, as reflected in the paper, the goal was to visualize a realistic future perspective. As the methodology was key in achieving this, a large part of this paper focuses on the process. Next to the methodology, the end result of the thinking process, and some in-depth analysis of the system that was key to formulating this future perspective received all the attention in this paper. For the sake of clarity most background information is to be found in the appendix.

2. Methodology

2.1 Transdisciplinarity

Agriculture, and food in general, is a topic relevant to every discipline. Not only is it highly cultural, it also is an economic activity, shapes the open space, and is both vital for and a threat to the survival of fauna and flora, which in turn influence our future food production possibilities. Any discipline will bring valuable insights to the (farm) table. The task for all disciplines will be the same: rethink the box. What do the predominant principles and insights of your discipline mean for the challenge at hand? Are they adequate, how can they become part of the solution? In this list, only a few disciplines are listed, at random and by no means exhaustively.

All of us, students of the 'Transdisciplinary Insights' Honours Programme (https://rega.kuleuven.be/tdi) and coaches, have different backgrounds: business economics, mathematics, human health, engineering, science in sustainable development, water resource engineering, philosophy, medicine, bioscience engineering, and cultures and development studies.

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How can these disciplines contribute to the challenge:

Science in sustainable development and Cultures and development studies: How can we envision and create a future for dairy farming that is sustainable? How can we meet the needs of the present, without compromising the abilities of future generations? Can we produce milk in a sustainable way? What is the impact of this business on the planet, on people? Should we look at alternatives? Which alternatives would be best? Etc.

Economic Sciences: The emphasis on economic growth and the free market economy shapes the agricultural sector to a big extent. Are these adequate in the light of proposed transition paths? How does the financial sector influence what direction the agricultural sector evolves in and what models we need to evolve toward the proposed transition paths? On a meso-economical scale, how can the local food market influence food production? How can local products and producers gain visibility? How can niches be upscaled?

Water resource engineering, bioscience engineer: What are the newest insights in agricultural studies, what technologies are available, how does farming influence the ecosystem, and what practices are available to optimize this? What are the possible impacts of different technologies and how desirable are they in the face of the proposed future? What are plant-based alternatives and can they be applied in Flanders?

Philosophy: Many aspects of food and agriculture are in fact ethical questions. From animal welfare to the concept of 'enough', philosophy could propose new insights into the problem at hand and the value of different solutions. Only by asking new questions can we find new answers.

Mathematics: How do system elements connect to the bigger system? How do we handle the complexity of interrelated system elements? How do we identify different system elements to take into account when formulating different paths of solution?

Human health engineering, medicine: Does the same amount of milk have to be produced in the future? Are there possible substitutes? Students of biomedical science can contribute in an understanding of the value of milk in a dairy healthy diet, or the consequences of hyper-processed food, or the effect of industrialized food on health, the impact of animal fodder on milk quality, etc.

The **aim of this project** is to converge all the disciplinary knowledge and insights into a shared and thus transdisciplinary future perspective.

Interviews and field visits served to incorporate the views of the stakeholders, and to enhance the understanding of the problem, the dairy farming system, and different paths toward potential solutions. These farmers and interviewees did not participate further in the process.

2.2 Pathways to understanding the system

Before looking to the future and creating sustainable perspectives, it is important to understand the system as it is today. Complex sustainability challenges, of which the future of dairy farming is one, require system thinking, not as a panacea for solving problems, but as a tool to detect, investigate, and focus the problem in order to contribute to a more sustainable approach. Systems thinking is an important phase to get to know, to understand the system and its complexity and to learn to think outside our own box.

Understanding a large and complex system such as 'dairy farming in Flanders' is not easy. We followed different pathways in order to identify the key factors of the dairy farming system, and more specifically the Flemish dairy farming.

2.2.1 Verify assumptions

An assumption is "something that we accept as true without question or proof." It is amazing how many of us believe in assumptions as absolute truth. Assumptions are not facts, but we often make the mistake of treating them as such, and there is the danger that they become etched as a belief. Therefore it is a good exercise to verify assumptions, to investigate them, and to find proof, or not. Meanwhile it is a good exercise to dive into the system and analyze parts of it.

In the problem sketch (challenge document, appendix 1) that was handed out many assumptions were made, such as "consumers demand sustainable products", "suicides are rising among farmers", "milk is not necessary for good health", and others. A list of assumptions was presented for investigation. In order to investigate these, current (and past) literature was analyzed. By doing so assumptions were proven, or not.

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This task provided us with the opportunity to dive deeper into the challenge, the system, and it gave the group a direction from which to perform the research.

Although the process started with this conscious reflection on assumptions made in the problem sketch, throughout the process it became clear that every individual has his own assumptions. As this influenced communication, it would be recommended to repeat this exercise during the process.

2.2.2 Introduction in system thinking

First, the concept of wicked problems was introduced. Complex systems such as the dairy industry in Flanders require breakthrough thinking. It is necessary to keep in mind that such a problem is a challenge that could not be solved in the traditional sense. The system was dissected through some exercises.

First, the most relevant system elements (key elements) were identified and classified via the PESTLE table (political, environmental, social, technological, legal, economic) (appendix 2). The advantage of being a diverse group and having a multitude of perspectives led to a holistic outcome.

In the following exercise, individual elements of the system were identified and the most relevant items of the system were presented as variables that can increase or decrease (appendix 2). Nouns instead of verbs were used to represent the elements, and these items were connected with arrows to indicate links of influence between the identified variables. A positive link from element A to element B does not mean "first A occurs and then B"; instead, it means "when A increases, B also increases." A joint sketch of the system was made that brought the individual insights together and it was conveyed to Kumu, an online tool to visualize complex systems (appendix 3). This sketch was continually updated throughout the research process. The appendix contains the end result, although we understand it is a never-ending story. That is what complexity is all about.

2.2.3 Actor constellation

The actor constellation is an exercise that sorts out the relevance of different actors involved in the challenge. It allowed us to develop a shared picture of who has which role and let us assess which stakeholders needed to be taken into account during the process (Actor constellation, no date, Retrieved December 16, 2019).

By doing the exercise we created an inventory of relevant societal actors connected to the challenge. The challenge was written in the middle of a big flipchart and societal actors were positioned around the challenge. The closer the actors come to the middle, the more important they are for the challenge (appendix 4). This actor constellation was used to determine the interviews of stakeholders later in the research process.

2.2.4 Farm visits

To understand the sector, the research group visited four different farms, from very small to medium, and big; from farms with only dairy production to farms with multiple functions and farms organized as cooperatives. We talked to the farmers, discussed these experiences in the group, and we also discussed them with a farm consultant. It gave us a better look and feel for the sector. The farm visits were real eye-openers; they ensured we became more involved with the challenge and that we were more able to empathize with the complex lives of farmers (appendix 5).

2.3 Start of the future thinking process

2.3.1 Collecting trends, megatrends, and weak signals (novelties) on Pinterest

This phase is about analyzing data. It is important, not only in the process of future thinking to draw and understand the system map, but it is also important to scan mega-trends, trends, and weak signals (Jalonen, 2017).

Mega-trends: are the most mature trends that have an obvious impact across a wide range of sectors and industries (e.g. globalization, Climate change….). Megatrends are changes that impact everyone everywhere. They have been around for decades and will continue to be so. In one of the sessions, we also made a map of these megatrends. (appendix 6)

Trends: are underlying patterns of change that have a relatively clear direction of change. They are changes in people's behavior, practices, attitudes, and values locally and globally (e.g. growing awareness in the field of health, a growing group that avoids meat and dairy, food waste used as animal food…). Trends, too,

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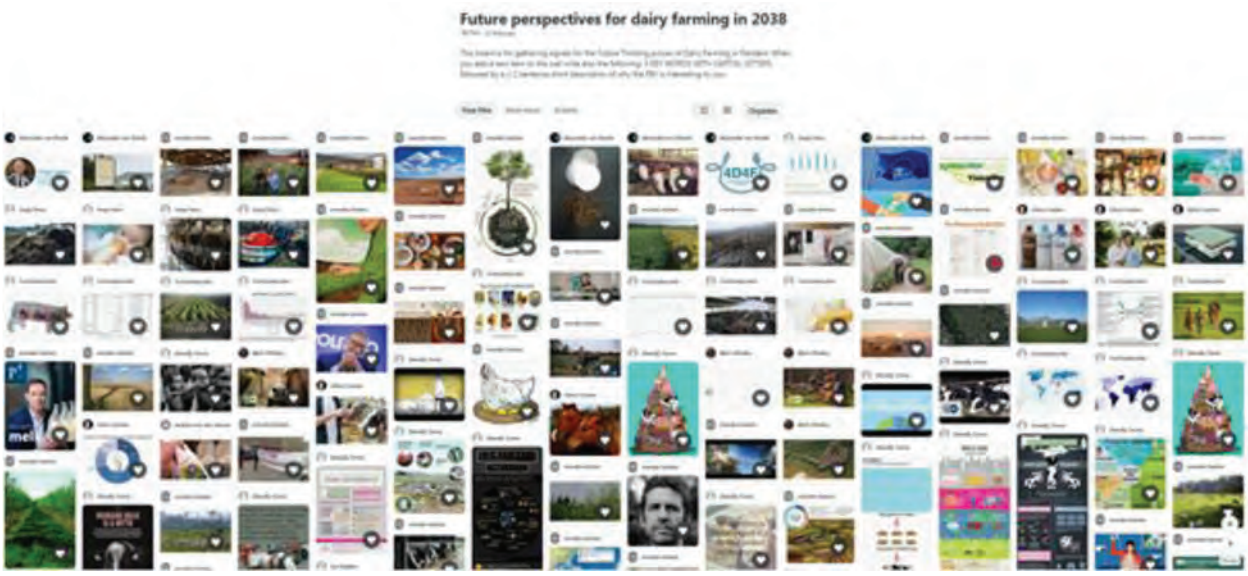

Figure 1. Snapshot of the pinterest board, an imaginative way of collecting mega-trends, trends, and weak signals

already exist and they have a specific direction. However the maturity of trends varies.

Weak signals: are either new, surprising, individual events and issues, referred to as weak signals, or novel manifestations of existing trends (inter alia, electric food, agricultural area as a nature reserve…)

In all the articles (but also visits, lectures) we have been reading we could detect mega-trends, trends, and/or weak signals. We tried to make them more visible and collect important articles on pinterest (Figure 1).

Looking to the future, it is very important to scan literature on weak signals (novelties, innovations, opportunities). These can have a big meaning in the future, so we gave them extra attention. Another important point: we looked system wide, by starting from the different key elements of the system we identified and looking at the Kumu map (explained in 2.2.2).

2.3.2 Creating future headlines

A future headline is a future story, or a story of change about an 'element' of the dairy system. Let us explain more in-depth how we created these future headlines. We call them future headlines because the title can be like the headline of a newspaper (Jalonen, 2017).

In group, we decided to construct 20 future headlines, starting from the key elements we detected (explained in 2.2.2) (appendix 7: example of 1 future headline).

For each key element we looked at the past, the present, and the future and tried to write a story about the patterns, the evolution of change, the change (towards 2039) that we can expect. We used the Pinterest board, but we also kept reading literature on detecting megatrends, trends, and weak signals. We kept adding these links to the Pinterest board.

Important questions we had to ask ourselves: what does the data tell us about the future? Why is change happening? And what is driving this change?

When reflecting upon the future headlines, it might have not been the best idea to research all of them. Time was short and, looking back on the process, fewer future headlines should have been generated.

2.3.3 Interviews

Individuals related to the dairy farming industry and selected as important actors during the actor constellation were interviewed. While we conducted these interviews we tried to fill the knowledge gaps in the system, collected different views on key elements, and different beliefs on how to evolve in the future. We tried to learn from them which trends are relevant and probable, which trends are desirable and why? With this information we elaborated the future headlines.

2.3.4 Personas exercise

Starting from the different future headlines (where we looked at the future we could expect) and all the knowledge we gained, we used a design thinking method called 'a day in the life' for telling the story of different farmers (2) and consumers (2). By using this

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method we tried to design a desirable, sustainable future for 2039 (appendix 8: Sustainability model we based upon). We described the personas in 2019, and looked at them in 2039 (appendix 9: Persona of consumer Sarah). Some questions we asked ourselves were:

2019:
Describe the persona, his/her interests, his/her needs & wishes, his/her challenges & struggles.

2039:
Where do they live in 2039?
What is the best way to reach them? Are they technically challenged?
What personality characteristics do they possess?
What is their environment like? Are they suburbanites? City folk?
Describe their day?
What headlines are important for them as a person?
What does a given future headline means for them in 2039, can we bring on solutions, insights that can make or increase their wellbeing and planet?
What other problems do they have? What specific challenges can you help them overcome?

For some individuals we could easily think about their future, given they have already made steps today to be progressive and sustainable. For one farmer we felt it was a very difficult exercise and we got stuck. It was the persona exercise about a farmer who has 200 cows today. A group of us wanted to see if this farm could grow to 1,000 cows. Another group had questions; is it possible to run it in a sustainable way? And do we want this growth, ethically? Some of us got stuck in their own beliefs (even if they were just assumptions).

We discussed a lot of things. Is it possible in Flanders to have farms of this size? If you mass produce cattle that live in non-free grazing conditions (under roofs, in stables), and if they are then fed 'special' fodder, is it possible to measure the amount of methane produced? Do we want cows to live inside and never go out? How can such a big farm become independent of fodder grown externally?…

You can meet the resulting personas in section 4: future perspectives.

2.4 Wrap-up methodology

In the previous section, the methodology used was extensively described. Due to the complexity of the sector and its challenges, the methodology was key to understanding the system, bringing together the different perspectives from several disciplines, challenging current beliefs, and learning to dream about a future that surpasses the continuation of the status quo. The model of sustainability on which our work was built is described in appendix 8.

The result of the steps taken throughout this process is illustrated in appendices.

3. System analysis

As the goal of this paper was not to describe profoundly and comprehensively the current challenges faced by the dairy sector in Flanders, the problem statement and description of the current state of this sector are very limited. A few system elements, however, are of such paramount importance to the global organization of this sector that this section aims at digging deeper into these selected topics, thus clarifying some central elements that form the basis of the future perspective. On this basis, the future perspective was built.

3.1 Big and small farms

This subsection covers what challenges and opportunities exist for big and small farms today and how they should evolve in response. We emphasize the difference between big and small farms because the significant factors are different, which implies that the evolution of these farms will also differ. The different farm sizes offer unique social, political, economic, and environmental challenges and opportunities that will impact stakeholders. On the other hand, the different types of farms exist in the same society and will therefore be forced to share several key factors such as the political atmosphere and the climatic conditions. Also, farms are moving toward these opposites and away from mid-sized farms in a trend called the disappearing middle. (Poppe, Krijn, et al, 2005)

We start this section by contextualizing big and small farms in the global context. Thereafter we will discuss how we perceive the current situation based on our stakeholders and we will provide some future perspective for the dairy industry in Flanders.

3.1.1 Contextualizing big and small farms

A question that needs to be addressed when discussing small and large agricultural holdings is whether or not

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large farms are more efficient than small ones. According to Montgomery (2017) there are three common myths when it comes to modern agricultural production. These are listed as: large-scale agriculture feeds the world today, large farms are more efficient, and lastly the assumption that conventional farming is needed to feed the world.

The first myth assumes that large-scale agriculture is feeding the world today. In fact, family or small-scale farms produce more than three quarters of the world's food, and less than a quarter of the world's food production is derived from large-scale agricultural production. However, it is large-scale industrial agricultural production that feeds the developed world (Montgomery, 2017). There is no doubt that the size of a farm has a significant impact on output and productivity. The challenge is the capability of smaller-scale farms to reach their productivity potential, which is often a challenge in countries that lack the resources to do so (Adamopoulus and Restuccia, 2014). Nonetheless small-scale agriculture can be productive under the right management and environmental conditions (Reidsma and Ewert, 2008).

The second myth assumes that, in general, large farms are more efficient than smaller-scale agricultural production. When it comes to profit production this statement may be true; however small-scale diversified agriculture is capable of producing twice as much food per hectare than large-scale agriculture (Montgomery, 2017). Another point mentioned by Montgomery (2017) is that, properly managed, small-scale alternative agricultural production systems use far less fertilizer, antibiotics, and medication, synthetic chemicals and pesticides than large-scale agricultural producers, which is favorable with regard to the environment and well-being of livestock. Research done on the western and Mediterranean regions of Europe (Reidsma and Ewert, 2008) with regard to the future uncertainties related to climate change found that larger farms in Europe would be inadequately adapted to these changes. It is also important to note that the capability of even the smaller farms to adjust to, and withstand, the adverse impacts of climate change depends on their diversity, efficient management, and adaptive capacity.

The third and final myth mentioned by Montgomery (2017) is the assumption that conventional farming is needed to feed the world. The total opposite of conventional farming, organic farming, has been shown to have lower yields. Organic farming is estimated to be nearly 20% less productive than conventionally grown crops (Montgomery, 2017). However, this 20% estimate is dependent on the farming methods used. When, for example, rotational farming is introduced to enhance the soil's health the productivity of this type of organic farming method is just below 10% less productive compared to conventional crops. A study done on dairy production in rural communities has shown the need for small-scale family-sized dairy farms in order to develop and protect local dairy markets. Family farms contribute to community development on various scales, from economic growth and community interaction to local empowerment (Lauer, 2009).

There are however some contradictions, or debates, when looking at these myths and the critique mentioned against them. There is a lot of research in planning with regard to the downscaling of the agricultural sector, the before-mentioned list of myths stands as just one example. One study done by Born and Purcell (2006) investigated the way in which downscaling and focusing on local production might raise some concerns. According to them (2006) the risk of the local trap is based on the premise that going local is inherently good; although one must take into account the various elements of the local context, namely: ecological sustainability, employment, social justice, democracy, improved nutrition, and food security. Balancing these elements is essential in order for the local ideology to actually be inherently good. If even one of these elements is not fully accounted for, a whole new problem can arise. Born and Purcell (2006) concluded by stating the importance of interaction and agreement between all the actors involved in order to avoid the local trap.

3.1.2 Big farm

Future farms with a herd size above 100 cows may be considered big farms. These farms are faced with a unique set of political, ecological, environmental, and social challenges that will exist in Flanders, Belgium, in 2038. This type of farming may be considered "specialized", with the entire farming operation focused on producing the maximum amount of milk year-round.

The growth in farm size can be explained on the basis of economic factors and historical and cultural roots. Large farms must compete on the market; in order to

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do so they grow to take advantage of economies of scale and to deal with the large capital requirements of technology. Historically this is associated with the period after World War II when the government of the EU decided to manage agriculture using subsidies and quotas to create affordable food prices and avoid hunger for the population (CAP 2017). Culturally, one must consider that the primary metric of success for a farm is how much it produces. Due to the family tradition of farming, the children of dairy farmers will inherit the belief that the farm has to grow. Hence, farmers may be predisposed to favor growth. (Jo Vicca, Interview)

For the same amount of milk a large farm will require fewer cows than multiple small farms. This could be a significant advantage with respect to greenhouse gas emissions and other environmental externalities. However, one should also take into account that large farms are rarely able to source all their feed locally. This may require the farmer to import his feed from other countries, which results in greenhouse gas emissions due to transport and global nutrient flows.

Technology is critical for large farms, as it is necessary in order to remain competitive, and without it it would not be possible to manage a large herd at all. Technology reduces the need to hire extra labor, which is very expensive in Belgium. Furthermore, by using precision livestock farming techniques the productivity and well-being of the animals can be improved. Technology can also help to reduce the environmental impact of these farms, for example by capturing methane or by using the excess manure in a biogas plant to generate electricity. The improvement in the well-being of the animals also means that less replacement livestock must be reared, which is also a significant environmental factor (Source: prof. Tomas Norton). In general, we may expect that a large farm will have a more precise level of control of its animals and environment due to monitoring abilities.

Currently, technology which aims to reduce environmental impacts can come in the form of end-of-pipe solutions instead of real systematic solutions which do not aid a systematic change but make the symptoms less severe (Frondel, Horbach, & Rennings, 2007). For example, using a biogas plant to account for a manure surplus on one farm does not address the fact that the surplus is caused by the large number of cows. Also, one must consider the fact that little nutritional value is left after the treatment. The manure could be used instead of chemical fertilizers on a nearby crop farm which could improve soil quality and thereby help close the nutrient cycle. In practice, the dairy farmer may choose the on-farm solution instead for logistical reasons or because of the difficulties of collaboration. From the farmer's point of view, it may not make economic sense to address the systematic problem unless incentives are provided or the surrounding market is changed. Technology and legislation could help overcome the logistical boundary and facilitate collaboration while taxes, subsidies, and sensibilization of the general public could aid change on the market level.

Increasing technology may reduce the amount of labor which is required. However, the farm's employees have to be skilled. It is possible that there will be a scarcity of skilled laborers, especially taking into account that farming is not seen as an attractive job, which means that technologically skilled employees may prefer other sectors. (Source FFA).

To be competitive a large farm needs to make big investments. These investments generally require a given size of farm to make sense. Hence, the farmer may feel a need to keep growing in order to justify his next investment. This makes it hard for the farmer to change the method of production or reduce the size of the farm because they are stuck in a contract with the bank. Also, the capital investments associated with technology can make farmers reluctant to try it. Technology companies are aware of this problem and are searching for solutions. Firstly, it is expected that the price of technology will reduce because of mass production. Manufacturers have also been experimenting with other business models such as leasing expensive equipment or installing it for free but requiring a subscription fee for access to the data. If these alternative models turn out to be successful that may help with the large capital requirements. However, these alternative models mainly make sense for data-intensive technology and not for one-time investments such as ventilation systems, hence capital requirements are likely to stay high. (Source prof. Tomas Norton). There are, however, alternatives to this difficult challenge facing large farms. As big farms grow, options such as crowdfunding are methods by which these farms can involve customers in their technological advancements. The internet has allowed this type of customer-producer interaction, and big farms, just like any large corporation, will have a "personality" as a method to engage support for capital ventures.

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Large farms are in a weak bargaining position with regard to the processors who buy their milk. The processors are typically large companies and buy their milk from a multitude of different farms. For the farmer, logistics imply that he will sell to only a single company. Because processors and retailers are in this stronger position they can force the farmer to sell his milk at minimal prices. There were even instances when the price of production was higher than the price in the stores. (Source prof. Tomas Norton.) The farmer's bargaining position with respect to the processors could be adjusted if farmers cooperated and bargained together to get better prices. More in the extreme, there are successful examples in the UK (South Caernarfon Creameries) and the US where farmers own the processing company. For farmers to get a better bargaining position they must cooperate, which has been difficult hitherto, partly because of competitiveness.

3.1.3 Small farms

Future farms with a herd size below 50 cows may be considered small farms. Some reasons for a farmer to start a small farm are that they desire more contact with the animals and the customer. Furthermore, they may want to have the freedom to choose how they produce based on their personal values. Because they are closer to the consumer they don't have to conform to the larger market but can choose some specialized ways to produce. Their local consumers will value the produce more since they know it is in line with their personal values and will hence be willing to pay more for it. There may also be a cultural dimension at play. A stakeholder who owns a community supported farm (CSA) mentions that agriculture is part of our culture and finds it sad that this is neglected.

Since small farms alone cannot exploit economies of scale their cost of production will be higher by default. This may increase further because of labor-intensive production methods such as organic farming. On the other hand, small farms may be able to utilize nearby resources to reduce the cost of their inputs. A small farm may be able to use grass from nearby nature reserves or by-products from human food production as feed for their animals. This feed may be less calorific than soy-based foods, but it is less expensive and more sustainable. It is important for farmers to mix energy and protein-rich feeds because the cows need both to produce milk. Furthermore, small dairy farms often grow vegetables and cereals; using their own manure as a fertilizer can make this system more efficient, especially for organic farms which cannot use inexpensive chemical fertilizers. (Jo Vicca, 2019). Small farms may also band together in an attempt to create a niche market in the economy that will allow them to exploit the economies of scale and compete with a larger farm. These farms would likely be situated close to each other in order to share resources and cooperate effectively.

Cooperation between small farmers could help with the logistics of local production. By bundling the produce of multiple small farms they could sell in supermarkets, enabling more customers to buy locally even if they don't have the time to go to the farm or farmers' market.

The capital expense of technology can be hard for small farmers to manage. Cooperation could allow small farmers to buy input and process resources more efficiently. For example, the cooperating local farmers could buy technology together, which would reduce the capital demands of the individual farmer. Furthermore, it could be advantageous for an arable farmer to cooperate with a dairy farmer. Surplus manure from the dairy farm could be used on the arable farm, while by-products from the arable farmer which cannot be used for human consumption could be used to feed the cows.

We hope that advances in communication technology will facilitate more efficient cooperation between farmers in the future so as to overcome logistical barriers to the cooperation. Generally cooperation among farmers would be desirable to give them more bargaining power in the dairy industry.

By specializing in a niche such as organic farming or CSA the produce can be sold at higher prices. A limiting factor is the number of customers who will purchase these niche products, given that the price is higher or there may be more effort required. A consumer may choose to buy products from a small farm anyways because they care about the environment or the local community. Furthermore, some small farms can offer an experience as part of the deal. For example, families who buy at a CSA can take their children to see the cows and to interact with the farmer.

It appears likely that future small farms will still depend on a niche. The future of small farms may hence follow where the customers for these niches go. One possible future niche could be local production or even tourist

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attraction, such as the example of Cow Cuddling in Turnhout. If the government or another instance chooses to actively promote a local label this would push local farmers to produce a diverse range of products, which would discourage monoculture. Furthermore, this could increase the number of customers who buy from small farmers, since they don't have to go to the farmers' market or farm but can get the produce at the supermarket. This may also aid social sustainability and farmer well-being because the farmer can see how he is helping his local community. As stated at the start of this paragraph most small farmers will probably still serve niche markets; however ideally the customer base would grow large enough for the small farmers to be able to outgrow the niches and serve a broader customer base.

3.1.4 Big or small: open question for the future

Although the topic has been widely discussed and researched throughout this process, the question remains to some extent unsolved. For the future perspective the choice was made to include both big and small. However, several questions remain unanswered and opinions continue to differ. This question touches upon normative questions, values, and beliefs, and although there is no evidence challenging our hypothesis that both big and small farms can be sustainable, when picturing both systems the practical implementation of both poses difficulties.

3.2 Planetarian diet

One of the most urgent global concerns is climate change. The food industry and our diet are counted among the causes of climate change. A result of this concern is the planetary diet approach, which was presented by a group of 37 scientists on the EAT-Lancet commission. The planetary diet focuses on two main points: nutrition and environmental impact. The current diet followed by society is not sustainable by reason of different factors such as high fats, sugars, and processed foods, which are associated with different diseases and conditions such as obesity, heart attacks, cancers, etc., which have been indicated as one of the leading causes of death in developed countries. The environmental cost of food is documented. Large agriculture and land-use systems are responsible for up to 30 percent of anthropogenic GHG emissions and about 70 percent of freshwater use. The sector produces the largest share of non-CO_2 emissions, including methane and nitrous oxide from livestock, manure management, fertilizer use, rice cultivation, and agricultural soils. In most developed countries that have a high affinity for processed food, emissions can be attributed mostly to the ancillary stages. Animal-based foods are a major contribution to GHG emissions. Finally, the great waste of food is another important factor to consider. Every year 1.3 metric gigatons (1.3 billion tonnes) of edible food goes to waste, according to a 2017 study from the University of California. Nearly 6.7 percent of all global GHGs come from food waste, according to the UN's Food and Agriculture Organization (Aggarwal, 2018).

The planetary diet, therefore, promotes a balance between what it is necessary to eat to maintain a healthy diet and its environmental cost. Vegetarian and vegan diets have gained popularity with people looking to reduce their carbon footprint and for ethical motivations such as avoiding animal abuse. While these diets manage to mitigate to some extent nutritional and environmental variables, these diets are not suitable for the entire population. Therefore, the planetary diet raises awareness in people so that food consumption is essentially motivated by a nutritional need over a need for consumption, decreasing the consumption of animal products but without limiting them in their entirety.

Specifically, the consumption of milk in the Flemish area is very important. Currently the average daily milk consumption is 245 ml; by 2039 it is estimated that there will be 12,396,000 residents in Belgium, so the demand for milk will be 3,037,020 liters per day. The main reasons that Flanders citizens drink milk are nutritional and cultural. However, most consumers are unaware of the environmental impact of their production and transportation process. These environmental effects will be described in the following sections. The main motivation of consumers for ingesting milk is due to its association with health benefits, which will be described in the next section.

As a result of our literature research we have found that there is a weak signal that shows a growing interest in people being willing to pay a fair price for ethical and socially responsible dairy products. Therefore, a planetary diet would help people to be aware of the true cost of their products by avoiding preferences for products that are preferred by their low economic cost. In addition, the planetary diet involves responsible consumption. This would help prevent people from over-buying and wasting a lot of food.

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3.3 Milk and alternatives

As climate awareness and awareness of animal welfare are rising, and because the incidence of lactose intolerance and milk allergy is rising, there has been an increased demand for the plant-based alternative milks around the world. In this section we will go deeper into the alternatives to cow's milk and the impact on human health. The main questions are if cow milk is actually healthy and what the impact on the environment and health is if we change to plant-based milks.

Cow's milk has been used as an important source of proteins and major nutrients like fat and carbohydrates. Besides, cow's milk contains several micronutrients such as vitamins, essential for the human body, and contains various beneficial anti-microbial proteins.

Despite these advantages, there are also various downsides associated with cow's milk.

First, the raw milk contains various pathogens like Salmonella and E.Coli. Moreover, cow's milk allergy is the most common allergy in infants and children and allergy is rising. With more than 68 percent of people worldwide being lactose intolerant, this is a big issue. 80 percent of people of African origin and up to 100 percent of people of Asian and American Indian origin are lactose intolerant. Thirdly, cow's milk contains a substantial amount of cholesterol and saturated fats, widely known to be detrimental to health in terms of an increased cardiovascular risk. Finally, because of the substantial environmental impact of dairy and because the awareness of animal welfare is increasing, vegetarianism and veganism are becoming more common, especially in western cultures.

The environmental impact of cow's milk is substantially bigger than of plant-based milk in terms of land-use, water-use, and carbon emissions. Producing one glass of dairy milk every day for a year requires 650 square meters of land, the equivalent of two tennis courts, and more than 10 times as much as the same amount of oat milk, according to this study.

Almond milk requires more water to produce than soy or oat milk. A single glass requires 74 liters – more than a typical shower. Rice milk is also comparatively thirsty, requiring 54 liters of water per glass.

However, it is worth noting that both almond and rice milk still require less water to produce than the typical glass of dairy milk. On a more local level, sourcing products made close to home may result in a smaller carbon footprint than products that have had to be transported a long way (Briggs, 2019).

When we compare the nutritional values of cow's milk to those of the alternatives there are some differences worth mentioning. Cow's milk is an important source of protein and essential nutrients like vitamins B2, B12, A, and D and minerals like calcium, phosphorous, potassium, magnesium, and zinc. These components are often, but not always, enriched in plant-based milks. It also needs to be mentioned that the bioavailability and total amount of these components is often lower than in bovine milk.

On average milk contains a lot more proteins than the alternatives (Vanga, 2018). Soy milk contains the highest amount of proteins amongst the plant-based milks, but still substantially less than cow's milk. Almond milk has got a better flavor but the nutrient density and total amount of calories are major hurdles, therefore essential nutrients should be available from other sources in the diet. Rice milk and coconut milk are not ideal as alternatives because of limited nutrient diversity. (Vanga, 2018)

It also needs to be mentioned that the bioavailability of vegetal proteins is less than in animal foods, which means that more vegetable proteins need to be consumed to provide the same amount of aminoacids for the body.

Hence, when consuming almond milk care should be taken that various essential nutrients are available through other sources in the diet in appropriate quantities. Rice milk and coconut milk cannot act as ideal alternatives for cow's milk because of limited nutrient diversity, but they are the options for consumers that are allergic to soybeans and/or almonds.

When it comes to energy, a large proportion of energy in plant-based drinks originates from carbohydrates and sugar, in comparison to fat in cow's milk. In general plant-based milks have a higher glycemic index.

Moreover, plant-based milk contains less saturated and more polyunsaturated fat; this has a positive effect on the LDL cholesterol in the blood, reducing the cardiovascular risk.

Finally, plant-based milk contains various nutrients not found in milk. These include soluble fiber in oat-based drinks, alpha linoleic acid in hemp-based drinks, and vitamin E in almond-based drinks.

All these factors and issues contribute to a rise in the demand for alternatives to bovine milk. Taking all this into account the recommended daily dose of milk and dairy products is limited to 250 grams per day, according to the planetary diet. Plant-based milk can perfectly fit in a balanced healthy diet (Schlichter, 2018;

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Nutritional differences between milk and plant-based drinks, no date, Retrieved May 13, 2019).

3.4 Environment

One of the bigger debates in the agricultural sector that needs to be considered is the conflict that arises between agriculture and the natural environment. Agriculture has been one of the root causes of biodiversity loss, and it was not until relatively recently that this came to public attention. There is no denying our need for agricultural production, as well as our need to conserve our natural resources, the biodiversity that thrives therein and the ecological benefits to be gained, but there needs to be a balance between the two.

There are two popular, yet very contrasting ways to go about this balance. The first is land sparing; this suggests a clear division between agricultural and natural land (Phalan et al., 2011). Through this approach land is used solely for its purpose, whether it is agricultural production or the conservation of natural landscapes. As agricultural and natural activities and objectives are separated, it is often assumed that this approach is the most efficient - however that is not necessarily the case. In a land-sparing system the natural landscapes set aside for conservation purposes often end up as 'islands' between agricultural fields and lack connection with one another. This poses many challenges for biodiversity amongst species but is deemed ideal for higher yields of agricultural production (Phalan et al., 2011).

The second approach is land sharing, where the agricultural land and natural elements function together in this ideally harmonious system, it includes initiatives like agroforestry and organic farming (Phalan et al., 2011). This approach is great for connecting different diverse natural areas, it encourages the integration of nature into agriculture and shifts away from the use of fertilizers, pesticides, and other chemicals; as a result plots of land practicing land sharing are much higher in diversity and may be more productive than land sparing when faced with unexpected changes in climate patterns. Yet, on the other hand, this approach is not as efficient when it comes to agricultural output based on the size of the farm, in many cases the production output depends on scale. Often the scale of operation for a land-sharing-based farm (more organic, agroforestry) requires a much bigger area of land in order to reach the profit (and level of productivity) of a smaller land-sparing farm (use of fertilizer, pesticides...) (Phalan et al., 2011).

The primary environmental concern facing the farmers of Flanders will be global climate change, not to mention the contribution of the dairy industry to climate change with regard to the amount of methane gas emitted from cattle into the atmosphere (Moss et al., 2000). This change will most notably be seen through drought in the summertime (Baguis, Roulin et al., 2009). This drought will primarily impact the production of feed/fodder, but it will also impact practices such as the field application or on-site treatment of waste. For example, anaerobic lagoons may flood from rain storms with higher intensity, posing a danger to the health and safety of urban areas within the watershed of the dairy farm. Two other concerns that are also connected to global climate change are economic health and political legislation regarding climate change. These factors will contribute to issues such as the price and cost of production of a product such as milk and waste such as manure. In the future dairy farms will have numerous issues, and many of these will be traceable back to climate change.

To combat this change dairy farms of the future will need to find alternative methods of feed production. Currently, industrial dairy farms import feed and purchase additives to exert precise control over the herd's diet. Importing feed requires a great expenditure of energy and may produce carbon, depending on the mode of transportation. Waste from these farms is commonly mixed with fresh water and treated on site with an anaerobic lagoon, or dried and shipped outside of Flanders, Belgium. Future dairy farms themselves are expected to consume much less energy sourced by fossil fuels as the grid they are situated on becomes greener. For this reason, the analysis of fossil fuel consumption in this study is limited to the farm itself. It can be assumed that modes and methods of transportation will constantly be improving fuel efficiency and reducing consumption throughout the entire duration of this study.

The small diversified farms of today are feeding cows with the rangeland grasses found on the property in the summer and with cereals grown on site. These farms, such as the small dairy farm visited on the periphery of Leuven, strive for diversity and balance in their production and therefore sell much more than only dairy products. When the cows are roaming during the

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summer season, the waste is deposited on the field. During the winter the waste is collected and distributed to growing operations such as those of the cereals. Regardless of farm size or type, dairy farming is considered to be an intensive form of land use with regard to land degradation and soil health. The trampling of animals exposes bare soil that may be blown away by the wind in dry periods or transported by water in wet periods. Healthy soil serves a reservoir for carbon removed from the atmosphere by grasses and other vegetation. This issue is an area where the dairy industry can be a useful resource in the effort to counter climate change. Innovative grazing methods may be employed with techniques such as the land-sharing form of agriculture which uses crop rotations where land serves multiple purposes for different times of the year or longer depending on the cycle of the farm. Due to the land-sharing approach, more land could be used for food production (e.g. grazing in nature reserves), but under stricter regulations.

It does not matter what size the future dairy farms of Flanders are; farms must seek to close the nutrient loop (very small farms would have to do this collectively), that is an inherent part of food production. All farming operations cycle nutrients and water, and it is impossible to achieve what is known as a 'closed loop' due to the natural element of farming and spatial constraints. The primary way to achieve this ideal is to strive for high diversity in products, either on a farm or in a region where one farm's rest products can be another farm's inputs. When diversity increases the environmental resilience of a farm will also increase. Dairy farms with healthy grazing routines will lead to an increase of biodiversity which is important for maintaining healthy soil. A more biodiverse environment measured by analysis and data collection of species interaction at different trophic levels is important for ecological studies. These studies in the future will also be able to inform farmers' decisions by relating the species interaction to the health of physical environmental factors such as soils' capacity to store carbon.

It is not only the ecological aspects of the farm that can be diversified. Large farms should diversify the type of waste treatment they use to allow for greater efficiency and higher nutrient removal before discharge to the environment. Methods of pre-treatment such as microwave application, ultrasonic treatment, ozone oxidation, alkaline or thermo-alkaline treatment, Fenton process and biological hydrolysis with enzymes (Rani, Kumar et al., 2013) may be considered for these large-scale operations. It is also the larger farms that have more land area and therefore are responsible for the health of large amounts of soil. The ecological studies of future farms will focus on maintaining homeostasis in the environmental condition methods of continuous monitoring for the development of negative feedback loops. Large farms have an opportunity to manage their land holdings in a way to promote carbon sequestration that will have a positive impact on the environmental situation.

Future farms will face challenges never before seen due to the changing climate, but there is much that can be done about it. Three basic groups can create incremental changes sustained over time to realize the optimal future for dairy farms. First, farmers must take steps to diversify their farms, add local feed to the diet of their herds and adopt new technologies for waste management. Second, policymakers should support the infrastructure on farms of all sizes provided it will reduce the environmental impact of dairy farming. Finally, consumers must make environmentally conscious buying decisions.

3.5 Consumer behavior

Consumers hold great power with regard to the products that are being sold at any retail outlet. This, however, is not new information; merchants have always sold products that are high in demand. It was not until relatively recently that there was an emergence of a more perceptive and socio-environmentally aware customer group that demand 'better' food. Here 'better' is associated with the source of production, the methods of production, as well as the distribution and retailing processes. This brought about the increasing trend in product labels such as organic, eco-friendly, fair trade, locally produced, and other sustainable conceptions such as farmers' markets and 'organic-weekly-basket' subscriptions.

The reason for this rise in conscious consumerism is greatly attributed to the awareness of stressing and alarming social and environmental issues such as deforestation, unjust working conditions, climate change, and the cruel and often unethical practices in animal husbandry. These issues are taking place on a global scale, and the whole of the global market system requires a change in order to overcome these socio-environmental and economic challenges. Fortunately,

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the increase in conscious consumerism is slowly pushing toward a more sustainable, socially just, and environmentally friendly global market with the steady popularization of 'fair-trade' products.

However, as mentioned before, these changes are occurring at a slow rate, and are more prominent in countries whose citizens can afford to choose between cheap non-fair-trade products and the often more expensive sustainable option. A study by Hanss and Böhm (2012) explored Norwegian consumers' understanding of various elements of sustainability and how their understanding of sustainability determines their consumption decisions. It was concluded that consumers had quite a high understanding of sustainability and its elements, and when it came to their consumption decisions they opted to choose products that were fair-trade, had recyclable packaging, practiced humane animal treatment, and had a low carbon footprint with low energy use (Hanss & Böhm, 2012). This study done in Norway found that consumers are very familiar with the green or eco-labels on products and do take them into account when choosing to purchase items. However this was the case for Norway; the context for Belgium is quite different.

A study performed with over 800 Belgian respondents by De Pelsmacker et al., (2005) took a similar approach and looked at the awareness respondents had of fair trade products and the willingness to pay for these products. When asked about the importance of purchasing fair trade products and the awareness of harsh conditions imposed upon lower-tier producers in the chocolate and coffee industry, respondents were aware of the unfavorable situations and claimed to support fair trade products (De Pelsmacker et al., 2005). However delving deeper into their investigation, the actual willingness to pay for these fair trade products was somewhat contrasting with their ideological support for fair trade, the average price premium consumer would pay for a product that is labeled fair trade is only 10 percent, compared to the cheaper non-fair trade product off the rack (De Pelsmacker et al., 2005).

This is unfortunately a worrisome truth; products that are mass produced, use cheap labor, and have a larger carbon footprint tend to be the cheaper choice, and even though consumers are aware of the negative elements of these products (De Pelsmacker et al., 2005), they would rather buy the cheaper product and save money. Ehrich and Irwin (2005) call this phenomenon willful ignorance, where the monetary price is of more concern than the social and environmental price, arguing that fair trade products are too expensive. Willful ignorance goes further to explain the perception of consumers, their intentional avoidance of guilt feelings (when not purchasing fair trade) by acting ill-informed, or justifying their actions by claiming their contribution in other areas (cutting down on meat consumption, driving an electric car, etc.). An important factor to point out with regard to consumer consciousness and willful ignorance is the divisions among social classes; some lower class individuals often have no choice but to purchase cheap mass-produced milk, whereas upper class individuals have the luxury of choice, which is where willful ignorance comes into play. Nonetheless, in Belgium there has been a significant increase in conscious consumerism, especially amongst younger and more informed individuals. The country has a much higher level of consumer consciousness than many other European countries, and the trend is steadily increasing (De Pelsmacker et al., 2005).

3.6 Government policy

In this section we describe the current dairy policy. In particular we consider the CAP in Europe and its particular implementation in Belgium. For the sake of perspective we also describe the dairy policies of Canada and New Zealand.

The EU's common agricultural policy, CAP, was founded in 1962 to guarantee food safety and food prices. However, by the 1980s production outstripped demand. In response the EU changed policy. (European Commission 2017) One of these policies was to introduce milk quotas which limited the amount of milk a farm could sell.

The European Union abolished the quota system in 2015 due to the increased export value of dairy products. By removing the quotas the EU hoped that exports might become an opportunity for European farmers. (European Parliament 2015) Due to the removal of the quotas shifts in production to countries with a comparative advantage were expected, and in the period leading up to the removal it was observed that the Netherlands and Ireland expanded and intensified their milk production (Läpple and Sirr 2019).

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The EU's common agricultural policy (CAP) supports farmers and sustainable farming through direct payments, market measures, and rural development measures. Most of the funding (72%) goes towards the direct payments. On average, nearly half of a farmer's income in the EU in the last 10 years has been from the direct payments. (European Commission 2017)

In the proposed CAP for the 2021-27 period there is a moderate reduction in funding due to the UK leaving the union. Some key policy changes include more support to smaller and medium sized farms, a mandatory maximum of EUR 100,000 on the amount of direct payments a single farm can receive. For the environment there will be mandatory requirements, and additionally the farmer can choose to participate in eco-schemes which try to incentivize eco-friendly farming. (European Parliament 2019)

During the 2014-2020 period the CAP allocated EUR 4.2 billion to Belgian farming, of which EUR 3.62 billion is allocated to direct payments. 30 percent of the direct payments budget goes towards greening policies. Flanders and Wallonia have different systems for their agricultural policy. Flanders has implemented an upper limit of EUR 150,000 on the amount of funding an individual farm can receive. Wallonia applies redistributive payments, which means that more funding goes to the first 30 hectares. This policy is intended to support small farmers. (European Parliament 2016)

Similarly to the European quota system the Canadian supply management system came into existence because of overproduction and price instability. The Canadian system has 3 main pillars, namely production control, pricing mechanism, and import control. The production control prevents surpluses or shortages by allocating quotas and imposing penalties for overproduction or underproduction. These quotas are a large asset; on a farm in Quebec with an average of 60 cows the quotas alone are worth CAN$1.5 million. The pricing mechanism entails that farmers are guaranteed a minimum price for their products. This is intended to give farmers a fair price while preventing price fluctuations for the customer. Import control imposes a high customs tariff on imports over a certain amount to prevent foreign products from flooding the market. Tariffs on dairy go up to 300 percent for butter. (Khamla Heminthavong, 2015)

This kind of system also has its downsides just like any other system. For the highly regulated Canadian system the main critics claim that consumers are paying a higher price for their milk in retail stores because of a lack of price competition. However a comparison of prices shows that they do not pay that much more when compared to other countries that do have free market-driven prices (Export Action Globel, 2018). Another criticism of this system could be the fairness of the system; how fair is it to bar entry into the dairy production industry for new farmers? How do you distribute the dairy licenses fairly? However that is a completely different and very complex issue of its own that dives into the underlying motivations behind policies.

New Zealand has a highly liberalized system with no subsidies. Nearly all diary is exported, with less than 4 percent of the milk being consumed within the country. (Shadbolt N.M. et. al., 2016) To understand the current system we must consider how it came to be. In 1984 government support for agriculture was about 30 percent of sales. This directed farmers to focus on goods which received the highest government support. The result was a system with high but inefficient production which was not competitive on the international markets. This agricultural problem coincided with a currency crisis. In response the government liberalized the country, withdrawing subsidies and imposing high interest and exchange rates. Initially this had a severe effect on the farmers, but currently New Zealand has become a highly competitive producer on the international market. (Evans, L. 2004)

Another feature of New Zealand's system is that cooperatives account for nearly 95 percent of New Zealand's milk production with the Fonterra Co-operative alone accounting for about 85 percent of the milk production (Shadbolt N.M. et. al., 2016). The establishment of Fonterra was enabled by the Dairy Industry Restructuring Act of 2001. To address concerns about the competitive effect of the merger there were a number of constraints imposed on Fonterra, the primary constraint being called 'open entry and exit'. This means that Fonterra has to accept all milk supplied by any dairy farmer who holds shares in Fonterra in proportion to their milk supply. Also, Fonterra has to ensure that the terms of supply to new farmers are the same as those to existing farmer shareholders with similar situations. Farmers are allowed to supply up to 20 percent of their weekly production to another processor and are allowed to leave the Co-operative if they wish. ("Industry Regulations," no date, Retrieved June 30, 2019)

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New Zealand's competitive dairy industry does come at an ecological cost. The 2002 'Dirty Dairying Campaign' addressed the declining health of the freshwater of New Zealand. The problem was acknowledged and addressed in the Dairying and Clean Streams Accord of 2003 and was renewed in the 2013 Sustainable Dairying: Water Accord. (Holland, P. 2015) Still Foote et al. 2015 claims that the environmental externalities are underestimated.

4. Future perspectives

4.1 The future perspective in 2039

Our ideal future for 2039 is that society is ready to collaborate in making a fairer and more sustainable society. When we analyzed the dairy industry, probably none of us could imagine the scope it has for our society. As a result of our discussions, stakeholder interviews, and final analysis an understanding of the problem is found. We went deeper into different areas which all converge in the view that the current way things are being done is not sustainable, and if we continue down this path the future that awaits us is not promising (Rosenthal, Elizabeth 2007).

Our ideal perspective is based on achieving harmony between all elements, i.e. consumers, producers, animals, and our environment, basing our decisions on social and environmental boundaries. The big challenge for 2039 is that Flemish residents should ideally become aware of the fact that what food they consume has economic and environmental costs. This is crucial. Currently there are people trying to contribute to environmental impact mitigation by being vegan or vegetarian. However, we think that the ideal of everyone following a vegetarian or vegan diet is neither feasible nor realistic. Rather, it would be more realistic and desirable for each person to freely adapt their diet according to their culture and their own motivations.

The planetary diet serves as an example of an ideal future global diet, where there is a balance between a healthy diet and the wellbeing of the environment. For the planetary diet to be successful a high level of commitment is required from consumers to evaluate and know their environmental impact so that their consumption decisions are not based on a wrong monetary model (e.g., low milk prices alone), which disregards sustainability at its own peril. In this way, it is possible to achieve an equilibrium if individuals who consume a large quantity of milk are conscious of their consumption, and in so doing compensate for their impact in other ways such as using sustainable transport, decreasing their electrical consumption, eating less meat, and so on. Another important factor to consider is that by 2039 animal milk substitutes are expected to increase their market presence, offering different alternatives as well as different kinds. For example, an increase is expected in the customization of attributes such as size and taste that meet individual nutritional needs using different ingredients to make them look like milk (e.g., cockroach milk). Diseases such as obesity, heart disease, and cancers will be mitigated through nutritious products that motivate the consumer's decision to opt for healthy options.

We imagine that by 2039 Flemish residents will be aware that food is a scarce resource when produced in a non-sustainable and non-environmentally friendly way, which can deplete environmental reserves. Accordingly, this dream entails a future where responsible consumption is essential, avoiding the over-purchase of products which might later be wasted without consideration. On the one hand, consumers will establish closer relationships with milk producers, requiring them to meet their demands by paying a fair price for the milk and purchasing a quantity of the product according to their needs. On the other hand, producers knowing their customers will be able to estimate how much milk must be produced to avoid the overproduction that might be wasted. The currently existing commercial scenario forces many producers to reduce costs, even if it means producing in an unsustainable way and involving the violation of animal rights. That is why by 2039 we would like Belgium's governmental policies to starkly discourage products that opt for productive processes that do not ensure sustainability. In this way competition between sustainable products can become efficient, contrary to unsustainable production, for it would run counter to the standardized competitive advantage (i.e., sustainability).

Within these strong cultural and governmental foundations, Flemish producers will be free to choose how their milk is produced. Land will be the limiting factor to herd sizes and due to technological advancement, sustainability and ethical considerations are achievable goals for both small and big farms. We hope this option will give them freedom to produce in

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small or large quantities. Sustainable production is the new concept of efficiency and competence. By having a society that appreciates the effort to produce sustainable products, the farmers will receive a fair price, preventing many producers from shutting down because they cannot compete with larger companies. In our scenario, by 2039 the dairy industry will have big and small farmers who are part of the community, i.e. producers know their consumers, their demands, and their requirements in order to give a personalized service. These big and small farms would operate with the premise of land sharing, where the demand for dairy and meat products is lower than ever, so that farms are not pressured to mass produce at rapid rates. In addition, Flemish producers would understand that collaboration between them is essential to achieve fair prices and that they adapt to the requirements established by society and government. In this way, they get a relationship where everyone wins, because the farmers can profit from their products without risking their physical and mental well-being (e.g., suicide rates will decrease) as is the case with the current competitive market.

Concern for the environment will be unanimous in this same dream scenario, i.e. the whole society in a cross-cutting way understands its commitment and responsibility for the care of the environment. During this time human impact on the environment would no longer be avoidable, and maintaining and managing sustainable practices would be of utmost importance. In this context, governments will push for measures that encourage the planting of different native species, and actively worry about deforestation and land use. Producers, aware of their carbon and water footprint, will implement technologies that help make their processes more efficient (i.e., following Kate Raworth's (2017) doughnut approach) and respect the basic conditions of living organisms through the implementation of practices like land sparing/sharing and environmental integrative methods (e.g., agroforestry, wildlife bridges, natural predators to deal with pests...). Complementarily, in this dream scenario the conscious consumer will choose sustainable products and reduce the consumption of those that have an unjustified detrimental impact. This will allow new technologies to emerge around improving process efficiency around environmental constraints. Finally, the use of inefficient and unsustainable models of energy production (e.g., fossil fuels) would be a thing of the past in 2039, where sustainable energy production methods (e.g., air, wind, solar and tidal) are the main sources of electricity. Energy consumption would also be more environmentally consciously driven where the source of energy (e.g., fossil fuels like oil, gas, coal) switched to more sustainable inputs as is the case with electric cars and tractors.

4.2 The future farmer

4.2.1 Arthur Kolost

Arthur's grandfather founded the farm in 1910 and his father developed the farm further into what it is today, milking 200 cows. Arthur is now responsible for the family farm and feels that it should innovate with the times. He is fascinated with technology and tries to stay up to date with all the recent advances by subscribing to multiple technological and agricultural journals. On the farm he is installing milking robots and automatic feeders to be able to produce more with less effort. To justify the capital investments of the innovations he had to double the number of cows on the farm. Negotiating the milk price with the processing company can be stressful because every cent matters and the processing company has a lot of bargaining power. The low milk prices are an important reason why Arthur feels that he has to increase the amount he produces. Taking care of his large farm takes a lot of time and Arthur struggles with his work-life balance, especially considering his newborn daughter for whom he wants to be an involved father.

In the 20 years between 2018 and 2038 a few of Arthur's colleagues left farming and he bought their farms. He is not involved with the day-to-day labor anymore but uses technology and a few employees for this. In fact, he moved away from the farm to the nearby city where his daughter is studying. In the morning he checks his phone and is immediately brought up to date on the production and well-being of his animals. Accurate monitoring of the animals means that he can ensure that they are comfortable so that they can stay in production for longer, which is good for the environment. Arthur and some other farmers founded their own processing company. By processing and selling themselves they can get all the proceeds of their milk. Living in the city facilitates cooperation with the other farmers and meeting with possible business partners who may want to buy the production of the

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cooperative. Arthur also negotiates with human food-production companies to get the scraps which are not usable for human consumption to feed his cows. His excess manure is processed on the farm to produce electricity and extract nutrients.

4.2.2 Eni Gaering

Eni is a dairy farmer with 20 cows and some pigs. Her friends describe her as passionate and caring about animals. These traits led her to become a young farmer, despite having no prior experience or family history of producing dairy. She is part of a cooperative farm that grows vegetables, cereals, and produces milk for 60 to 80 clients per week. Daily she faces a heavy workload and is seeking a suitable work/life balance. Eni is interested in future technologies that could ease her workload and looks forward to the completion of infrastructure projects on the land she works. Eni is the model of a Community Shared Agriculture (CSA) farmer in the present day.

By the year 2038 Eni's life and business will have seen dramatic changes. The advent of new technologies has allowed her to work less, but take on more cows. The herd size has doubled to 40 cows due to the stable demand of a loyal consumer base. The connection between the animals and consumer is strong via the internet and remote sensing. The workload on the farm is shared by some of the more dedicated consumers, which allows Eni to spend time away from the farm educating and training the new generation of farmers. Climate change continues to be the major issue pushing innovation and driving management decisions on the farm. The infrastructure projects started 20 years ago are complete, and have been continuously updated to fulfil government regulations and customer demands. The CSA Eni is associated with continues to be a model for small-scale dairy farming in the year 2038.

4.3 The future consumer: Sara Leef

Sarah is a rebellious teenage girl, fortunate to be born into a rather wealthy family. She grew up at her parents' house in Tervuren. Her parents are very spiritual people, and brought Sarah up in a spiritual, environmentally conscious manner. Her father is a lawyer who has his roots in Freetown, Copenhagen. Her mother is a real-estate broker from Kinrooi, Limburg. Sarah has a rebellious nature; she is a proud vegetarian. She often attends environmentally related protests with her parents and is generally involved in activism. In her free time she enjoys acting, indoor rock climbing, biking with the family on sunny days and buying fair trade products online. Still she is scared about what the future will hold for society and the environment. Her parents are very proud of her. Sara has a rebellious nature that makes her somewhat unpopular with peers who do not share similar beliefs with regard to vegetarianism and social ideals. She is also a somewhat attention-dependent millennial, online and offline; however her image still greatly depends on the likes she has on instagram. With regard to her health; Sarah requires a variety of food supplements to support her growing body. There are nutrients that are not abundant in her vegetarian diet. These additives are expensive, yet necessary for her to maintain a healthy lifestyle.

By 2038 Sarah is an architect who designs eco-friendly buildings. She works from her house in Ghent, which she shares with her partner Chad and their two children. They do not own a car and rely solely on bicycles and public transport. They also started a roof-farming initiative in their neighborhood, where they built vegetable gardens alongside the building's fully equipped and functional solar panels. Sarah does not force her vegetarian beliefs on her children, although she encourages them to eat healthily and tells them about the importance of reducing meat consumption. Her partner shares similar beliefs. However he does not shirk the opportunity to eat a good steak. The family uses cow's milk, although not regularly, and they purchase from a local farm where the children sometimes go and play with the little lambs, piglets, and bunnies. Sarah and Chad always purchase fair trade products and try to live as organically as possible. There are however those times when Chad forgot to get something from the local neighborhood's farmers' market on his way from work, when he would make a quick stop at Carrefour - fortunately Carrefour has a rather extensive collection of eco-friendly products in stock.

4.4 Possible directions for future policies

The earlier sections listed potential directions for the future in the next decades. To move toward any of these futures government policy is required, as it can play a vital role in future developments. Here will be described some possible policies that should lead the

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way toward a more sustainable future and two main scenarios are distinguished. The first scenario is subsidy-based and localized. The other scenario is market-based but is accountable for its externalities. Some policies are applicable in both scenarios and these policies will be discussed first.

Both scenarios can agree that customers should be aware and informed of what they are buying. Hence the government may want to create new labels which convey this information to the consumer. For example, a local label would be of use for small farms. Currently, Flemish culture has a deeply ingrained belief that milk is healthy. The government should establish a commission to research the health consequences of dairy. If the results are negative then the VLAM marketing department should be required to stay away from falsehoods such as 'milk is good for all'. To counteract the cultural belief of the health of milk it may also be desirable to establish a campaign to disseminate accurate information.

To aid in collaboration between farmers it could be possible to have a course as part of the curriculum in some of the educational programs which lead up to becoming a farmer. Also, workshops could be made available to farmers who are already in the field. Farmers can be expected to engage in cooperation only if they know of all the options. Some of these courses and workshops could be for the purpose of introducing technology which facilitates collaboration among the farmers. This could be as simple as showing them what apps exist.

With regard to the weak bargaining position it would be desirable if farmers established cooperatives to sell their milk together. The government could help spread the idea and aid in the starting of these cooperatives, but ultimately the choice has to remain with the farmers themselves.

4.4.1 Subsidy-based and localized policy

The type of policy described here has the goal of maintaining local production of dairy with little export for the sake of the environment and farmers' income, with stable prices for the consumer. The main tools in this approach are government support such as subsidies and government restrictions on the amount of production.

To help with the capital requirements small farms could get assistance in the form of government subsidies for basic farm technology such as tractors, as well as other subsidized inputs like feed, fertilizers, seeds, and fuel. However, subsidies for all these elements are quite idealistic. Small farms should be more self-reliant and therefore must make a convincing case for these subsidies to be issued to them.

To ensure that farmers make a fair income it is possible to keep subsidizing them generally. However, these subsidies should be conditional on the farm's environmental sustainability. Measurements of soil and water quality should be taken before a farm is eligible, and if these environmental measurements are declining then the level of support should reflect this. Subsidies can also be used to reduce the capital requirements of environmentally friendly technology.

Currently, Flanders produces more dairy than is required for our own population. In this scenario export is not desirable because of its environmental impact, hence the amount of production has to decrease. One way to achieve this is by reintroducing the quota system, although the question remains how to determine how the quotas are assigned. One approach would be to base assignment on the amount of production the land can sustainably support. One questionable feature of this approach is that it clearly favors larger farms.

4.4.2 Market-based but accountable policy

The type of policy described here has the goal of a competitive market which is adjusted so that farms and producers are accountable for their externalities. The main tools in this approach are taxes and fines; subsidies are avoided.

The reason to avoid subsidies in this approach is that they distort the markets by causing farmers to prefer whatever is subsidized most. One significant example of this distortion is that it is held that the growing size of farms is at least partly caused by the system of subsidies. In this approach subsidies would be decreased significantly or totally removed. Due to the currently highly subsidized nature of the industry the removal of subsidies has to be done carefully to minimize ill effects to the farmers. For example, farmers could be offered a buy-out if subsidies are removed quickly. Otherwise subsidies will have to be reduced slowly. In any case it will not be possible to avoid farmer discontent in the short term.

The emissions of cows and the import of their feed could be accounted for by taxes proportional to the environmental damage caused. Similarly, export could

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be taxed in proportion to the damage it causes. After these taxes it can be expected that the number of cows and export will tend to be sustainable.

A disadvantage of this approach is that the price of dairy is likely to increase in the short term, which would be damaging to those with the lowest income. The example of New-Zealand shows that the dairy prices decreased again in the long term due to the competitive market. In the short term the taxes and removed subsidies could be used to support the buying power of those who are most disadvantaged by the change.

An issue which this method cannot address on the governmental level is the capital requirements of farming and technology. These are intrinsic to a free-market system and will have to be resolved by loans and investors. Possibly, the government could help to attract international capital by reducing the risk of the investments. However, it is unclear whether this would be a desirable approach.

5. Conclusion

This transdisciplinary research team from the KU Leuven compiled comprehensive research into the dairy industry in Flanders through communication and teamwork. While this team has been striving to include a perspective as diverse as possible, we acknowledge that our work is the result of individual interests and potential biases. We encourage future teams to reflect on their own convictions to reduce bias as much as possible.

The group put forth different hypotheses for testing and sought to prove them by examining scientific literature, visiting farms, and interviewing stakeholders. Next, real world attributes were given to future personas to represent different directions that a wide variety of people may take in future interactions with the dairy industry of Flanders. Finally, five categories were created to analyze and describe possible futures for the dairy industry in Flanders in twenty years. These categories are: planetary health diet, environment, big/small farms, consumer behavior, and government policy. Each of these categories contains opportunities for further research and suggestions for what the future may be. The future is unknown, but with cooperation it can be optimized for all to take part.

The dairy industry is facing various challenges, and is likely to have to overcome even more challenges in the future to reach the point where the industry is just and sustainable. Flanders and its unique socio-economic and environmental circumstances was the central focus of this paper. Starting from the different future headlines and all the gained knowledge, futures were envisioned for various actors and individuals and their relation with the Flemish dairy industry. It enabled us to place ourselves in the shoes of these fictional characters and develop our future scenarios from there.

One of the elements studied was the planetary diet, which has its core in two important factors; nutrition and environmental impact, and seeking the ideal balance between a healthy diet and environmental cost. The current average global diet has proven to be unsustainable, with high levels of unhealthy food consumption, unsustainable and exploitative food production methods, as well as the detrimental impact on the environment. In the research it was found that the dairy industry has negative impacts on the environment, and much of the production is driven by consumer demand. Fortunately a change in consumer behavior can alter the nature of the future Flemish dairy industry. More consumers are requesting more nutritional, sustainable, and environmentally friendly products, which include green-label products and even alternative milk products like soy, rice, oat, and almond.

Modern society was built on agricultural advances. However the agricultural sector poses a great threat to the natural environment. Today, in this time of global warming and environmental degradation, new advances in the agricultural sector are needed. Currently a lot of attention is devoted to finding the optimal sustainable agricultural practice method; this includes approaches such as land sparing, land sharing, and also organic farming. The best model is still a subject of debate. When considering the level of productivity and sustainability between small and larger agricultural holdings it was found that one of the biggest differences (apart from physical scale) is the nature of the value chain. Larger dairy producers often have a weaker bargaining position with regard to the processors who buy their milk, whereas smaller producers often rely on a niche market where the consumers are mindful of the production processes and methods.

In an ideal future scenario the Flemish dairy industry ought to overcome the niche and consist of more small-scale farms supported by the local community, where consumers are able to build a connection with producers. Although large-scale farming will probably not vanish, as it is unfeasible to think that every

consumer will be willing to go to their local farmer for fresh (dairy) products, the remaining large farms would however change a lot in their nature. They would be more environmentally friendly as societal (and environmental) pressures pushed them towards more sustainable production methods (e.g., land sharing, organic farming, species integration, wildlife bridges...).

Consumers play a major role in where we expect to see the future Flemish dairy industry in 2039. It is however difficult to predict what these consumers would be like. Although looking at current trends towards eco-friendly and green label products, as well as the increase in veganism and vegetarianism and the demand for alternative milk products, it can be assumed that the future consumer would be much more mindful of what they purchase and where it comes from.

The future of the Flemish dairy industry is still very unclear. Many elements play a role in how the future would unfold (dairy production methods, consumer behavior, governmental policies, the global market., etc.,). And the direction in which the Flemish dairy industry is going can be assumed from the research done in this paper. However, the consistency of these assumptions will change over the years to come, as new animal rights movements may emerge, changes in policies could occur as well as the rate and intensity at which Flanders would experience the impacts of climate change.

Supplementary material

1. Original challenge document
2. Key elements of the system
3. Kumu map
4. Actor constellation (working state)
5. Farm visits
6. Megatrends
7. Soil as a weapon
8. Sustainability model
9. Persona of consumer Sarah
10. Video of the presentation of the results.

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Supplement 1: Original Challenge Document

FUTURE PERSPECTIVES FOR DAIRY FARMS IN FLANDERS

Key words
Flemish agriculture, Dairy cattle, Sustainable way, Sustainable development goals, Climate, Future thinking, Field visits, Transition support for farms, Animal welfare, Import/Export, Local trade, Income, Traditional vs innovative, Agro-ecology, Milk and nutrition

Summary

FUTURE PERSPECTIVES FOR DAIRY FARMS IN FLANDERS

How will dairy be produced in 2038? Did the increasing sustainability demands of consumers change the face of dairy farming? Where will we buy dairy? Do we still see cows in the landscape? What will farmers earn? What place does dairy take in our diet? How has the sector adapted to climate change? Who holds the power in the production chain? The aim of this challenge is not to guess what the future will look like, but to predict it based on trends, and to choose the most sustainable future and pathways of making that happen. After this process we will decide in group what supporting steps we want to take.

ABOUT YOUR CHALLENGE

NAME OF THE CHALLENGE

Future perspectives for dairy farms in Flanders.

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

A Search for Sustainable Future Perspectives for Dairy Farms in Flanders

To produce one food calorie today we use 7-10 fossil fuel calories, or 24 times less efficiently then in 1940 [1]. One-third of the Earth's land surface is degraded [2]. Agriculture is responsible for over 50 % of the total nitrogen discharge to surface waters in most of Europe, leading to eutrophication of coastal waters and the seas [3]. Globally, the second largest source of greenhouse gas is agriculture (11%) [4].

Furthermore, research in France discovered that farmers are 22% more likely to commit suicide than any other occupation [5]. Despite the lack of statistics for Flanders, estimates point in the same direction.

795 million people still suffered from hunger in 2015 (FAO et al., 2015b), with two billion afflicted by the 'hidden hunger' of micronutrient deficiencies (Bio[di?]versity International, 2014) [6], while the world produces enough food to feed everyone, even 10 billion people [7]. Around 85% of farms worldwide are 'small farms' or smaller than 2ha. They use less than ¼ of the agricultural land, but produce more than half of the world's food. Yet they are under the constant threat of loss of land, have limited access to resources, and are vulnerable to hunger themselves [8]. Contrary to popular belief, the 15% big farms, mainly monocultures using 75% of the farmland worldwide, provide food for only less than half of the world's population.

Following Kate Raworth's Donut Economy, an economy has to be organized between minimum social requirements and maximum planetary capacity. As an economic sector, agriculture is no different. The previous pargraph showed that the current agricultural system crosses both societal and planetary boundaries.

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Flanders is by no means an exception. With a rapidly ageing farmer population, a comparatively low percentage of organic farms, increasing psychological problems amongst farmers, decreasing biodiversity, intensive import and export of agricultural products and an input-intensive farming system, the pressure on both social and ecological boundaries is not to be underestimated.

A number of these challenges are faced by the agricultural sector as a whole. Nevertheless, every subsector faces a specific set of challenges according to its characteristics. In the challenge at hand, the dairy sector is under scrutiny.

The dairy sector is characterized by large investments, costly external inputs like fodder, and extreme price volatility. Furthermore, Flanders faces a manure surplus due to the abandonment of the link between fodder production and the number of cattle on the farm. On the other hand, cattle farming makes for an excellent conversion of grass into edible proteins. These grasslands could play a big role in climate change mitigation and the countering of biodiversity loss.

Another remarkable thing about the dairy sector and milk production is the following. Milk is one of today's staples of the Western diet. But in fact that is only a very recent phenomenon. In Europe and the United States in the 19th Century, the people who were supposed to consume cows' milk regularly were primarily children. Cheese and butter have longer histories as universally consumed goods. For centuries, they have been a good way of preserving milk for later, since both last much longer than fresh milk does. But because of many studies, mainly funded by the powerful dairy sector, and a glorification of the nutritional value of milk in the past (today, the consensus is less sure) we still think of it as a fundamental food even though it is possible to have a healthy diet without milk at all.

Maybe we should dare to ask some fundamental questions like: Could we have wound up drinking something else every morning? A shake of pureed wheat, perhaps? Or a palate-pleasing shot of tomato juice? Or something hyper processed? [9]

The question at hand is the following:

In what direction should this sector evolve if it is to face these numerous challenges?

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?

Numerous solutions or partial solutions have been proposed over the years. Some believe in technological solutions. Others believe in a closer collaboration with nature. Some believe in a mix. Often these proposed solutions are motivated by one ideology or world view. This influences which aspects of the problem are more or less emphasized.

The objective of this challenge is to value each aspect of the problem equally, be it social, economic, or ecological. By looking for the underlying ideology behind different solutions, and taking into account every aspect of the challenge, new sets of solutions can be proposed, breaking loose from the predefined toolboxes. Thus, not only does it become possible to combine partial solutions that have previously been opposed to each other, this mindset also creates the space and conditions to find new solutions.

On the one hand, students should form an image of the most wanted future for the sector, taking into account the insights gathered during the exploration phase. On the other hand, they will develop strategies/tools/materials/networks/…, based on their insights into the needs and characteristics of the sector, to guide individual farms in their transition towards this future.

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[3] file:///D:/gebruikersgegevens/snijdeev/Downloads/EU%202010%20Biodiversity%20baseline.pdf

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Supplement 2: Key Elements of the System

Political	Environmental	Social
- EU agricultural policies - International negotiations - International trade (dumping) (imports) - Policies on carbon/methane?	- Soil - Farming & biodiversity - Farming to deal with pollutants - Drought (water level table)	6. Change of farmer mindset 7. Consumer behavior (health environment, ethical) 8. Knowledge – farmers (connections, agents, products)
Technology	**Economic**	**Legal**
9. Artificial/alternative food/ milk 10. Future tech for farming 11. Cow breed (selection)	12. Market/competitiveness/ changes 13. Farmers' income, sources? PES? 14. Dairy value chain	- Food safety regulation - Animal health/veterinary regulations - Agroenvironmental measures, regulations

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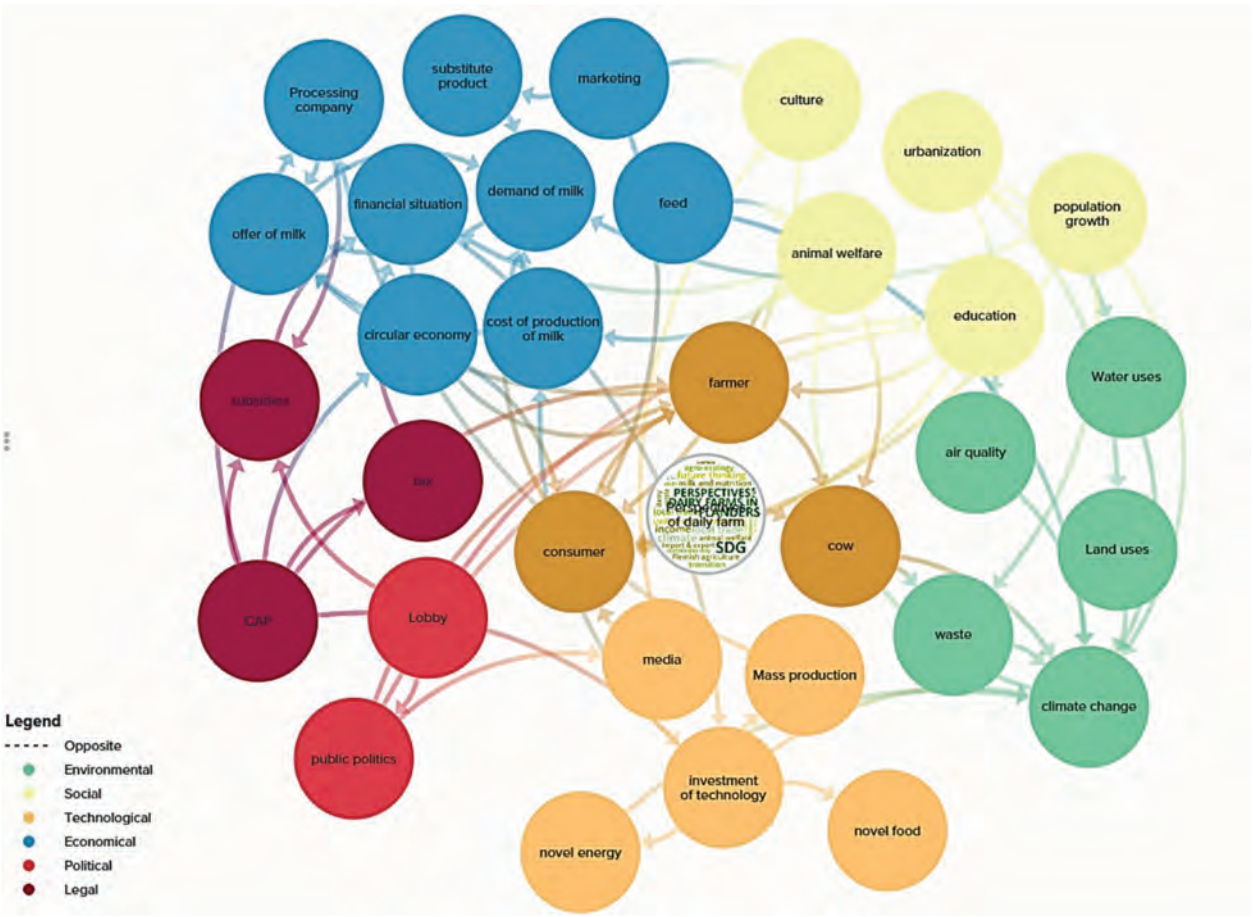
Supplement 3: Kumu Map



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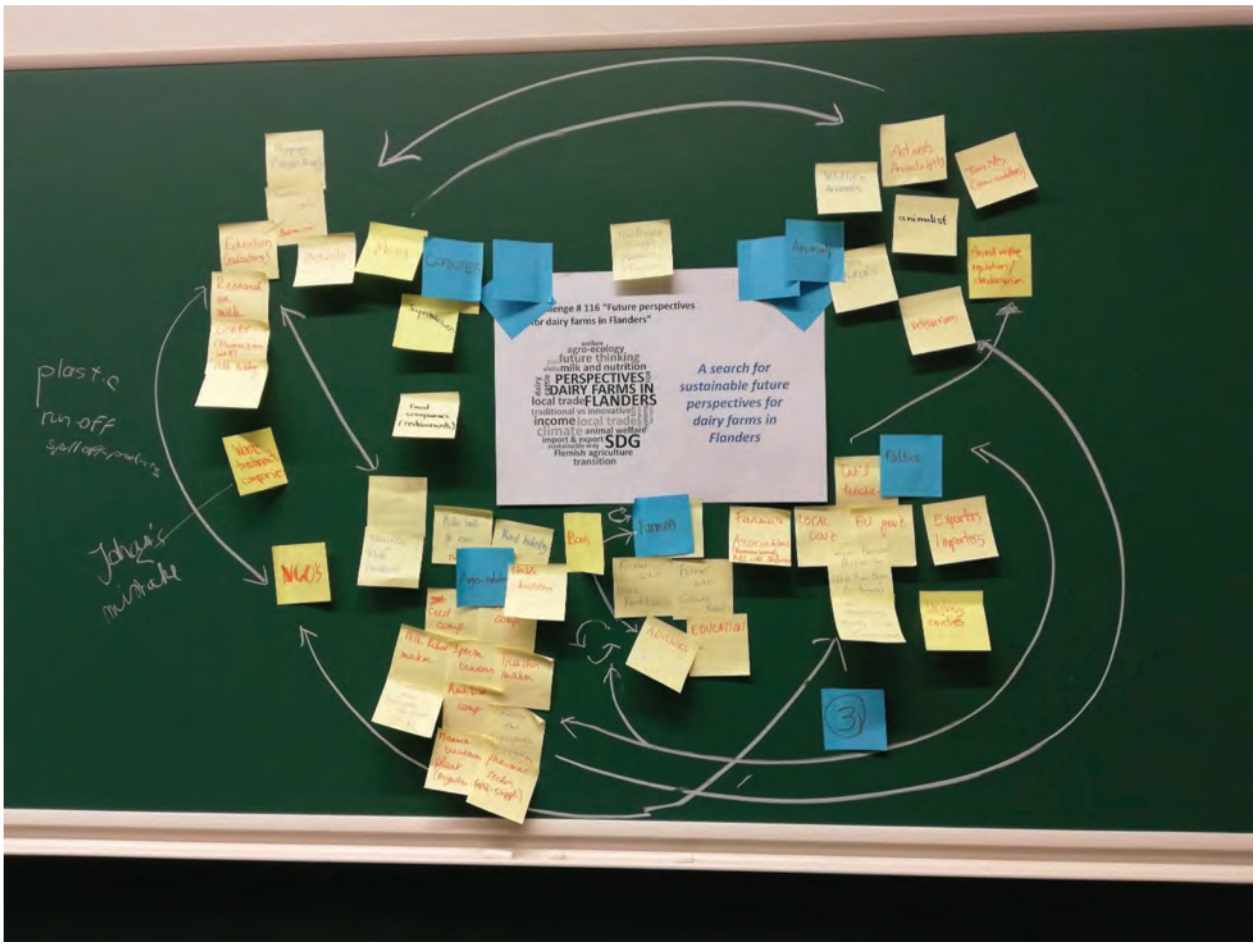
Supplement 4: Actor Constellation (Working State)



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Supplement 5: Farm Visits

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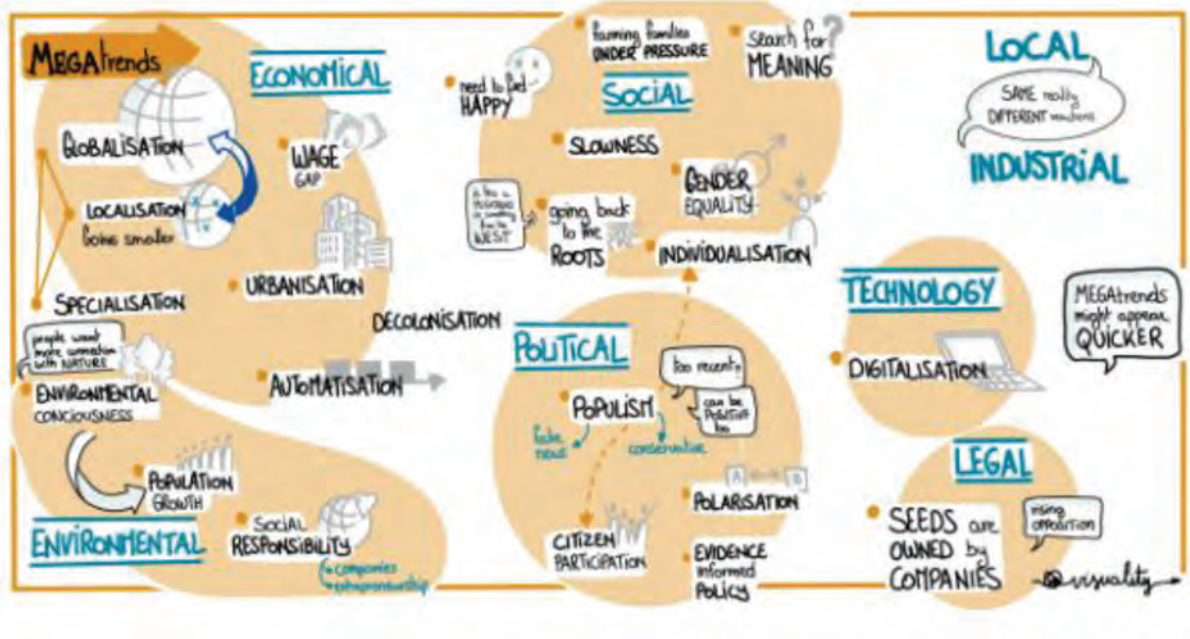
Supplement 6: Megatrends



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Supplement 7: Soil as a Weapon

Soil as a weapon

'Towards a land-based dairy farming that contributes to a vital soil'

Grassland and agricultural soils have a big potential to fix carbon, thereby removing a considerable amount of CO2 from the air.' By boosting the organic matter content in their soil, farmers can increase this potential. And by not tearing grassland (= plowing to grow crops), they prevent existing carbon reservoirs from being released into the air as CO2.

There is still controversy whether the soil that captures carbon will continue to capture it after the soil is getting warmer. Researchers are not sure about that impact. It could also be that these carbon reserves will eventually deteriorate climate change. But still, agriculture and land management practices that increase soil carbon provides many other benefits. Fertile soils produce more food, promote biodiversity, hold moisture better, and are less susceptible to erosion, floods an nutrient loss. More microbes in the soil enable plants to grow deeper root systems that allow them to tolerate drought better, and be more resistant to pests. Enhanced carbon in soils improves soil and water quality. These are all effects that will help society feed the growing global population and be more resilient to the impacts of climate change.

Agro-ecological techniques increase soil carbon. Some are already more or less established (organic agriculture, compost, crop rotation, non-plowing), others are still relatively unknown, such as mixed cultivation or forestry. All these techniques have in common that they store carbon in the agricultural soils.

In order to encourage more carbon storage on dairy farms, it therefore seems that we are going to a future where dairy farms are obliged to maintain a percentage of grassland. In addition, rules will be imposed with regard to soil cultivation, no tillage, rotational grazing, the wider use of catch crops and ground cover plants after one-year cultivation and the wider use of carbon sources from outside agriculture (particularly compost). This measures have positive side effects with advantages for simple soil fertility, biodiversity, water infiltration and tenacious power. However, the applications for this are considerably larger outside dairy farming (in arable farming), with the exception of grazing and adapted grassland management.

Other names of agricultural forms that are related to this are 'carbonfarming' and 'no-till agriculture'.

Driving Forces

Climate change, Growing pressure on business management, animal welfare, Soil degradation, biodiversity loss

Keywords

Soil – Agro-ecology – Climatechange – Carbon - Grassland

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Supplement 8: Sustainability Model

Through this project our transdisciplinary team researched for desirable future perspectives for dairy farming in Flanders. Looking at the social and environmental challenges we face today, it is important to think about how the dairy farming industry can (or should) evolve.

A generally accepted definition of 'sustainable development' is the one launched in 1987 by the World Commission on Environment and Development[3] (WCED), launched in 1987 in the Brundtland report:

"Sustainable development is a development that meets the needs of the present without compromising the ability of future generations to meet their own needs. It contains within it two key concepts: the concept of 'needs', in particular the essential needs of the world's poor, to which overriding priority should be given; and the idea of limitations imposed by the state of technology and social organization on the environment's ability to meet present and future needs" (WCED, 1987, p. 43).

Sustainable development is a compass when we look for answers to complex challenges. Sustainable development comprises three core ideas:

Enough: we must strive to meet the basic needs of every person on this planet (people, planet, and prosperity).

For everyone: everyone in the entire world is entitled to an acceptable standard of living (the space dimension of sustainable development: here and elsewhere).

Forever: The current generation must be careful with the environment and with the stock of natural resources. Let us think about future generations (the time dimension of sustainable development: now and later).

Kate Raworth's Donut model (Raworth 2017) served as a way to describe these sustainable aspirations. The outer edge represents the planetary boundary and the inner edge the social (lower) boundary. Between the planetary ceiling and the social basis there is a space in the form of a donut in which people can shape and grow society safely and justly. In every choice we make on a profit level, we have to take into account the capacity of our planet and of individuals and societies (people). The economic system is embedded in the social system, and these two systems do not exceed the limits of the ecological system. In the 'developed' countries this is not the case now. The economic and social system can only continue to function within a healthy natural environment.

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Supplement 9: Persona of Consumer Sarah

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Supplement 10: Video of the Presentation of the Results

The results of this work have been presented at the symposium “KU Leuven facing the future?”, 8 May 2019, Leuven, Belgium. A video of this presentation can be found here.

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TRANSDISCIPLINARY INSIGHTS E-JOURNAL
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Prosumers Everywhere: Investigating the Driving Forces Behind Prosumer Behavior in Different Socioeconomic Strata

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Abstract

A systematic change towards a circular economy can alleviate some of the problems associated with today's linear economy, such as pollution. In a circular economy products are recycled, repurposed, re-manufactured, re-used, repaired, and upcycled, thereby minimizing the use of materials, devaluation of products, and output of waste. This requires that producers change manufacturing and design, whilst consumers become 'prosumers', more actively involved in prolonging the life cycle of products through applying methods like repair and re-use.

The consumer to prosumer change is urgently needed, given the current climate and pollution problems. To explore this wicked problem and identify how such a change in behavior can be accelerated a transdisciplinary approach is needed. Therefore, a team of students from different disciplines joined forces, engaging stakeholders with various domains of expertise in and outside the context of the city of Leuven. The need arose for more knowledge about prosumer behavior within the diverse population groups in Leuven, and the team focused on the possible relationship between socioeconomic status and certain reasons for prosuming. It felt that the growth model of the linear economy, aiming at increasing consumption, in the context of a growing world population that strives for welfare, is also indirectly related to social inequality. A questionnaire was created together with several stakeholders asking about socioeconomic status, drivers for prosumption - more specifically necessity, information, and awareness - and perceived downsides to prosumption, aimed at the clients of a second-hand store in Leuven. A similar

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questionnaire can be used at other circular economy hot spots in the city, to collect a broad database of responses.

The key to facilitating a transition is to change the behavior, mindset, and attitudes of consumers. The questionnaire was intended to generate a better understanding of why people prosume in certain conditions, and the team assumed this will allow to develop strategies to encourage people to act as prosumers.

Key words

Circular economy, prosumer, pro-environmental behavior

Introduction

Challenge statement

This paper is the result of the work of a team consisting of 5 students, their coaches, and stakeholders. They worked on a challenge from Transdisciplinary Insights, an Honors Program allowing students to tackle problems in a transdisciplinary manner (TDI, https://rega.kuleuven.be/tdi). The challenge concerned drivers for prosumer behavior in the context of a circular economy in the city of Leuven. The challenge document argues that the throw-away economy not only confines consumers to the role of passive users but also limits the circulation of products within the economic value chain. The transition towards a circular economy requires multiple stakeholders to be engaged. Shifting consumers toward prosumers involves systemic and behavioral changes. These changes are known to be slowed down by structural inertia such as consumer habits and stakeholder immobility. However, there are forces that can accelerate the transition.

The challenge is to understand the dynamics for such systemic changes in the lifestyles of consumers, discovering and understanding the pro-environmental behavior and day-to-day decision processes of Leuven-based stakeholders. The challenge was submitted by one of the stakeholders, “Maakbaar Leuven” (https://www.maakbaarleuven.be/), a new organization at the core of a broad circular economic ecosystem. The submitted challenge document is added as suppl 1.

Concepts

We define here the concepts in the way they were used during the research process:

“Consumer”. “A consumer is a person or organization that uses economic services or commodities” Within the context of economies and marketing a person or organization pays to consume goods and services. The consumer is the end user in the chain of distribution (Cross, 1997).

“Prosumer”. The word “Prosumer” combines the words “Production” and “Consumer.” The “prosumer” influences the products created, and actively participates in keeping products in the highest value form for as long as possible. (Gunelius, 2010; Scammell, 2003, Blättel-Mink & Hellmann, 2010).

“Circular Economy”. “A circular economy is one that is restorative and regenerative by design and aims to keep products, components, and materials at their highest utility and value at all times (VITO, 2019).

Prosumers in a circular economy

Our current economic system is thresspassing the limits of our planet. The planet’s resources are becoming more and more scarce as the population’s material consumption and the population itself increase (Jackson, 2011). Next to this, climate and pollution problems caused by the consumption and production of products and materials are harming natural ecosystems including the one we live in. Therefore, an alternative economic system is urgently needed in which economic development is decoupled from linear production practices through the circulating of materials and products that are already present in the ecosystem. This alternative economic system, known as the circular economy (CE), is a system where products and materials are kept at their maximum value and functionality for as long as possible (VITO, 2019). This is contrary to the traditional economic system where the used material is discarded as waste to be burned or dumped (Ellen MacArthur Foundation, 2013). In these final steps the products and materials not only immediately reach their lowest possible values to society but also directly add to climate and pollution problems. An active consumer can save used materials from the waste stream by giving them a second lifecycle. This can, for example, be done by repairing and/or reselling used items. In this cycling of products the value is kept relatively high. This way the product can still add value to society and contribute to GDP growth. These active consumers are called prosumers, and increasing their presence in our society can contribute to increased

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welfare in all layers of society and circumvent the environmental problems of the traditional linear system. However, as stated in the challenge document, structural inertia such as consumer habits and stakeholder immobility can inhibit the proper functioning of the circular economy and prosumer behavior (suppl 1).

How to become a prosumer

The scheme in Figure 1 demonstrates the differences and interactions of the circular economy vs the traditional economy. It also shows the different ways in which a prosumer can give a second life to products and materials. When starting from the bottom, a consumer can become a prosumer by repairing or repurposing a certain product. The consumer can also return the product to the original store, whereupon the product can be resold. However, since not many stores offer this service, this has led to the rise of second-hand stores where products can be resold regardless of their origin. A product does not need to be sold, but can also be given to a person in need of it and so be given a second life. Those cycles usually do not exclude each other but can be found in different combinations and interactions. In the outer two circles, the product can be repurposed, remanufactured, or recycled, but since those extensions are rather too technical for a general consumer, thus not well suited for prosumer behavior, they are considered less important for this research and will therefore not be mentioned again.

Socioeconomic context

Some driving factors that impact the way consumers may engage in more prosumer behavior relate to differences in socioeconomic classes, since different environments created by differences in social classes lead to different needs and expectations. For example, a rich person owns some "positional goods" (e.g. branded clothes or clothes in excess of what is strictly necessary) in order to flaunt his socioeconomic "position" to others. Usually these goods will be bought new as rich people can afford it. A poorer person, however, may lack the financial resources to buy such a product new and will have to repair an old one, or buy it second hand. Even for "necessity goods" (e.g. baby clothes) prosumer behavior differs among socio-economic classes. This way the driving forces will change according to the prosumer's position on the

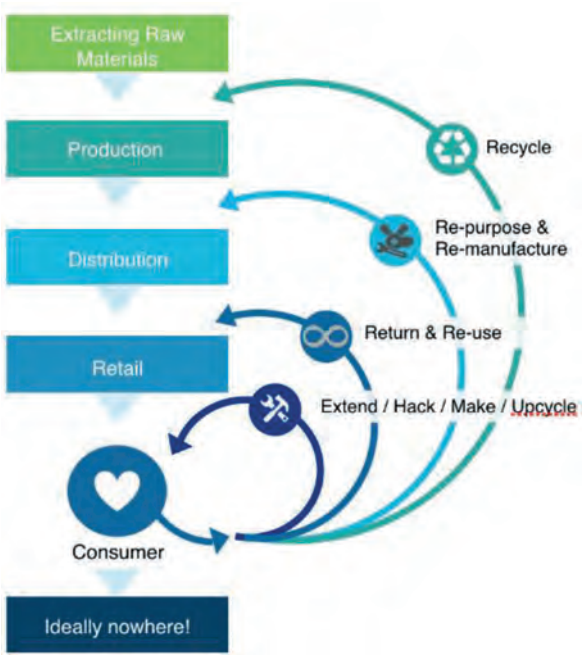

Figure 1. Scheme of the circular economy (IBM, 2019) (Graph reproduced with permission from Eva Heukäufer and IBM)

socioeconomic ladder. The questionnaire is mainly targeted at the socio-economically disadvantaged stratum of the Leuven population, up to the middle class, hereby excluding the rich upper class. It tries to solicit answers by which one could identify how the driving forces change according to socioeconomic class in order to find different strategies to make prosumer behavior more attractive for different target populations originating from different socioeconomic classes.

Hypothesis and research question

Prosumer behavior is already present in the lifestyles of the economically disadvantaged population of our society out of necessity. However, prosumer behavior may transform into general consumer behavior when the economically disadvantaged person escapes poverty. On the other hand, information and awareness about the negative sides of general consumer behavior and the positive sides of prosumer behavior could transform a consumer into prosumer, or prevent a prosumer changing into a consumer when rising in social class. It is unclear whether information and awareness are sufficient as drivers to instigate pro-sumer behavior, or whether other drivers also play a crucial role. We believe that developing a questionnaire that probes these drivers is a step in the right direction.

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Methods

Research process

Assumption analysis

During the planning phase of our project we analyzed the assumptions set out in the challenge document. This part of the process was essential to minimize the risk of building a project based on wrong assumptions. The analysis took place during meetings where team members identified all the assumptions, and on a one by one basis explicitly stated what the inaccuracies or inconsistencies of the assumption were, based on information gathered in the literature. In the cases where the assumption was not deemed well grounded, additional research was needed in order for us to understand the assumptions in the context of our project that was being developed.

Three types of knowledge

The team followed the ten steps of transdisciplinary research (Pohl, 2017) in which they reflected on the three types of knowledge. In this step recent publications on circular economy and pro-environmental behavior were studied (state of the art literature review) in order to form new insights and identify knowledge gaps needed to develop strategies to increase prosumer behavior in the city of Leuven.

Actor constellation

In addition to the assumption analysis an actor constellation exercise was needed to identify implicit biases on each actor's relevance to the project. The team identified actors, labeled local and external stakeholders of the circular economy in Leuven, and jointly decided on an adequate position. The perceived contribution of an actor to the project was expressed as the distance at which the actor was placed from the research question at the center. The actors with the highest stakes were placed closer to the center, while actors with less importance were placed further away from the center of the map.

Stakeholder Meetings

During a stakeholder meeting organized by maakbaar Leuven, the team had the opportunity to discover and interview many of the stakeholders of circular economy in Leuven. The stakeholders were asked to explain the services and products they provide, where they are situated in the city, and what their target population is in order to gain more insights into the current state of prosumer behavior in Leuven.

Results

To explore the wicked problem of changing consumers' behavior to becoming prosumers a transdisciplinary approach is needed, using as its definition the one from the Institute for the Future (https://rega.kuleuven.be/tdi/Home). A team of students from different disciplines (see author list) joined forces, and together performed the assumption analysis, reflected on the three types of knowledge, and performed the actor constellation exercise. They then engaged with stakeholders to try to include their view in the research process.

The assumption that changing the behavior, mindsets, and attitudes of actors in the circular economy was the key to making the transition from consumers to prosumers happen laid the foundation of our hypothesis. This assumption implies that the challenge of the project lies in understanding the conditions and drivers of consumers in regard to dealing with the life cycles of consumer goods.

In the context of the three types of knowledge, to check the current state of driving forces towards circular economy and prosumer behavior in society a literature research was performed using LIMO and Google Scholar. The main focus was put on the most recent articles. The first key word was 'Circular Economy' and led to four useful articles (Table 1). However, only the last two articles mentioned driving forces or barriers to changing consumer behavior. Second, the word 'Prosumer' was searched, but this word did not lead to relevant scientific papers on the topic in the way the word is used in this research. Since more information was needed on drivers toward behavioral change the key phrase 'behavioral change' was added. This led to finding the first source mentioned in the list regarding pro-environmental behavior. Since this seemed to be a relevant article on the subject of 'driving forces towards behavior change', we went deeper into the sources used for this article and the eight most relevant sources were used and served as inspiration for our research. Afterwards, we also found an article on sustainable

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Table 1. List of article titles that were collected for the literature study.

Circular Economy articles:
The circular Economy – A new sustainability paradigm? (Geissdoerfer et al., 2016)
Circular Economy – The concept and its limitations (Korhonen et al., 2017)
Barriers to the circular economy: Evidence from the European Union (Kirchherr et al., 2018)
Consumption in the circular economy: A literature review (Camacho-Otero & Pettersen, 2018)
Pro-Environmental Behavior articles:
The potential of behavioral change for climate change mitigation: a case study for the European Union (van de Ven et al., 2018)
Identifying Barriers and Catalysts to Fostering Pro-Environmental Behavior: Opportunities and Challenges for Community Psychology (Quimby & Angelique, 2011)
Pro-Environmental behavior and public understanding of climate change (Masud et al., 2013)
The dragons of Inaction – Psychological barriers that limit climate change mitigation and adaptation (Gifford, 2011)
Values, environmental concern, and environmental behavior (Poortinga et al., 2004)
It's not (just) "the environment, stupid!" – Values, motivations, and routes to engagement of people adopting lower-carbon lifestyles (Howell, 2012)
Unpacking the relationships between Pro-environmental behavior, life satisfaction, and perceived ecological threat (Schmitt et al., 2017)
Public perception of climate change – Voluntary mitigation and barriers to behavioral change (Semenza et al., 2008)
Environmental concern, attitude toward frugality, and ease of behavior as determinants of pro-environmental behavior intentions (Fujii, 2007)
Sustainable Consumption article:
Low carbon lifestyles: A framework to structure consumption strategies and options to reduce carbon footprints (Schanes et al., 2016)
News articles and opinion pieces:
Blessed are those who are poor because they will save the climate (Malfliet, 2019) (Original: Zalig zij die arm zijn want zij zullen het klimaat redden – DeStandaard.be)
Why people in poverty and young people with migration backgrounds stay away from the climate march. (Marraha, 2019) (Original: Waarom mensen in armoede en jongeren met migratieachtergronden wegblijven van de klimaatmars – VRT.be)
Redefining Environmentalism: The Paradox of Wealthy Environmentalists (Brady, 2016) (Huffpost.com)

consumption leading to low carbon lifestyles using the key word 'Sustainable consumption'. However, next to this some non-scientific articles also caught our eye during the research in the form of news articles and opinion pieces. Those articles mentioned the presence of low-carbon lifestyles in the poorer strata of society, whereas the scientific papers on circular economy and PEB did not mention this aspect.

Performing the actor constellation allowed us to form a representation of what we thought the important actors were. A subsequent stakeholder meeting allowed us to interpret the representation of actors in the Leuven prosumer ecosystem. This stakeholder meet-up, organized by Maakbaar Leuven, allowed us to interview individuals and organizations involved with the repair economy in the Leuven ecosystem. We compiled a list of the interactions we had and located them on a physical map of Leuven. We subsequently used this information and repeated the actor constellation exercise to get a better idea of how the activities of certain stakeholders are linked (Fig. 2). We concluded that there are multiple important connection hubs (local communities, second-hand stores) where the repair economy plays an important role. This observation pushed us forward to further question, without assumptions, what the underlying drivers were of the prosumers involved within these interconnected hubs.

Based on a talk during the stakeholder meeting with a representative of an organization offering circular economy tools to poorer parts of society and based on the news articles and opinion pieces found in the literature research, we concluded that there was a strong representation of actors and stakeholders that focused on facilitating and enabling prosumer behavior in the

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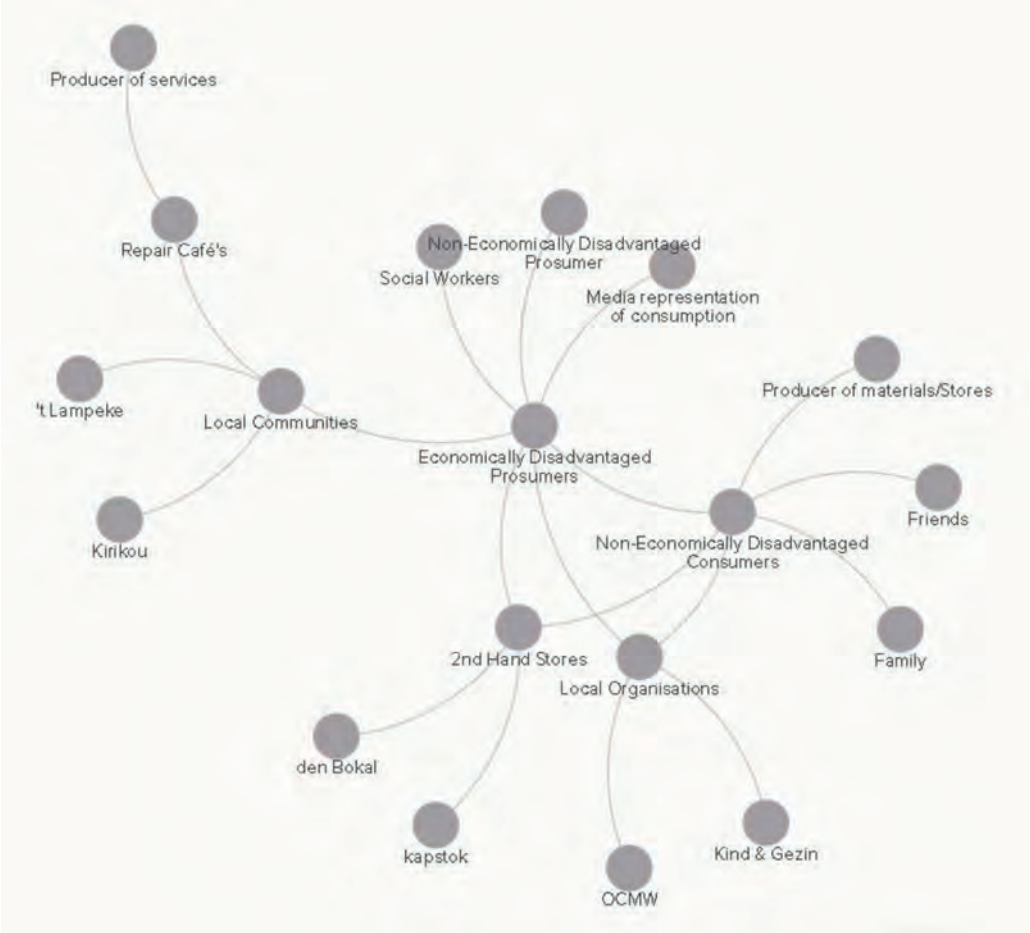

Figure 2. Result from the actor constellation exercise. The actors represented here are those we met during a stakeholder meeting in Leuven organized by Maakbaar Leuven (see text).

socio-economically disadvantaged stratum, followed by the middle class consumers that were already participating in more active and pro-environmental behavior.

However, by reflecting on the three types of knowledge, the team found that the literature generally did not study the presence of circular economy tools or pro-environmental behavior in the poor classes of society, but focused more on the reasons for the absence of circular economy and pro-environmental behavior in the middle class (*Kircher et el., 2018; Camacho-Otero & Pettersen, 2018).* When the authors of those publications examine the 'barriers', 'catalysts', or 'driving forces', they usually do not link the findings to socioeconomic class *(van de Ven et al., 2018; Quimby & Angelique, 2011; Masud et al., 2013;* Gifford, *2011; Poortinga et al., 2004;* Howell, *2012;* Schmitt et al., *2017; Semenza et al., 2008; Fujii, 2007).* Repeating the literature search in Web of Science and Environmental Innovation and Societal Transitions and Nature Climate Change using ""socio-economic status" AND behavior; "economic status" AND behavior AND consumer; did not result in more relevant literature and revealed that most studies focused more on the relationship between circular behavior and attitude toward climate and the general sustainability transition mechanism and the reasons for the absence of pro-environmental behavior.

This way they not only miss the fact that the driving forces can change depending on where a person finds him/herself on the socioeconomic ladder, but also miss why circular economy and pro-environmental behavior can be attractive in some situations.

The need for more knowledge about prosumer behavior within the diverse population groups of Leuven arose, and the team focused on the possible relationship between socioeconomic status and certain reasons for prosuming. It felt that the growth model of the linear economy, aiming at increasing consumption, in the context of a growing world population that strives for welfare is also indirectly related to social inequality. The

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insights we gained from the above-mentioned processes pointed us in the direction of developing a tool that might deliver us valuable information about driving forces of prosumer behavior and its relationship to socioeconomic status.

Based on our literature research, we found our line of research to be new in the sense that behavior change is investigated in relation to socioeconomic circumstances. We wanted to investigate whether there is a relation between socioeconomic class and the driving forces of behavior change of the general consumer who transitions into prosumer, and whether there might be differences with respect to the driving forces related to pro-environmental behavior.

The team opted to develop a questionnaire for various reasons (Suppl 2). Questionnaires can be filled in using an electronic device present on site, making it easily accessible, efficient, and cost-friendly to gather information quickly (Neckebroeck et al. 2018). The gathered information can be transformed into numeric data, which makes it possible to compare different response rates for each answer and statistically analyze the responses, such as determining correlations between responses from different questions. It also allows us to generalize the findings for the entire target population if the sample is representative. We communicated our insights to the public during a symposium (Suppl 3).

A questionnaire can be used to probe whether or not prosumer behavior was (1) based on necessity since prosumer behavior is often cheaper and can therefore lead to monetary savings; (2) based on information and awareness, where the knowledge of the societal costs of general consumer behavior acts as a driver; or (3) based on another driver. Such a questionnaire enables us to relate the answers on driving forces to information about the socioeconomic status of the respondents. This knowledge can then lead to a better understanding of what the main driving forces are that make people exhibit prosumer behavior in each layer of society and if and why these motivations change with social status mobility. It also allows us to develop different strategies in cooperation with stakeholders to change the mindset, attitude, and behavior of consumers in order for them to act as prosumers.

A questionnaire was created based on our interactions with several stakeholders asking about socioeconomic status, drivers for prosumption - more specifically necessity, information, and awareness - and perceived downsides to prosumption, aimed at the clients of a second-hand store in Leuven. We went through an iterative process during the development of our questionnaire, speaking with stakeholders, experts, and citizens, where at each step incremental improvements to the questionnaire were made. A similar questionnaire can be used at other circular economy hot spots in the city to collect a broad database of responses.

Our questionnaire contains two questions that probe qualitative aspects of prosumer behavior (Suppl 2, question 6 and 7 of the 2nd group). The main benefit of questions in free format that can be used for qualitative research is that additional information can be captured that might have been lost with a purely quantitative approach. It is an opportunity to further characterize certain motivations of people. Since quantitative and qualitative research are complementary to each other, combining both into one questionnaire gives us the opportunity to combine the benefits of both types and minimize the drawbacks of using only one type.

To gather the information, random people on site at organizations offering prosumer tools or services in Leuven, e.g. the ‘SPIT’ second-hand store in Leuven, can be interviewed in a systematic way using this questionnaire. The questionnaire contains mainly multiple-choice questions (for quantitative analysis) and two open questions (for qualitative analysis). This resulted in a questionnaire containing 18 questions divided into three groups; 16 are multiple choice, and two are open questions. Every group of questions investigates one driving factor. The first group investigates the socioeconomic status of the respondent in six questions. The second group explores the respondent’s need for the tool/service in nine questions, where it also asks about the advantages and disadvantages of the tool/service in open questions. The last group containes four questions that probe whether the respondent is concerned with ecology and sustainability and whether people in his/her environment support the prosumer behavior or not. The collection of responses of the survey could result in a broad database that can be further analyzed.

Discussion

In an iterative process following feedback from stakeholders, our research aimed to develop a useful questionnaire that can probe the drivers of specific

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participants in the circular economy. With this questionnaire we wanted to probe the validity of our hypothesis, which stated that multiple drivers might contribute to prosumer behavior, more specifically necessity, information, and awareness and socioeconomic status. We intended to develop a set of questions that can characterize each of these drivers as accurately as possible.

Many aspects determine the efficacy of the questionnaire. The types of questions we decide to ask, how they are formulated, the order in which they are presented, the length of the survey, the medium used, and where the survey is conducted all have to be taken into account since all of them have an influence on the result. We designed our questionnaire around the idea of making it accessible and approachable for people from all walks of life. The questionnaire is meant to be deployed at various "prosumer hotspots", such as repair cafés, thrift stores etc. where we can gauge which parameters we need to tweak in response to user feedback. Optimizing the questionnaire for different target audiences will be an ongoing task and is part of a continued iterative process and design.

Trying to understand why certain actors exhibit specific behavior is not an easy endeavor. The current version of the questionnaire is limited by the scope of the three drivers that are being probed. Having too broad a scope would hamper the resolution of each driver. Relating the interacting drivers to the observed behavior would not be possible with too narrow a scope. We argue that developing sets of questions for a limited group of drivers at a time is the compromise that makes the most sense.

Conclusion

We have combined and illustrated the information acquired from assumption analysis, literature research, actor constellation exercise, stakeholder interviews, and iterative feedback sessions. We constructed guidelines for the questionnaire in agreement with research interests and boundaries. These discussions led us to kickstart the development of a questionnaire designed to probe specific drivers related to prosumer behavior, and more specifically how these drivers might change in different socioeconomic strata. We assume that a better understanding of why people prosume in certain conditions could help in the process of developing strategies to encourage people to act as prosumers.

The development of the questionnaire is an ongoing and iterative process where feedback from stakeholders has to be incorporated. Our questionnaire went through one such cycle after direct communication with SpiT (the second-hand store in Leuven), asking its opinion about the questionnaire and whether or not we could eventually deploy it in one of its stores. Its input and cooperation proved to be very valuable in optimizing our questions based on its experiences. Due to time constraints, we could not involve the stakeholders as intensively as we had wanted, given that we were aiming at a transdisciplinary effort.

The addition of a complementary questionnaire that probes the drivers of actors that function as "employees" at organizations that are set up at prosumer hotspots would allow future researchers to better understand the dynamics of the whole prosumer ecosystem. The questionnaire we delivered is still a work-in-progress and still requires multiple cycles of optimization which should be the result of further direct communication with stakeholders, sharing their experiences, and potential feedback from the prosumers contributing to that specific organization.

We believe that a bottom-up approach toward strategies that promote prosumer behavior and prosumer drivers of the actors is a powerful but at the same time practical approach.

Acknowledgements

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Supplementary Material

1. The Original Challenge Document
2. The Questionaire, in Dutch and English
3. Video of the presentation at the symposium "KU Leuven facing the future", May 8, 2019, Leuven, Belgium.

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Supplement 1: The Original Challenge Document

BANK OF TRANSDISCIPLINARY CHALLENGES

HONOURS PROGRAMME TRANSDISCIPLINARY INSIGHTS

NAME OF THE CHALLENGE

How can citizens in Leuven become 'prosumers' in giving a second life to discarded or broken things?

Proposed title

From consumers to prosumers: reducing waste and extending sustainable use of consumer products in Leuven by repair and other strategies.

Main coach:

Jan Larosse/Erik Beatse, manager Maakbaar Leuven

Supporting coach

Prof Karel Van Acker

Key words

Circular economy/transition/consumer-driven/prosumer/repair/Leuven Living-Lab/accelerated obsolescence/citizen science/action research/repair commons/decision making support/data/on-demand spare parts/new business models/taking care of things

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 transition towards a circular economy is a structural change in the organization of material flows (from linear to closed loop, and from flows to stocks), but even more in the organization of economic interactions between producers and consumers. In a consumerist 'throw-away' economy the consumer is limited to the role of a passive user, to which a producer wants to sell as many products as possible. But in a circular economy this consumer will become a more active user who takes care of products in their life cycle, and is encouraged to give them a second life if possible. The evolution of consumer to 'prosumer' (including production activities to assemble, maintain, repair, even co-design) has multiple levers, but the enhanced consumer function in a circular economy is a major one.

The circular economy transition is a process that is slowed down by structural inertia (such as built-in obsolescence in products and consumerism). But there is an urgency to accelerate these transformations because of the impact of materials extraction and waste production on climate change. The adoption of new business models for circular economy such as leasing, that gives all product liability to the producers, can have the disadvantage of maintaining consumers in a passive role instead of mobilizing their creative energy as prosumers. An important lever for change is the position of the consumer of a product as a citizen in a community. His experience with sustainability issues at city level can influence new attitudes. The challenge therefore is to understand better the conditions for systemic changes in the daily life of consumers, dealing with matters of 'life or death' of consumer goods. Concretely: How can citizens in Leuven become 'prosumers' in giving a second life to discarded or broken things?

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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?*

The question is how citizens in day-to-day decision processes for disposal or renewal of consumer goods can adopt more sustainable alternatives such as shared use and repair. What are the drivers for consumers to behave as 'prosumers' and as 'citizens' when making decisions related to consumer goods (and to act accordingly). Some case-studies can be instrumental for this: on electrical devices, on building material, on pharmaceuticals.

Action research on citizen-driven transition activities towards the circular economy should be solution driven. What can work? The practice of Maakbaar Leuven can be a reference. Maakbaar Leuven is a social innovation practice for building a repair ecosystem, using the repair commons as lever.

Indicators on the volume and effects of the repair economy are difficult to define, since a big part is informal economy. However, it is clear that the project finally aims at a considerable increase in the life of consumer goods, and hence a reduction in environmental impact and resource consumption.

The challenge is to discover a common (cross)disciplinary approach that enriches our understanding of prosumer behavior and its activation in a 'Leuven living lab' context. How can citizens in Leuven become 'prosumers' in giving a second life to discarded or broken things?

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 order to answer such challenge for structural change in consumer behavior towards 'prosumer' behavior a multi-disciplinary research approach needed to be developed, including explorative and action research with consumer involvement (citizen science). But to lay the ground of such an integrated approach better understanding of the context of this behavioral change is required:

- What are the structural barriers that in the first place make the average life of products decrease ever more and that limit the role of consumers (information and expertise)?
- What are the specific conditions of daily decision making in Leuven households? I.e.: which are the problems in different categories of things that are broken, worn out, unused; which things are more vulnerable; which solutions are available and how can they be shared in the community?
- What is the present market for repair and re-use services?
- What is the role of new technologies like 3D printing to provide on-demand repair components?
- Which regulations are influencing the design for longer life, repairability, and re-use? What are the legal issues (like liability for repair)?

After stock-taking of what knowledge already exists and what the opportunities for new approaches are, the research will identify the domains, topics, action lines where research can make a difference in accelerating the pace of transition to a new circular economy agency, focusing on prosumer behavior. The focus on the prosumer as agent is studying not only an economic or sociological phenomenon, but also a political subject. It involves thinking about value creation in a wider (philosophical and ethical) dimension. It is about the role of 'commons' (shared knowledge, expertise, and infrastructure) among prosumers in this transition and the role of IP regulations in this agency. It is about prosumer-friendly product design, technology interfaces, and information platforms. But such study of emergent behavioral patterns is also about capturing data on consumer behavior and early signals of changes (data analytics, pattern recognition). It is about a thing-pedagogy of taking care of things as a medium for self-deployment and social meaning.

The challenge is to discover a common (cross)disciplinary approach that enriches our understanding of prosumer behavior and its activation in a 'Leuven living lab' context. How can citizens in Leuven become 'prosumers' in giving a second life to discarded and broken things?

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Therefore many disciplines can be involved from different science groups that are needed for joint solutions (not limitative):

Humanities and Social Sciences Group:

Business and Economics: New models about value-creation and new business models in the frame of the circular economy

Law: Intellectual property in the framework of the circular Economy and specific legal issues and liabilities (e.g. on recovery of sold but unused pharmaceuticals)

Social Sciences and Psychology: consumer attitudes and social behavior towards the circular economy

Philosophy: to contribute about the philosophical foundations and ethical dimension for the challenge

Biomedical Sciences Group

Medicine: Health risks associated with repair (dangerous materials)

Pharmacology: Risks in disposal of medicines

Rehabilitation: Restoring work-life balance and particular disorders (incl. burn-outs) by DIY

Science, Engineering and Technology Group:

Sustainable development: environmental impact of repair and re-use, impact on resource efficiency

Additive manufacturing: 3D printing as a key function for circular economy

IT Platforms: how to organize repair activities, follow up life-times, share repair information

Waste resources engineering: define the best way to dispose safely of broken parts

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?*

Maakbaar Leuven 'Maakbaar Leuven: hier brandt de lamp voor een slimme en circulaire regio!'

Maakbaar Leuven is a new initiative for the promotion of a new repair economy, established on June 21, 2018 in the city of Leuven. It aims at impact at local level with a global vision. It is a partnership of more than 40 organizations that are committed to supporting a sharing platform for repair knowledge, expertise, and infrastructure (such as repair cafés and Fablabs) to enable citizens in the Leuven region to make choices for sustainable repair solutions. This platform is at the core of a broad ecosystem (with 'quadruple helix' approach, involving citizens, research, business, and the public sector in the value chain of repairable goods). The cooperation is based on a Charter and an action plan.

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Supplement 2: The Questionaire in Dutch and English

DUTCH VERSION

Circulaire economie in Leuven

Beste lezer,

Wij zijn vier studenten van KU Leuven die deelnemen aan een onderzoeksproject. Ons onderzoek gaat over circulaire economie en 'prosumenten' in Leuven. Een prosument is een persoon die een product consumeert en produceert. 'Prosumptie' slaat op de praktijk waarbij één persoon bepaalde producten en diensten creëert, en uiteindelijk ook zélf dit product gebruikt. We onderzoeken in ons project hoe men consumenten kan omvormen tot prosumenten, met als doel een meer duurzame en circulaire economie te creëren in Leuven.

We besloten om in ons onderzoek te focussen op het prosumentengedrag bij economisch benadeelde personen in Leuven. Prosumentengedrag is volgens verschillende bronnen reeds aanwezig in de levensstijl van armere personen. Ze repareren vaker hun eigen spullen, lenen dure voorwerpen en gereedschappen en kopen tweedehands om zo dure kosten te vermijden.

Door dit onderzoek willen we te weten komen wat de grootste drijvende krachten zijn die ervoor zorgen dat iemand prosumentengedrag vertoont. Verschilt dit afhankelijk van iemands plaats in de samenleving? Verandert het prosumentengedrag wanneer iemands sociaaleconomische status verandert?

Deelnemers aan dit onderzoek worden willekeurig geselecteerd. We gebruiken verschillende vragenlijsten afhankelijk van het doelpubliek. Zo is er een vragenlijst specifiek voor klanten van de tweedehandswinkel, en één voor de werknemers van de tweedehandswinkel. We hopen aan de hand van deze vragenlijsten informatie te verzamelen waardoor we in de toekomst succesvol consumenten kunnen motiveren om prosument te worden.

De vragenlijst is volledig anoniem. Er zijn geen juiste of foute antwoorden, u kan gewoon antwoorden vanuit uw eigen ervaring. Als u een vraag niet begrijpt, mag u altijd meer uitleg vragen.

Het invullen van de vragenlijst duurt een 5-tal minuten. Bent u bereid om de vragenlijst in te vullen? Indien u tijdens of na het invullen van de vragenlijst zich bedenkt, kan u steeds stoppen en zeggen dat we jouw antwoorden niet mogen gebruiken in ons onderzoek.

Alvast bedankt en vriendelijke groeten,

Julie, Faysal, Nick en Mante

Er zijn 18 vragen in deze enquête onderverdeeld in 3 groepen.

Status

In deze vraaggroep willen we graag informatie verzamelen over uw sociaaleconomische status

1. *Welke diploma's hebt u reeds behaald?*
   - Geen diploma
   - Lager onderwijs
   - Algemeen secundair onderwijs (ASO)
   - Technisch secundair onderwijs (TSO)
   - Kunst secundair onderwijs (KSO)
   - Beroeps secundair onderwijs (BSO)
   - Professionele bachelor

- Academische bachelor
- Master, licentiaat, postgraduaat of hoger

2. *Wat is uw arbeidersstatuut?*
   - Werkloos
   - Vrijwilliger
   - Student
   - Arbeider
   - Bediende
   - Zelfstandige
   - Gepensioneerd
   - Informeel (zonder contract)
   - Andere: ……..

3. *Heeft u ooit niet kunnen voorzien in een van onderstaande zaken voor uw gezin? Duid aan welke. (Meerdere antwoorden mogelijk)*
   - Voedsel
   - Kleding
   - Huisvesting
   - Gezondheidszorg
   - Transport
   - Geen van bovenstaande

Indien u 'geen van bovenstaande' antwoordde, sla vraag 6 en 7 over.

4. *Indien u ooit niet heeft kunnen voorzien in één van bovenstaande zaken, hoe regelmatig was dit?*
   - Dagelijks
   - Enkele keren per week
   - Enkele keren per maand
   - Enkele keren per jaar
   - Eén keer per jaar
   - Minder dan één keer per jaar

5. *Ervaart u momenteel nog steeds deze moeilijkheden?*
   - Ja
   - Nee

6. *Hoe gemakkelijk kunt u/kan uw huishouden rondkomen met het totale beschikbare inkomen?*
   - Zeer gemakkelijk
   - Gemakkelijk
   - Eerder gemakkelijk
   - Eerder moeilijk
   - Moeilijk
   - Zeer moeilijk

Noodzaak

In deze groep vragen willen we te weten komen hoe belangrijk deze organisatie is voor u.

1. *Hoe vaak komt u langs bij deze organisatie?*
   - Meerdere keren per dag
   - Dagelijks
   - Wekelijks

- Maandelijks
- Jaarlijks
- Bijna nooit

2. *Moet u minder spaarzaam met geld omgaan door deze organisatie?*
   Ja/Nee

3. *Hoe gemakkelijk is het om de diensten en producten van deze organisatie te gebruiken?*
   - Heel gemakkelijk
   - Gemakkelijk
   - Matig gemakkelijk
   - Niet gemakkelijk
   - Helemaal niet gemakkelijk

4. *Hoe bereikbaar is deze organisatie voor u?*
   - Heel bereikbaar
   - Bereikbaar
   - Matig bereikbaar
   - Niet bereikbaar
   - Helemaal niet bereikbaar

5. *Hoe noodzakelijk is deze organisatie voor u?*
   - Heel noodzakelijk
   - Noodzakelijk
   - Matig noodzakelijk
   - Niet noodzakelijk
   - Helemaal niet noodzakelijk

6. *Wat zijn de grootste ongemakken die u ondervindt bij het gebruiken van de diensten of producten van deze organisatie?*
   ……

7. *Wat zijn de grootste comforten die u ondervindt bij het gebruiken van de producten of diensten van deze organisatie?*
   ……

8. *Indien je meer geld bezat, zou je de diensten of producten van deze organisatie nog steeds gebruiken?*
   - Zeker wel
   - Waarschijnlijk wel
   - Niet meer of minder
   - Waarschijnlijk niet
   - Zeker niet

9. *Zou u deze organisatie missen indien ze niet meer bestaat?*
   - Ja, heel hard
   - Ja, toch wel een beetje
   - Niet ja of nee
   - Nee, niet echt
   - Nee, helemaal niet

Informatie en bewustzijn

In deze vraaggroep willen we meer te weten komen over uw bewustzijn over de gevolgen van uw consumenten-gedrag.

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1. *Bent u begaan met uw ecologische voetafdruk*?*
   **De ecologische voetafdruk is een getal dat weergeeft hoeveel biologisch productieve grond- en wateroppervlakte nodig is om je consumptieniveau te kunnen handhaven, en om de afvalproductie te kunnen verwerken (Bewustverbruiken, 2018).*
   - Ja, heel hard
   - Ja, toch wel een beetje
   - Niet ja of nee
   - Nee, niet echt
   - Nee, helemaal niet

2. *Hoeveel moeite kost het u om duurzamer, milieuvriendelijker of klimaat neutraler te leven?*
   - Heel veel
   - Veel
   - Matig
   - Weinig
   - Heel weinig

3. *Moedigen organisaties en media je aan om duurzamer te leven?*
   - Ja, heel veel
   - Ja, toch wel
   - Niet ja of nee
   - Nee, niet echt
   - Nee, helemaal niet
   - Geen antwoord

4. *Moedigen personen in je omgeving je aan om duurzamer te leven?*
   - Ja, heel veel
   - Ja, toch wel
   - Niet ja of nee
   - Nee, niet echt
   - Nee, helemaal niet
   - Geen antwoord

ENGLISH VERSION

Circular economy in Leuven

Dear reader,

We are four students from KU Leuven who are participating in a research project. Our research is about the circular economy and “prosumers” in Leuven. A prosument is a person who consumes and produces a product. “Prosumption” refers to the practice whereby one person creates certain products and services, and ultimately uses this product himself. In our project we are investigating how consumers can be turned into prosumers, with the aim of creating a more sustainable and circular economy in Leuven.

In our research we decided to focus on prosumer behavior among economically disadvantaged people in Leuven. According to various sources, consumer behavior is already present in the lifestyle of poorer people. They more often repair their own things, borrow expensive items and tools, and buy second-hand ones in order to avoid expensive costs.

Through this research we want to find out what the biggest driving forces are that ensure that someone exhibits prosumer behavior. Does this differ depending on one’s place in society? Does prosumer behavior change when someone’s socioeconomic status changes?

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Participants in this study are randomly selected. We use different questionnaires depending on the target audience. For example, there is a questionnaire specifically for second-hand store customers and one for second-hand store employees. We hope to gather information from these questionnaires so that we can successfully motivate consumers to become prosumers in the future.

The questionnaire is completely anonymous. There are no right or wrong answers; you can simply answer from your own experience. If you do not understand a question, you can always ask for more explanation.

Completing the questionnaire takes 5 minutes. Are you willing to complete the questionnaire? If you change your mind during or after completing the questionnaire, you can always stop and say that we may not use your answers in our research.

Thanks in advance and best regards,

Julie, Faysal, Nick and Mante

There are 18 questions in this survey divided into 3 groups.

Status

In this group of questions we would like to collect information about your socioeconomic status

1. *What diplomas have you already obtained?*
   - No diploma
   - Primary education
   - General secondary education (ASO)
   - Technical secondary education (TSO)
   - Art secondary education (KSO)
   - Vocational secondary education (BSO)
   - Professional bachelor
   - Academic bachelor
   - Master's degree, postgraduate degree, or higher
2. *What is your worker status?*
   - Unemployed
   - Volunteer
   - Student
   - Worker
   - Clerk
   - Self-employed
   - Retired
   - Informal (without contract)
   - Other:

     …… ..
3. *Have you ever been able to provide your family with one of the things below? Indicate which. (Multiple answers possible)*
   - Food
   - Clothing
   - Housing
   - Healthcare
   - Transport
   - None of the above

   If you answered "none of the above", skip questions 6 and 7.

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4. *If you have never been able to provide for one of the above, how regular was this?*
   - Daily
   - Several times a week
   - Several times a month
   - Several times a year
   - Once a year
   - Less than once a year

5. *Are you still experiencing these difficulties?*
   - yes
   - no

6. *How easily can you/can your household survive on your total disposable income?*
   - Very easily
   - Easily
   - Rather easily
   - Previously difficult
   - Difficult
   - Very difficult

Need

In this group of questions we want to find out how important this organization is for you.

1. *How often do you visit this organization?*
   - Several times a day
   - Daily
   - Weekly
   - Monthly
   - Annually
   - Almost never

2. *Do you spend less money by using the services or products of this organization?*
   Yes/No

3. *How easy is it to use the services and products of this organization?*
   - Very easy
   - Easy
   - Moderately easy
   - Not easy
   - Not easy at all

4. *How accessible is this organization to you?*
   - Very accessible
   - Accessible
   - Moderately accessible
   - Not accessible
   - Not accessible at all

5. *How necessary is this organization for you?*
   - Very necessary
   - Necessary
   - Moderately necessary

- Not necessary
- Not necessary at all

6. *What are the biggest inconveniences you experience when using the services or products of this organization?*
   ……
7. *What are the greatest benefits that you experience when using the products or services of this organization?*
   ……

8. *If you had more money, would you still use the services or products of this organization?*
   - Certainly
   - Probably
   - No more or less
   - Probably not
   - Certainly not

9. *Would you miss this organization if it no longer existed?*
   - Yes, very much
   - Yes, quite a bit
   - Neither yes or no
   - No, not really
   - No, not at all
   - No information

   +–

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Supplement 3: Video of the Presentation at the Symposium “KU Leuven Facing the Future”, May 8, 2019, Leuven, Belgium.

The results of this work were presented at the symposium “KU Leuven facing the future”, May 8, 2019, Leuven, Belgium. A video of this presentation can be found here.