



Facing the Future: A Blueprint for a Resilient and Equitable Society: Connecting the Functional Building Blocks

**F. Bocken^{1,2*}, E. Brennan^{1,3*}, N. Claessens^{1,4*},
D. Claeys^{1,5*}, S. Debeausaert^{1,6*}, T. Dubois^{1,7*},
A. Franken^{1,8*}, B. Vanwyngaerden^{1,9*}, J.R. Nova
Blanco^{1,10}, K. Becher^{11,\$}, P. Vandebroeck^{11,\$}.**

¹KU Leuven – University of Leuven, Honours Programme Transdisciplinary Insights, Leuven, Belgium;

²KU Leuven – University of Leuven, Master student Criminology, Leuven, Belgium;

³KU Leuven – University of Leuven, Master student International Business Economics and Management, Brussels, Belgium;

⁴KU Leuven – University of Leuven, Master student Physics, Leuven, Belgium;

⁵KU Leuven – University of Leuven, Master student Digital Humanities, Leuven, Belgium;

⁶KU Leuven – University of Leuven, Master student International and European Law, Leuven, Belgium;

⁷KU Leuven – University of Leuven, Master student Linguistics, Leuven, Belgium;

⁸KU Leuven – University of Leuven, Master student Biomedical Sciences, Leuven, Belgium;

⁹KU Leuven – University of Leuven, Master student Philosophy, Leuven, Belgium;

¹⁰KU Leuven – University of Leuven, Department of Microbiology and Immunology, Rega Institute for Medical Research, Clinical and Epidemiological Virology, Leuven, Belgium.

¹¹shiftN cvba, Leuven, Belgium.

*These authors contributed equally to the work.

§Email: kb@shiftn.com, pv@shiftn.com

Abstract

Contemporary society is plagued by a number of issues and inconsistencies on both an environmental and a socio-economic level. Reliance on bank loans forces debtors to seek means to repay their debts, thus facilitating the current boundless economic growth in which long-term, environmental considerations typically come second. On the individual level, since virtually nothing is free, everyone has to ensure his or her own livelihood, mostly in the form of wage labour. For fear of poverty, the unemployed must adjust to the needs of the job market and risk not being able to fully explore their potential. Other socio-economic groups also face stigmatisation, and inequality is rampant as a result of the pervasive market-based pricing mechanisms. In view of these issues, it seems unjustified to accept these terms and conditions in the future, especially since the West has to cater to its ageing population and the ensuing pressure this will exert on welfare systems. Therefore, as a transdisciplinary team assisted by various experts and armed with insights from a wide

variety of sources, we propose an alternative model of society based on the values of *fairness*, *inclusion* and *transparency*, with the goal of developing a representative systems map for a *future*, *resilient* and *equitable* society. The exact workings of this society are captured by several building blocks, which together endeavour to cover the full range of functions and responsibilities associated with society today, and jointly promote democratisation while guaranteeing equal political representation for all members of society.

Key words

Equitable and resilient society, fairness, inclusion, future, Universal Basic Income, social wealth fund, money creation, governmental structure, commons

Challenge Statement

Develop a causal loop diagram as a blueprint for a future, resilient and equitable society

1 Introduction: Our Current Predicament

Today's world is undergoing a variety of radical changes. The economic and technology sectors have recently experienced unparalleled and largely unchecked growth, while environmental issues intensify and large-scale demographic shifts in contemporary societies imply future complications. While there are local grassroots initiatives to address these global issues, governance structures and policymakers are slow to adapt to this new reality.

The transition that society is experiencing affects every corner of the globe. Advances in automation technology have resulted in the widespread loss of jobs in the manufacturing industry, and as machines become more advanced many other industries may be threatened in the future (Sundararajan, 2017). Demographic changes, such as the ageing population in the West and the incipient problem of overpopulation, will eventually lead to challenges for existing welfare structures (Deboosere, 2018). As for the environment, global warming and the ensuing rise in the sea level threaten both natural and human systems. Climate scientists warn of an impending 'tipping point' after which these negative changes become irreversible (IPCC, 2014). While these external challenges must be addressed by the governments concerned, they also

affect economic systems. Unsurprisingly, the economic system is fraught with problems: the economic crisis of 2008 revealed that the current capitalist system is unstable, and there is still no solution for the growing problem of inequality (UN, 2011). Yet another related issue in most western societies is the general increase in public distrust of the government and its institutions, leading to a rise in populism and political extremism (Goodwin, 2018; van der Meer, 2017).

However, emerging global trends and local initiatives give hope for the future. Progress in information technology has enabled the rediscovery of an old form of economic activity, namely that of collaborative production. This economic domain includes the sharing economy, cooperative currencies, and commons-based peer production. This is in part due to new sorts of goods, services, and production methods, which neither fit the traditional logic of the market nor adhere to the customary managerial hierarchy (EC, 2018). All of this points to a new paradigm, in which individual interests are tied to the common good and vertical hierarchies are replaced by more open, horizontal types of collaboration. Examples of collaborative production include urban farming initiatives in many metropolitan areas worldwide and local currencies, such as the Bristol Pound (Demain, 2017). Another emerging concept in this context is the Universal Basic Income (UBI), which is being tested through pilot programs in a number of countries. While the idea behind the UBI is not new (it was first proposed in the 18th century), it may help in addressing contemporary issues including job scarcity and overly complex and poorly structured welfare systems (IMF, 2017).

That these remedies are valuable in their own right is beyond doubt, yet none can singlehandedly resolve the current predicament. Therefore, it is in the opinion of the authors that there is a need for fresh ideas and viable alternatives to the workings of contemporary society, based on a structured combination of such alternatives. This study introduces a vision for a better future through a schematic 'blueprint,' which is meant to represent a society that combines humanistic values with resilience, adaptability, and equitability. To begin, the next two sections discuss the long history of utopian writing and link it to our interpretation of the equitable society. Section 3 details the methodology we employed to collect insights and necessary information on the relevant topics of inquiry. Section 4 introduces and defines the 'functional building blocks,' or the core

mechanism and components that support a resilient and equitable society. Section 5 discusses the workings of these building blocks when integrated into the blueprint, and it highlights the key connections they share with other aspects of the model. Finally, section 6 addresses the limitations of this study and points to areas for further research.

2 The Guiding Vision

The guiding vision for this project has been to develop a blueprint for a future society that is both equitable and resilient. This project is by its nature related to a long intellectual history of utopian thinking and utopian schemes. The term ‘utopian’ applies to any social, intellectual, or political scheme which is impractical at the time when it is conceived (Rousseau, 1901). This history of utopian thinking starts with Plato’s ancient *Republic*, in which he proposes a model for a virtuous city, in contrast to other, inferior types of government systems. His virtuous city involves the exclusion of certain ideas and the limitation of private wealth. At the outset of the sixteenth century, Thomas More’s *Utopia*¹ (1516) would almost completely reverse the utopian vision of Plato. He portrayed a utopian society as an insular state with no private property, no inequality, and no ideological disputes. As such, it promotes pluralism instead of the restrictive measures advocated by Plato. For Marx and Engels, utopias should not simply be the result of a thought exercise or a literary means to critique society, but should instead be perceived as a goal to achieve (Paul, 2017: p. 137). Their *Communist Manifesto* (1848) refers to More’s *Utopia*, arguably placing More as the first historical writer in the communist, and perhaps even the socialist, movement. In the twentieth century, Rawls’ work on social justice and Nozick’s *Anarchy, State, and Utopia* (1974) integrate utopian thinking into political theory. Nozick argued for the ‘minimal state,’ which is aimed at protecting the liberty of the individual. Rawls introduced his ‘ideal theory’ and argues for a ‘realistic utopia’ that focuses on peaceful international relations and human rights (Brown, 2002). His ‘ideal theory’ acknowledges the necessary societal conditions for a utopian society, while his insistence on his theory being realistic highlights the importance of working towards a better society today.

Similarly to Rawls, this project introduces a vision of society that is slightly idealized but gives meaning to

the current initiatives working in that direction. However, we deliberately refrain from proposing a static or fixed masterplan society and the way it should be structured. Instead, we present a coherent set of building blocks to be the driving force behind an increasingly equitable and resilient society. As stated in the introduction, these building blocks figure together in a blueprint designed to be flexible and reactive to whatever relevant changes affect society. Due to the “checks and balances,” such as the many feedback loops between stages of decision-making, society is highly complex but also more equitable and resilient. The intended audience are citizens of today’s world; we hope to engage individuals, communities, and nation-states to work flexibly towards more equity and resilience. In that regard, a fitting motto for our project is the following adaptation from the *Utopian Alphabet*²: “utopists with ambition, are supposed to hope to not stay utopists for long.” (Abicht, Absillis, & Aelberts, 2011)

3 Approach

Society’s intricate and global troubles can be defined as a wicked problem.³ For one, there are many contributing elements that cannot be subsumed under one single field of study. Similarly, many stakeholders must be actively involved. Not only should the proposed solutions be open to revision, updating, and improvement but, most importantly, research should be applicable to society’s current issues. As demonstrated by Rawls, research in the form of utopian thinking also requires a realistic frame. Such a wicked problem demands a broad way of thinking in order better to understand the interactions between contributing factors and stakeholders. Besides, an approach that takes everything into consideration will also be able to evaluate possible solutions better.

Therefore, such problems cannot be solved by a single discipline and must instead be addressed from preferably a ‘transdisciplinary’ perspective.⁴ Not only does a transdisciplinary approach combine the insights of various disciplines, yielding a holistic view of the problem, but transdisciplinary research also specifically endeavours to find solutions for the current problems in society. A truly transdisciplinary approach blurs the division between academic fields, and as a result it requires a new way of thinking (Bernstein, 2015; Pohl, Krütli & Stauffacher 2017).

To provide this transdisciplinary framework and the insights it may offer, the research team consisted of master students from various academic backgrounds.⁵ Over the course of the study, the team was assisted by two consultants, Kim Becher and Philippe Vandenbroeck, who helped them achieve a transdisciplinary mindset, and who provided insights from systems thinking and design thinking, which are particularly useful when dealing with wicked problems.⁶

At a first stage, the team sought to identify and structure the problem. To do this, the team engaged in a slightly modified version of the ‘Actor constellation game,’ which helps to identify the stakeholders or societal actors as well as the network they build around the central issue (Pohl, Krütli & Stauffacher 2017).⁷ This is a crucial process because the identified stakeholders can prove to be part of a viable solution. This exercise yielded to two tangible deliverables: a web of the relevant stakeholders (e.g. government, educators, businesses) and a defined list of overarching values and characteristics that are necessary for any society to be equitable and resilient (for instance, active participation in decision-making by the people in society, and knowledge being freely accessible to all). Ultimately, it provided a general outline of the actors and values that are relevant to the problem, which remained an important source of information throughout the research process. Additionally, it allowed the team to identify which experts and stakeholders to consult for their expertise in order to grasp the problem better. More specifically, the team held interviews with Prof. Dr. Andrew Vande Moere, professor of architecture, Prof. Dr. Antoon Van De Velde (KU Leuven), professor of philosophy and economics, and Prof. Dr. Eric Mathys (KU Leuven), professor of bioeconomics. Each expert offered their insights on the relevant topics for which the team lacked necessary information.

At a later stage, we gathered further material from all sorts of data on the problems societies currently face, and we evaluated current initiatives, local or global, that seek to tackle these issues. In this respect, one particularly informative source of information was the documentary ‘Demain,’ which shows how pioneering initiatives are currently re-inventing energy, agriculture, democracy, education, and even the economy.⁸ From such sources, we were able to determine which concrete actions could be taken in the future and how these fit into the envisioned blueprint of a more equitable and resilient society.

Furthermore, we compiled insights gathered from the literature on alternative models of economy and governance. In so doing, we endeavoured to consider solutions and arguments from the whole ideological spectrum found in the literature.⁹ Afterwards, the newly-acquired knowledge was synthesised into systems maps with the help of the assisting consultants, who familiarised us with systems thinking through Kumu, a web-based data visualisation platform.¹⁰ Visualisation through systems maps offers a more nuanced understanding of the interactions between elements (Pohl & Hadorn, 2008). Each systems map was then analysed in order to extract the values and potential solutions that corresponded best to our interpretation of an equitable and resilient future.

Once these values and solutions had been selected and evaluated, we discussed and decided on the essential components of the envisioned society, i.e. the core machinery of the envisioned society which provides the basic outline of the blueprint. A preliminary version of the blueprint was presented to an expert panel consisting of representatives and stakeholders from the community and academia, Prof. Dr. Jef Peeters and Prof. Dr. Anne Snick.¹¹ Based on their feedback, final adjustments were made to the map, producing the final version of the blueprint as displayed in this study. The following chapters describe each of these building blocks found in the blueprint and explain the way in which they interact.

4 Functional Building Blocks

The subsections cover the following components: a social wealth fund, a democratic monetary system, universal basic income and basic services, a commons-centric economy, and citizen-led governance. Rather than representing a fixed master plan, the blueprint and its building blocks are intended to remain relevant in a dynamic and increasingly equitable society.

4.1 A Social wealth fund

Our first building block, the social wealth fund, aims to democratize and equalize financial citizenship. It is designed to capture and invest public revenue in order to fund social interests and create public wealth. As such, this repository for investment funds represents the component of society on which the other building blocks ultimately rely for their funding. This does not mean that it is more important than the other components, but

rather that it is necessary to first discuss the workings of social wealth funds.

Existing funds comparable to the present conception of the social wealth fund are either state-owned 'sovereign wealth funds' which invest globally to benefit the national economy, or specific 'social funds', investing in specific local targets which are either community-led or governed by a local institution (i.e. the Local Development Fund in the Republic of Malawi¹²). Two concrete examples of a Social Wealth Fund can be seen in the Alaskan and Norwegian governments, which are investment funds of which each citizen is considered to be a shareholder. The Permanent Fund of Alaska was created by a bottom-up initiative in 1976 to save a portion of the state's oil revenue for the future.¹³ Every citizen in Alaska is issued an annual universal basic dividend as part of the Permanent Fund Dividend Program. Likewise, the Government Pension Fund of Norway collects the wealth surplus of its petroleum trade which is used to finance its generous welfare system.¹⁴ This government pension fund is the domestic branch of the Norwegian Global Investment Fund. It was established in 2006 to manage the government's accumulation of long-term financial assets. Norway's Social Wealth Fund receives the net central government receipts from petroleum activities and returns the amounts needed to finance the non-oil deficit. Another example is the Australia Sovereign Wealth Fund.¹⁵ As of 2006, this fund has been operating independently of the government and instead relies on a board of members (so-called 'guardians') selected by the ministry. The Australia Sovereign Wealth Fund manages different specific public asset funds with the aim of investing for the benefit of future generations and strengthening the Commonwealth's long-term financial position.

It thus seems safe to say that the prevalence of sovereign wealth funds is increasing globally (IFSWF, 2018). Most strictly governmentally-financed wealth funds comply with a formal set of principles and practices outlined by the International Forum of Sovereign Wealth Funds (IFSWF), called the 'Santiago Principles' (IFSWF, 2018). In practice, local funds are also government agencies set up as semi-independent institutions. These government-financed funds contrast with funds that derive their means from a bottom-up initiative, viz. democratically-financed funds. However, to democratize the funds and allow for more directly involved citizenship, there is need of a different

ownership structure from that based on the public-private dichotomy.

One possible theory that can provide such an alternative structure of ownership is that of asset-based welfare (Lennartz & Ronald, 2017). This economic theory proposes a redistribution of productive assets rather than individual income. The acquisition and accumulation of assets can guarantee economic prosperity because the ownership and investment of assets generate a basic income. Traditionally, the poor are forced to spend the majority of their income on consumption and retain very little to save and invest in assets. A social wealth fund that is structured as asset-based welfare acts as the guarantee of assets for every citizen and therefore guarantees a basic asset-based income.

Access to assets for every citizen is linked to access to 'common goods,' which are the natural resources of the planet. In this regard, Pogge T. (2001) criticizes the uncompensated exclusion of the poor from the use of natural resources. His proposal for due compensation therefor is the 'global resources dividend' (GRD). This GRD is to be paid by governments to their citizens, who have an "inalienable stake" in all limited natural resources, and hence the government owes them compensation for monopolizing the resources. Pogge's proposal of the GRD is criticized by Hayward T. (2006), who pertinently states the following:

"allowing states to choose exactly how to raise the requisite funds within their own jurisdiction is recognition of their *sovereign* rights; *requiring* them to do so is recognition of their responsibilities as *co-inhabitants* of a delicately-balanced global ecosystem." (Hayward, 2006: p. 368, emphasis added).

Like the Australia Wealth Fund, the social wealth fund described in this paper would keep funds for immediate socio-economic needs while it would reallocate funds to cover long-term risk management. Hence, the social wealth fund is connected to a different repository, viz. the Risk Fund. The idea of a risk fund is inspired by Ulrich Beck's *Risk Society: Towards a New Modernity* (1992). He argues that environmental risks are no longer just an unpleasant but manageable side-effect of heavily industrialised societies, but that they have indeed become the most influential and important factors to consider. Like the uneven distribution of wealth in society, the distribution of socioenvironmental

risks is also skewed. After more than twenty years, this observation is still relevant in discussions on ways to achieve a more sustainable and resilient society. The Risk Fund provides the safety net that serves to preserve environmental resilience. Moreover, the proposed social wealth fund provides the financial basis necessary to support an equitable democracy.

4.2 A democratic monetary system

From the big credit crunch of 2008, it is clear that the current financial system is flawed. Not only must the government keep economic activity in check, but the system is also unstable from a medical, social, environmental and even psychological perspective. Yet, almost ten years after the credit crunch, serious structural reforms have yet to be enforced. Instead, governments have imposed austerity measures on their populations to save the banking system without taking the necessary steps to avoid a similar or worse kind of economic cataclysm in the future. Meanwhile, many layers of society are suffering from the consequences of precariousness and poverty: public services are being cut down, inequality is mounting, trust in authorities and politics is eroding while populism and extremism are on the rise.

Increasing inequality resulting from the current economic system may be tackled by adopting a new monetary system. A look at the history of the European welfare state reveals that the systems in place have predominantly focused on the distribution of existing money and wealth, while the distributive effect of money creation has essentially remained within a blind spot. In fact, there are several direct and indirect channels through which the money system aggravates inequality (Zeddies, 2018).

A fact that is widely ignored is that 90% or more of the circulating money is currently created by private banks (Positive Money, 2018). Whenever a bank lends money to a person or a business, the bank creates that money, albeit in the form of an obligation to pay back the principal and the interest on that loan. However, the interest is not ‘created’ together with the principal, which means that the borrower must ‘find’ it elsewhere. As a result, many debtors have problems paying their debt because there is not enough money in the system. This systemic scarcity results in relentless competition and structural unemployment. To acquire these funds, the economy has to grow constantly, even if this comes

with environmental destruction (Lietaer & Dunne, 2013).

As Lino Zeddies (2018) from the German sovereign money reform organization “Monetative” points out:

“[By enabling] banks to fuel asset bubbles and booms through extensive credit creation into the asset markets... [the current system] creates huge profits for banks, financial markets and ‘the haves’ in general.” (Zeddies, 2018)

The effect described can be aggravated through special accounting practices, like derivatives. If the rules were fair, those profits from bubbles would disappear when the bubble bursts, but in our current system the banks are ‘too big to fail’ since they must provide most of the money and control the payment infrastructure for the outside economy. Without banks, the current system would collapse entirely (Zeddies, 2018).

Furthermore, the current system also favours big corporations over small businesses: big corporations have the means to set up their own corporate in-house banks, which provide them with a huge funding and liquidity advantage over small companies relying on external funding. The European Central Bank has started to buy bonds from multinationals in order to drive down their costs as part of its Quantitative Easing program, which gives big companies another unfair advantage (Zeddies, 2018).

Another characteristic of today’s money is that it is used for very different and often contradictory purposes, namely as a means of exchange, a unit of account, and a store of value. Money that is stored tends to be withdrawn from circulation in order to increase its monetary value. When significant amounts of money are stored, there may not be enough money in circulation to maintain a healthy economy.

In the past, experiences with new types of currency have shown their ability to reduce the sharp inequalities that are inherent of a debt-based money system. One of the most compelling cases is the “Wörgl,” a cooperative currency named after the Austrian town where it was introduced in 1931 (Lietaer & Dunne, 2013). With a third of the able population unemployed, the mayor of Wörgl developed a new currency, based on the principle that money needs to circulate extensively in order to create more wealth collectively. To achieve this, work certificates were distributed, which lost their value if they were not spent before a given expiry date. As a result, the Wörgl circulated 12 to

14 times more than the national currency. Soon, full employment was a reality and economic activity soared: a bridge was built and the people of Wörgl even started investing in forestry projects to accommodate future generations. Other towns followed Wörgl's example and even French president Daladier paid a visit to the town. This triggering event led the Austrian central bank to assert its monopolistic power in prohibiting the issuing of cooperative currencies like the Wörgl (Lietaer & Dunne, 2013).

Historically, the power of central banks dates back to the 17th century, when monarchies and bankers formed a powerful alliance (Lietaer & Dunne, 2013). Monarchs financed their wars through bank debts, which were ultimately paid by the population through taxation. One would assume that, in modern societies, central banks are public entities controlled by the parliament, but this is in fact not the case in many countries: Cédric Frère, the grandson of Belgium's notorious financier Albert Frère, was recently installed in the 'Council of Regents' of the National Bank of Belgium, without prior parliamentary consultation (HLN, 2018). William Alexander of Orange-Nassau was a board member of the Dutch Central Bank before becoming King of the Netherlands. Hence, private and public interests are strongly interwoven in our financial system, especially so in the United States, where it is not uncommon to switch between working for the government, private banks, rating agencies, the Federal Reserve, accounting firms, etc.

In recent years, various civil initiatives have emerged in Europe that advocate a reform of the monetary system to create more wealth, equality, and stability. Examples of such initiatives are 'Ons Geld' (Netherlands), 'Vollgeld Initiative' (Switzerland) and 'Positive Money' (UK).¹⁶ These initiatives all have in common that they want to put an end to the ability of banks to create money in the form of bank deposits when they make loans. This monetary reform would transfer the ability to create money exclusively to the state, creating what Positive Money has termed a 'sovereign money' system. In this paper, we will not go into detail about what such a system would look like, but we can name a few of its advantages:

"Taking the power to create money out of the hands of banks would end the instability and boomandbust cycles that are caused when banks

create too much money in a short period of time. It would also ensure that banks could be allowed to fail without bailouts from taxpayers. It would ensure that newly created money is spent into the real economy, so that it can reduce the overall debt burden of the public, rather than being lent into existence as happens currently." (Positive Money, 2018)

This also means that money could be created and directly transferred, under democratic scrutiny, to places where it is needed and beneficial for the public. To summarize, there are two potential changes to the monetary system that could be implemented within our blueprint. First, a new central bank could feed directly into the social wealth fund and act as a 'partner state' to support cooperative, commons-based initiatives at all levels of society. Overall, the financial system would become significantly more transparent and easier to govern from an economic perspective. Second, this new 'sovereign' monetary system could co-exist with local, regional, and complementary currencies that would circulate more frequently and would help to strengthen the commons-based economy, especially since these currencies help to create a better understanding of what money can do for the community. Complementary currencies aim at linking unmet needs with unused resources. By doing this, they create a culture of solidarity and reciprocity, which is also key to making commonsbased initiatives thrive (Lietaer & Dunne, 2013). While neither initiative is directly represented on the systems map, both potential changes have the capacity to drive equity and financial resilience in society.

4.3 A Universal Basic Income

A central component of our model for the future is the Universal Basic Income (henceforth UBI), which would now be perceived as a form of welfare. More specifically, a Universal Basic Income should satisfy the following five characteristics (Basic Income Earth Network, 2018):

1. Periodic: it is paid at regular intervals, not as a one-off grant.
2. Cash payment: it is paid in an appropriate medium of exchange, allowing those who receive it to decide what they spend it on.

3. Individual: it is paid on an individual basis and not, for instance, to households.
4. Universal: it is paid to all, without a means test.
5. Unconditional: it is paid without a requirement to work or demonstrate a willingness to work.

The idea of a UBI is not new: Thomas Paine (1737–1809) first came up with a ‘territorial dividend,’ which is a form of compensation every citizen ought to receive in exchange for being born after most things were acquired as private property by predecessors (Paine, 2013).¹⁷ While the idea has not always been popular since it was first formulated, the growing issue of inequality, on both a local and a global scale, brought to the fore by Thomas Piketty with his influential ‘Capital in the Twenty-First Century’ (2014), has inevitably rekindled debate on the viability of a UBI. As Victor Hugo famously said, there is nothing as powerful as an idea whose time has come.

In his paper ‘Why surfers should be fed’, Philippe Van Parijs states the following:

“a defensible liberal theory of justice, that is, one that is truly committed to an equal concern for all and to nondiscrimination among conceptions of the good life, does justify, under appropriate factual conditions, a substantial unconditional basic income.” (Van Parijs, 1991)

As an argument in favor of UBI, he mentions that it would help people out of the unemployment trap¹⁸ while simultaneously improving the life quality of people with low-paying jobs. Moreover, it would massively redistribute income from men to women, who are still overrepresented in occupations without pay, such as child care and elderly care.

Ironically, it is only when an occupation entails revenue that it is considered to be useful, which in turn justifies why it should be remunerated. From this perspective, one could suggest that the UBI permits lazy people to remain lazy or, put differently, that people will inevitably exploit this opportunity without contributing. However, payment does not entail that a given job contributes to society more than any other occupation per se. In this respect, the anthropologist David Graeber published his theory on so-called “Bullshit Jobs” (2018): jobs that do not necessarily contribute to society. Similarly, the fact that an occupation does not entail a livelihood does not mean that this occupation is without value. As a result, the exact demarcation between true “work” and

what is considered more of a hobby so to speak is rather vague and arbitrary. For instance, being a babysitter can be a full-time job, yet being a babysitter does not, a priori, involve more skills than being a stay-at-home parent.

Providing a UBI to all individuals would indeed make it a lot easier to choose (or to remain occupied in) jobs that do not yield significant revenue. Instead of being obliged to adjust to the needs of the market, the individual will be able to enjoy whatever occupation he or she likes, without having to sacrifice financial autonomy.

Although it is unwarranted to prevent people from accumulating capital in order to provide for the next generation – from a moral standpoint, that is (see Rand, 1967) – in other words, some justified inequalities will remain, the UBI ensures that it is unnecessary to accumulate this wealth to begin with, as the UBI offers freedom and opportunities in itself. In view of these undeniable advantages, it is no wonder that Van Parijs thinks that “basic income is one of those few simple ideas that must and will powerfully shape, first the debate, and next the reality, of the new century,” (Van Parijs, 2004: p. 8). Van Parijs argues that until now, there has only been one unmistakable instance of an implemented Universal Basic Income, the Alaska Permanent Fund Dividend, which was created in 1982, and provides every Alaskan a dividend amounting to an average of \$1200 a year, in a lump sum (Van Parijs, 2004).

However, there are a number of common objections or arguments against a universal basic income. For one, one may find it unfair to grant everyone, including lazy yet able-bodied individuals, a basic income which is financed through the taxation of working individuals (Elser, 1986). Another closely-related matter concerns the costs of introducing a UBI: if the UBI is financed with taxation money levied on labour, then enough people must be willing to contribute. If not, the cost of implementing the UBI may simply be too high.¹⁹ Another key concern with the UBI is that it could discourage people from working.²⁰ As for the latter concern, studies on Win-for-Life winners suggests that even when livelihood is assured, people choose to keep on working (Marx, 2018).²¹

At present, research is in the process of weighing the pros and cons of the UBI.²² For example, a study conducted in Finland in Kela, in which 2000 unemployed

participants each receive a monthly payment of € 560,-.²³ The researchers at Kela hope to investigate how social security can be restructured to address the changing nature of work and to promote active participation and provide a stronger incentive to work while reducing bureaucracy. Originally, the research project, which is due in 2019, was more ambitious until the Finnish administration agreed on a more modest version. Admittedly, this project does not qualify as a true UBI. The amount is relatively

small and cannot be considered viable, the participants were homogeneous to the extent that they were all unemployed, and the experiment is for a limited duration of two years, all of which contradict the full definition of a UBI, as stated above. Hence, the research endeavour has already been criticized because it is inherently incapable of yielding relevant results concerning the UBI.²⁴ Nevertheless, the researchers are convinced that the experiment can yield valuable insights into UBI.

The co-existence of a UBI and the ‘care economy’

Among ‘nondiscrimination’ in respect to conceptions of the good life, the UBI provides citizens with the opportunity to leave the workforce and care for their loved ones. This will create a universal social insurance program through which families can access elder care and childcare. Eligibility for this program is not someone’s income or assets, or the availability of family care providers; it is actually on functional need.

Next to the individual benefit, this adaptation of the system is a huge saving to the health system as a whole, e.g. emergency care visits and readmissions to hospitals can be abandoned because there are more home and community-based supports in place (Gupta, Brown & Gingerich, 2017). Another means of reducing the workload of practitioners is to develop a digital platform where experts give professional advice to patients in order to reduce the number of real-time consultations, which are part of the Universal Basic Services (UBS) and as such are financed by the government. Additionally, such digital platforms improve transparency and health literacy, given that patients may be advised by more than one professional on which step to take next.

In view of the ageing population in the West, it is essential that helping older adults who are marginalized can contribute to an increase in social engagement. By increasing social solidarity and decreasing social burden, lower health care costs are obtained, and a workforce decrement is prevented from happening as the population ages. The latter has positive influences on society; whereas workforce decrement is associated with the involuntary isolation of the elderly from society and subsequently leads to increased health care costs and demands on social services (Kim & Belza, 2017).

An example to promote solidarity in elderly care is demonstrated by The Fureai Kippu welfare system in Japan, in which people earn credits for caring for the elderly, which they can save for themselves as they age, or transfer to other family members (Hayashi, 2012). In the Netherlands, on the other hand, students can live in nursing homes and provide 30 hours of volunteer work per month in exchange for free accommodation (Jansen, 2015).

That people are actually fearful of aging into poverty, and that families feel they do not have the means to support their aging loved ones, is not acceptable, so it should not be accepted.

4.4 A commons-centric economy

An equitable and resilient society is one that has the flexibility to accommodate economic shifts, allows individuals the freedom to pursue the work of their choosing while encouraging an economic environment that provides social and environmental benefits. In this respect, one of the most important components of an equitable and resilient society is the ‘commons economy’. In broad terms, a commons is a community of people who share a resource. Access to the resource in question is regulated by rules agreed upon by the community (Bauwens, 2017). In this sense, commons

are autonomous in that they not only represent both demand and supply, but also adopt the function of market regulator. The focus on community entails that a commons goes beyond a strictly economic model and must instead be conceived of as an essentially social organisation. As such, the commons represents a means to create both economic and social value, since it is based on cooperation rather than competition. From an economic perspective, a commons-based economic model differs radically from the current economic model, where supply and demand rule over pricing mechanisms, which in turn are linked to profit, investments and the rate of production.

From a conceptual point of view, the traditional economic model is extractive. By purchasing a given product, the buyer has obtained the right to possess said product, i.e. to make it part of his or her personal capital. Closely related to extractive economic models is the notion of scarcity (Bauwens, 2017). As the name indicates, scarce materials (so-called ‘heavy products’ in Bauwens, 2017) are limited by definition, which justifies an extractive model. As product supply is partially determined by its degree of scarcity, the price is directly affected by the availability of the product. Hence, scarcity can be a good indication of what a product or service is worth, which further lends support to extractive market-based pricing mechanisms. Nevertheless, the technological developments of the past century or so have given rise to so-called light products (Bauwens, 2017). Light products, like software, are not scarce as they can be copied indefinitely, nor do the creators incur more costs with each distribution. For the sake of progress, it is undesirable that such products should be artificially withheld from the public domain through extractive pricing mechanisms. Luckily, a commons-centric society (Bauwens, 2017) aims to make as many services and products as possible available in the public domain. As a result, extractive models are replaced by generative alternatives, and a market with economic actors becomes a network with users and contributors.

Perhaps the greatest achievement of the commons is that it endorses a social organisation that is based on cooperation, transparency, and intrinsic motivation. Whereas not everyone possesses the same information in hierarchically-structured, value-creating structures, commons strive to spread knowledge and information to all members (Bauwens, 2017). Since commons are a priori universally accessible, such transparency in the distribution of information is encouraged to ensure better management and decision-making.

In contemporary society, time spent working for a salary is valued more than time spent otherwise. To give a concrete example, a stay-at-home parent is not remunerated for their time, whereas a babysitter obviously deserves payment for doing an arguably less elaborate job. Moreover, individuals see themselves forced to work jobs they would rather not do in order to ensure a livelihood. In this case, the salary becomes the main reason why someone chooses to spend time

working. The motivation is extrinsic as it results from the fear of poverty and the desire to acquire money. By contrast, peer-to-peer communities distinguish themselves from profit-seeking firms in that the so called ‘commoners’ (Bauwens, 2017) are by no means required to contribute. Rather, members choose to contribute as they wish. Hence, their contributions are driven by intrinsic motivation²⁵ (Bauwens, 2017). In the long run, the differences between profitable work and hobbies or occupations would become irrelevant and with it, the current stigmatisation against non-salary work.

The more optimistic generative and unbiased approach of peer-to-peer communities, combined with their appeal to intrinsic motivation, is able to dominate in those sectors where both peer-to-peer communities and extractive competitors occur. The example of Wikipedia comes to mind: because of Wikipedia’s accessibility to contributors from the general public, it has an insurmountable competitive edge over the Encyclopaedia Britannica. Likewise, the successes of Über and others reveal the potential of peer-to-peer communities, although Über is, strictly speaking, an example of netarchical capitalism (Bauwens, 2017). Typically, netarchical capitalists such as Über and Facebook make a profit off a platform that accommodates value-creation through peer-to-peer activity (Bauwens, 2017). Ideally, all value created by peer-to-peer participants should be used to further facilitate and promote peer-to-peer activities. Nonetheless, these netarchical capitalists clearly dominate the competitors that do not exploit peer-to-peer technology (Aslam & Aqib, 2017), which again hints at the potential of the commons.

Our blueprint proposes a hybrid value-creating model, in which the commons is not the only avenue for value-creation; the model also leaves room for economic actors to create value according to the principles of scarcity. Ideally, commons-based activities would be responsible for comparatively more economic activity than scarcity-based ones, so that one could truly speak of a commons-centric society. Nonetheless, a fully commons-centric society seems unlikely, due to three concerns that hinder the expansion of the commons. A first problem relates to how commoners are meant to ensure their livelihood if their work immediately becomes part of the public domain without remuneration. In the blueprint, the solution to this problem is considered in the form of a Universal Basic Income (UBI).

By means of pre-distribution rather than redistribution (Bauwens, 2017), basic services and a monetary amount are given to all members of society so that peer-to-peer initiatives are supported.

The second, more challenging question deals with the adaptability of the commons for products that are indeed scarce, which have come to be termed heavy products (Bauwens, 2017). For one, it is difficult to imagine how certain heavy products and the corresponding economic sectors could be commonified on a large scale. Even if a given heavy product is indeed available through a commons in the public domain, other problems may arise. These can in principle easily be prevented by determining how much of a shared resource may be consumed without jeopardizing the resilience and the availability of the resource over time. For instance, peer-to-peer communities that deal in heavy products are susceptible to falling prey to the so-called 'tragedy of the commons' (Hardin, 1968), which occurs when the individual members consume more than they should, i.e. without regard for the needs of the other members and the future generations. Additionally, for many heavy products, it is also necessary to determine what level of joint consumption is most reasonable from an ecological point of view. It seems obvious that ecological considerations should determine joint consumption, which regulates consumption by the individual members.

Finally, the question arises whether supply can meet demand in a truly commons-centric society and whether it is justified to leave demand unsatisfied. Say, for instance, that a famous and well-liked celebrity fully shaves his head. As a result, it is now trendy to shave one's head, and all of a sudden, the demand for razor blades soars. The commoners who are incidentally responsible for razor blades, a scarce (or heavy) product, do not feel like producing more, and so demand remains unsatisfied. Admittedly, this is a trivial example, but the question is much more pressing if farmers, for instance, decided not to meet demand. With the hybrid economy portrayed in the blueprint, the problem does not occur: if the commons cannot meet demand, the potential profit to be made from this market will attract businesses which operate according to principles of scarcity. If for some reason, the scarcity-based fraction of the economy is unable to react on the incentives of demand, which then remains unsatisfied, the government can step in to import the required product or to fund its production with means from the

Risk Fund. Admittedly, when exactly it is justified for the government to step in to satisfy demand remains to be determined, but it seems intuitive that in the case of insufficient food production the government intervenes, whereas it is more debatable whether the government should cater to fashion.

However, our model accommodates this tension by creating a flexible system of value creation, incorporating both the commons and traditional economic structures, which are better suited to deal with scarce products. While the ultimate aim of this future society would be to 'commonify' increasingly more sectors, money-motivated businesses would remain in place for those products and services that are better suited to traditional economic structures. Once the UBI ensures that wage labour is optional, people will have the freedom and flexibility to take part in the value creation system that best suits their needs, aptitudes, and motivations. Moreover, money-motivated firms are taxed in order to sustain the Social Wealth Fund, whereas commons-based contributions, i.e. work that directly benefits everyone, would be exempt from taxation, unless commons sold for profit outside a defined community.²⁶ Additionally, Creative Commons licensing or an adaptation thereof would prevent competitive businesses from patenting and exploiting inventions that have appeared on the public domain as a result of peer-to-peer activity (Creative Commons, 2017).

Moreover, an economic model that encourages commons is better suited to accommodate the incipient automatisisation in many sectors. Currently, automatisisation is not always a welcome development: less labour force is required, with more competitiveness and unemployment as a result. By contrast, the commons are generative, and by consequence they strive to provide products and services to everyone for no cost. Automatisisation does not entail poverty, since it is prevented by the UBI, but simply redounds to more efficiency in providing products in the public domain. Commoners can instead deal with other pressing issues. This highlights the cooperative and evolutive nature of the commons-centric society: once a problem has been dealt with, society jointly deals with the next problem on the way to prosperity for everyone.

Clearly, the hybrid model strives to become more commons-centric over time: activity by the commons is not taxed, participation is made possible thanks to the UBI and it appeals to intrinsic rather than extrinsic motivation. Admittedly, this seems to force people to engage in activity by the commons, although it is

admissible that some individuals may strive to pursue a successful career. In fact, it would still be entirely possible for individuals to strive to attain this goal in the scarcity-based fraction of the economy which still functions with wages. Nonetheless, two remarks are in order. For one, the drift towards a more commons-centric society entails that ultimately all but the most resilient and scarcity-driven heavy products would be produced by the commons. Hence, individuals who seek to pursue a career have limited options, so these individuals may not be fully satisfied with the sector in which they work. However, there is no reason to pursue such a career to begin with: if most things are freely available in the public domain, and buying power becomes less important, there is no advantage to accumulating personal capital.

The more challenging problem, by contrast, is how such an economy would interact on an international level. For the heavy products, the aspect of community in the commons inherently calls to mind rather small-scale, local groups. Admittedly, a drastic change towards a commons-centric society may yield surprising results in terms of productivity and efficiency, yet it certainly seems more intuitive that it should lead to less economic exchange between countries if these countries maintain the current economic models, since production no longer aims for profit and instead seeks to cater to national demand first and foremost. On the other hand, commons may very well overproduce, in which case foreign transactions may form a good outlet for overproduction and an additional means to finance the various funds.

'Commonsense' Drug Pricing Policy

Currently, research on drugs is conducted by private pharmaceutical companies which are funded either by the government or by their own profits from selling popular drugs such as Zoloft (Vaidhyanathan, 2017: p. 59) which they are able to sell at artificially high prices since they hold the patent and, by extension, the exclusive rights to rule over pricing, distribution and manufacturing of their drugs (Vaidhyanathan, 2017: p. 12). Technically, these prices are not justified, since the government funds private research from taxation, so that the population has already covered the costs of developing the drug. If, on the other hand, the government plays no role in funding research, pharmaceutical companies are forced to keep their prices high if they wish to have the funds necessary to conduct research on new drugs. As a result, the pharmaceutical sector is characterised by a so-called 'patent thicket' accompanies an increase of commons-based activity, which in turn entails that more services and products are available in the public domain. Hence, the Universal Basic Income will decrease over the development of the commons-centric society. (Vaidhyanathan, 2017: p. 47), or more fittingly, 'tragedy of the anti-commons' (Vaidhyanathan, 2017: p. 48). Patent thickets occur when researchers of different pharmaceutical companies are unable to share their knowledge due to technology being protected by the many patents, which eventually slows down progress towards better drugs, and more importantly, it has led to what economists have labelled the 'welfare loss', i.e. the fact that it has become more expensive to stay healthy due to popular drugs becoming less accessible.

The commons may disappoint regarding the accessibility and pricing of drugs. If drugs are developed, distributed and manufactured by actors in the public domain without patents, fake drugs may circulate freely (Vaidhyanathan, 2017: p. 6–7). Hence, patents certainly serve their purpose as a reliable indicator of quality in the pharmaceutical industry. However, the need for a patent does not entail that the pharmaceutical companies themselves should have the exclusive right to distribute. Rather, there are two alternative ways more fitting to our model of society which ensure affordable qualitative drugs while catering to demand. On the one hand, further research on less common diseases should not be funded by private companies through revenues from important, yet basic drugs, but rather by the government itself, which would fund and stimulate its universities and research laboratories to invent new drugs while retaining the exclusive right to produce and distribute the drugs at fair prices. As the government has other sources of income, it is not forced to raise its prices artificially.²⁷ Besides, if funds are directed to a limited number of laboratories or universities, knowledge is less fragmented so that progress is quicker, while also ensuring that the negative effect of the patent thicket, viz. high prices, does not occur. A second, perhaps complementary possibility is to grant prizes and grants to the research organisations (including commons) that have solved certain health-related issues for which the government grants monetary remuneration (Vaidhyanathan, 2017: p. 53) while retaining the exclusive right to distribute the invention. Practically, the state cannot provide cheap access to all types of drugs because patents hold on a supranational level, i.e. beyond the boundaries of the proposed alternative society, so that some products will probably have to be imported at higher prices.

4.5 Universal Basic Services: an equitable education system

In addition to the Universal Basic Income (UBI), all members of society are given Universal Basic Services (UBS), which represent an additional building block of the equitable and resilient society. Whereas the UBI hands a monetary amount to all citizens, the UBS offers them access to various kinds of services, ranging from healthcare, education and transportation to legal services. Often, a minimum amount of education and free or affordable health services are considered to be fundamental human rights (Ports, Reed & Percy, 2017; Troncoso, 2018). Many countries offer such basic services to a certain extent: most provide education free of costs up to a certain age, and some countries already offer universal health care. Which services the UBS may cover while remaining affordable is yet to be determined, but it seems uncontroversial that basic education be a representative part of the package. Moreover, education plays a crucial role in society, which is why this subject is highlighted in this section.

Indeed, the very future of any individual is heavily influenced by their education. If all members of society are given more or less equal opportunities for education, equality can severely diminish in the long run. In our society, a fraction of the Social Wealth Fund would serve to finance public education. While it is beyond doubt that an equitable education system is necessary, the question arises as to what exactly constitutes equity in education, and how to best implement relevant policies.

In conversations about equitable education, the terms ‘equity’ and ‘equality’ are sometimes used interchangeably but, as Espinoza argues, the concepts must not be confused:

“The ‘equity’ concept is associated with fairness or justice in the provision of education or other benefits and it takes individual circumstances into consideration, while ‘equality’ usually connotes sameness in treatment by asserting the fundamental or natural equality of all persons.” (Espinoza, 2007)

It is unlikely that all children would receive the exact same education and opportunities, and the UBS is not so ambitious as to completely nullify individual differences. Instead, the public educational systems should try to minimize these differences as far as possible through equitable solutions.

For education to be considered equitable, it must be both fair and inclusive. As defined in an OECD Policy Brief, education is fair when “personal and social circumstances – for example gender, socio-economic status or ethnic origin – should not be an obstacle to achieving educational potential,” (OECD, 2008). Fairness goes beyond mere equality: whereas equality (only) entails that everybody be given an education regardless of personal or socio-economic circumstances, fairness also takes into account the cultural and historical context of the child’s environment. On the other hand, inclusion implies that all individuals be educated to a certain minimum level. For example, all students should be able to read, write, and complete simple maths (OECD, 2008).

It is an immense challenge to implement both conditions into education policy effectively in a way that functions as desired, i.e. as a means to promote fairness and inclusion without adverse effects. Moreover, whatever solution is found now will be outdated in fifty years: as the sociocultural environment changes, so does education. Be that as it may, it seems intuitive that education models that are sensitive to individual children’s needs should be more successful at providing an equitable education.

The documentary *Demain* looks into a Finnish school where children’s success did not rely on standard teaching methods and tests. Instead, teachers modify their style of teaching to fit the needs of the student, who might prefer a kinetic approach to learning. Moreover, teachers tried to create a closer bond with their students, for instance by eating lunch with them. Hence, each student receives an education more or less tailored to their learning preferences. Additionally, the learning program of the Finnish school also pays more attention to values, expression, the process of learning itself. Hence, education can also acquaint students with concepts such as equity, diversity, resilience and civic responsibility while encouraging a critical mindset. Indeed, the students of today should be the responsible citizens of tomorrow. They should be aware of their role as members of a democratic society. The lottery-based representation in the policy system (see 4.6 on citizen-led governance) also requires citizens to be informed about the structure and history of their government.

Furthermore, individuals should be self-reliant to some extent, i.e. they should be able to sew, cook, or execute simple repairs. Education should also teach health

literacy (see below), financial responsibility and respect for the environment, which should offer students a deeper understanding of the world that surrounds them.

The final and most important asset of the 21st century citizen is the faculty to adopt a critical mindset: continuous reassessments enable society to continue improving.

Integrating health literacy into basic education

Health literacy goes far beyond knowing facts about good health; it implies people's cognitive, behavioural, and societal skills and abilities to access, understand, appraise, and apply health information (Sørensen, J. et al., 2012). Its importance is increasingly recognized as research has revealed a correlation between limited health literacy and poor health status. As a result, many attempts have been made to build a comprehensive and integrated conceptual model of health literacy. This model can be used as a tool to help develop interventions that enhance health literacy and in doing so, these interventions promote a healthy lifestyle and support the practice of healthcare and disease prevention (Sørensen, J. et al., 2012).

Because the degree of health literacy of the individual is determined by numerous diverse factors, any comprehensive, systemic model of health literacy should take these stakeholders into account. In the proposed society, professionals from health and social care services would be supported by other stakeholders. With respect to health literacy, for example, the educational sector plays a role in assisting professional caregivers indirectly. Moreover, a part of the responsibility is carried by communities, which can range from immediate care given by the family members, to large-scale organizations that help provide the required medical attention of all sorts, possibly in the form of a commons, as detailed in the healthcare box under section 4.3 on the UBI, entitled "The co-existence of a UBI and the 'care economy'". Due to their recognized status as stakeholders, they would have the possibility to help enhance overall wellbeing and rectify current imbalances or injustice in the healthcare system.

An example of a local initiative to improve health literacy is the *Healthy Eating for Young Children (HEY!)* programme. HEY! is a project which seeks to improve the future health of children in families who live in the most disadvantaged areas by promoting healthy eating to their parents and by promoting Skills for Life learning (Roberts, 2015).²⁸ Such Life Learning skills include literacy, numeracy, the importance of healthy eating and the effects of a proper diet towards the improvement of future behaviour and concentration skills. Such a skill set would allow disadvantaged communities to have more opportunities in the future (HEY project). These Life Learning Skills are taught through practical activities and group discussions in children's centres. An evaluation of the HEY! Programme revealed that parents and caregivers had indeed become more knowledgeable about matters of health as reflected by their checking of food labels.

4.6 Citizen-led governance

As outlined in the previous sections, the proposed model of an equitable and resilient society unconditionally provides individuals with a Universal Basic Income and Universal Basic Services. The recipients of these services should enjoy enough financial freedom to be exempt from the obligation to work for a livelihood. By virtue of the UBS, the basic life necessities of each citizen, including food, shelter and some insurances, should also be covered. The regulation, distribution, and implementation of the UBI and the UBS is led by a policy system (Walker, 1998: p. 14).

This policy system consists of various bodies with different responsibilities. The bodies not only depend on each other system-internally, since they must also continuously adjust themselves and the policies they push to system-external factors, i.e. they must be

flexible with their policies so as to accommodate factors that cannot be controlled through the authority of the bodies, such as natural disasters. Due to this inherent flexibility and the adaptability of policies, the society the bodies represent should be able to deal with all sorts of influences because its policy-system is designed to be resilient (Walker, 1998: p. 8–9).

Strictly speaking, all stakeholders in a certain matter would be guaranteed political representation. On the micro level, the individuals that represent the stakeholders would be selected through a lottery system (Walker, 1998; Van Reybrouck, 2017). The individuals that are selected and wish to be active in policy-making do not jeopardize their livelihood because their expenses are covered by the UBI and the UBS. As a result, decision-making is led by the members from within society who are assisted by experts rather than

by professional politicians. The reasoning for what policies are ultimately implemented is guided by interaction and cooperation between the stakeholders or, more specifically, their selected representatives. Moreover, a bottom-up lottery system allows the stakeholders with most experience in a certain issue, but without professional political background, to offer their insights and solutions (Van Reybrouck, 2017: p. 44–5). Nonetheless, individuals picked through lottery may, of course, decline this responsibility, in which case another potential representative is selected.

The proposed multi-body system with representativeness based on lottery originally derives from Van Reybrouck, who designed a blueprint for what he considers to be a legitimate government (Van Reybrouck, 2017). Van Reybrouck suggests that the selected representatives should be compensated for their efforts, although it is possible that intrinsic motivation suffices to draw volunteers. A citizen jury is legitimate because it promotes representativity while reducing corruption (Van Reybrouck, 2017; Espejo, 2017). “Government of the people, for the people and by the people” is the adage to live by (Espejo, 2017: p. 42).

Responsibilities

a) Capture-signals body

A flexible policy-making system is required because society is in constant flux, provided society in its totality is considered to be a very complex system shaped by interacting factors which may counteract each other and which, as a result, prevent society from attaining a balance or state. Because the contributing factors not only affect society in isolation, but also make other elements fluctuate, it seems intuitive that society is never static. More concretely, ecological, technological, demographic and economic developments continuously disrupt the status quo. If policy fails to adapt to ongoing change, the long-term resilience of society is jeopardized because policy covers other core aspects of the society portrayed, among which the UBI and the UBS (Walker, 1998; Harari, 2011).

Therefore, the policy system should be able to keep track of the fluctuating factors thanks to a body designed for this purpose. Simply put, this capturing body can be said to be attentive to the signals that changing factors emit. Future predictions on the basis of present cues or signals are customary in economics.

The members of this body are picked by lottery and assisted by experts in order better to interpret the meaning of signals. The body then gives feedback on the basis of the captured signals and their implied consequences to the body devoted to the revision and evaluation of implemented policies. In other words, the capturing body and the “policy-revising” body (cf. *infra*) are linked directly to ensure such an exchange of information and feedback (Walker, 1998: p. 64).

b) Revision body

In principle, the policy-revising body intervenes when the captured signals call for an adjustment. It consists of a main body and various sub-bodies dedicated to the different essential mechanisms of society, such as the UBI, UBS etc. Such policy adjustments can come in all shapes and forms, but they all aim towards more optimal policies in the present and for the future by focussing on the resilience of the revised alternatives (Walker, 1998; p. 11).

The revision of existing policy or the introduction of a new policy is a two-step process. First, the sub-bodies capture the signals relevant to their component.²⁹ Once the signals have been interpreted and the problems have been identified, these individual bodies put forward policy reforms, which are then considered together by the main body that endeavours to reach a compromise between the desired revisions for each building block of society. The revisions also directly influence how the means of the Social Wealth Fund are allocated among the components (Van Reybrouck, 2017: p. 1345). This plan is transmitted to the following body, which is responsible for the final vote on the revision plan, and as such it represents the final step before implementation.

In addition to reports from the body that captures signals, people who are not part of that body can appeal to the revision body for problems that have escaped the capturing body. In Hasselt, a city in Belgium, CitizenLab allows people to contribute their ideas to make public spaces more attractive based on their impressions and needs.³⁰

Again, the members of the revision body are drawn by lottery and assisted by experts in the relevant fields, who have expertise in education, economics, health-care etc. The experts lead the discussion and play the role of mediator between non-expert stakeholders and representatives.

c) Voting body

Because implementation ultimately depends on a board of representatives selected by lottery. Hence, it is the citizen rather than the professional politician or policy-maker who determines whether a plan forwarded by the revision body becomes implemented. To ensure responsible decision-making, revision plans should be sufficiently transparent. Ideally, the final vote should take the form of a simple yes-or-no question. Crucially, the contents of the revision plan, i.e. the proposed solutions themselves, should not be the object of discussion at this stage of policy-making, in order to prevent favouritism, lobbying and peer-pressure from threatening voter independence (Van Reybrouck, 2017: p. 135). Additionally, a new board of voting representatives is selected each time a revision plan is presented. In Scotland, for instance, a citizen jury participates in discussions on health-care issues (Scottish Health Council, 2018).

Because different stakeholders, often characterized by contradicting motives, are in principle equally represented politically, it would be difficult to attain unanimity. Hence, for a policy to be implemented, it should be approved by at least to two thirds of the members (Walker, 1998: p. 66). If a revision fails to reach the required majority, it is sent for review to the capturing body, which will reevaluate it with respect to the signals before the policy-revising body is given new instructions.

Nonetheless, this discussion of policy leaves several gaps unaddressed. For instance, how accepted revisions are to be implemented and enforced, or how many voters are required to guarantee proper representation of each stakeholder remains in the dark for now and requires more empirical testing (see Carson et al., 2004). Furthermore, social media are said to influence public opinion and indirectly, policy-making, but the exact details of this influence must also be left to future research (Espejo, 2017: p. 42).

4.7 Law and governance

Checks and balances

The governance of the envisioned society seeks to maintain a strict division between the judicial, legislative, and executive organs (or ‘bodies’).³¹ Although this division is often attributed to Montesquieu’s *De l’esprit des lois* (1748), Montesquieu did not suggest that these powers should be divided. Rather, he

recognized and highlighted the need for these powers to be balanced (Foqué et al., 2009: p. 347). If there are strict divisions between the three powers, then the division is also found in the organs that represent these powers. By contrast, the way in which the law is applied in the society at hand is more flexible. Hence, the law must not necessarily be applied in a word-by-word fashion if a more equitable solution can be attained with a little tweak in the interpretation of the law. For instance, the judges of administrative bodies enjoy some discretionary powers that allow them to act on a case-by-case basis, which often results in a verdict considered more equitable and fair to the general public. Besides, if the law were to be applied literally, both the legislating and the implementing organs would face difficulties. The legislator cannot appeal to general clauses, because every clause should be able to cover all possible scenarios, while it should be sufficiently specific to be functional and efficient according to the implementing body.

Nonetheless, such discretionary powers come with much responsibility and authority, which may have dire consequences if these powers are used incompetently or with evil intent. Hence, the judge or the administrative body concerned should not decide autonomously. Instead, the verdict will first be reviewed by two additional instances, which must also support the decision. Because the judicial system is based on checks and balances, the judicial organ as a whole is held accountable for any decision made *contra legem*, i.e. a verdict that violates the law in some respect according to some other law. In addition to the system-internal checks and balances, the public also guards against unfair verdicts. In fact, it is through a diagnosis of public opinion that the fairness of a passed judgment or a new law is assessed (Beyens & Vanhamme, 2008: p. 350).

In sum, the law is an instrument that helps to regulate society, but it does so in a way that promotes fair treatment where it is justified. For such a system to be resilient, the verdicts must be the results of the proper balance between (i) the adaptability of the law and (ii) the different checks that hamper or encourage the proposed verdict, viz. the public and the two additional bodies that validate the decision by the judging instance.

Law of the Commons

The commons-centric economy of this hypothetical society is not free from the influence of the judicial,

legislative or executive powers. This section focuses on the benefits proper policy-making can have for the commons. Three points are relevant in this respect.

First, legislative power can provide the legal frame necessary for the commons to be universally accessible, and to formulate a legal definition of a commons on the basis of certain characteristics. Guaranteeing legal access to the commons, entails that the commons cannot discriminate against any potential candidate. Otherwise, they are no longer defined as commons, because they do not evince the core characteristics of a commons, namely transparency and universal accessibility. Hence, legislative power ensures that the commons remain unbiased and by extension, it redounds to more equitability for society as a whole (Bollier, 2015).³²

A second aspect of judicial power that protects the commons is *intellectual property law*, which provides legal boundaries to the use of ideas. At present, being the creator of a revolutionary idea often comes with financial benefits, thanks to their exclusive right to market their invention as they see fit. Although intellectual property law is often invoked to create or maintain a monopoly, it does prevent the invention from being exploited. In a commons-centric society, where the boundary between private property and the public domain is blurred, intellectual property law can protect the commons and their inventions. Otherwise, any idea by the commons would quickly be exploited by businesses of the scarcity-based fraction of the economy. More concretely, intellectual property should be designed in such a way as to permit the exchange of knowledge and information while protecting the original inventor. A successful open source initiative that resembles intellectual property law and that encourages the spread of information while acknowledging the wishes of the inventor, is the Creative Commons Licences³³ by Larry Lessig, which allow the inventor to choose which aspects of property rights he or she wishes to retain in a modular fashion.³⁴

Finally, the commons can be protected through a so-called *legal generality*, a legal concept first introduced by Ann Carette in 1997. A legal generality is a property regime, composed of rights and obligations, which is meant to protect the environment and the goods and services it provides.³⁵ More specifically, it obliges individuals and the government to respect the environment. If this obligation is violated, compensation is due, which is spent into rebuilding the damaged

ecology. In order to safeguard the existence of the biosphere, the regime and the protection they offer would remain a part of governance, on top of the existing rules for the different aspects of ecology as it were. Concretely, the concept of a 'legal generality' introduces a property regime that serves as an overarching structure. Its protection rules would come on top of the already existing rules of each individual component of the ecosystem.

5 Bringing It All Together

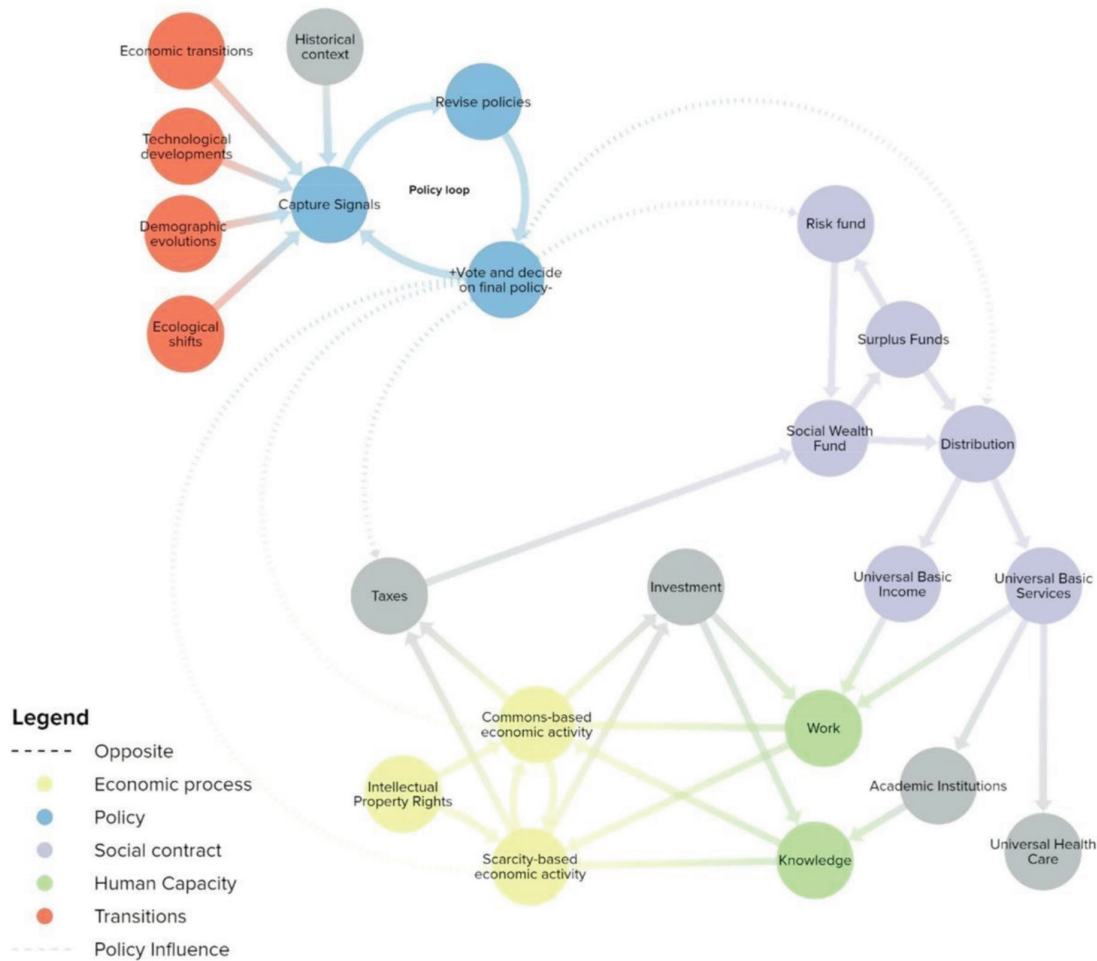
5.1 Overview of the map

The functional building blocks that constitute the core of the envisioned society interact with each other. All components are designed to be flexible and self-organizing, which contributes to the resilience of society as a whole. For example, the yellow zone on the blueprint, which represents the value-creating elements³⁶ in the model, embodies the hybrid economic sector which leaves room for the currently prevailing scarcity-based pricing mechanism and market economics, while also facilitating and encouraging commons initiatives. Although, most occupations, products and services should become commonified in the long run, the system is supposed to allow a flexible exchange of value-creating activity between the economic models. Another component that is developed to be resilient is the proposed system of governance, which is characterized by a bottom-up approach to political representation and an unbiased voting mechanism.

In addition to its resilience, the society was designed with an eye on equitability. In this respect, the Universal Basic Income is meant to allow each member of society to dispose of their time as they think to be valuable. Similarly, the Universal Basic Services provide additional security as they include basic health services etc. As to equitable political representation, the unbiased selections of citizens in governance further democratizes the political sphere.

The blueprint can be explained by focussing on three main areas of the map:

1. The policy loop (blue), which consists of the capture-signals body, the revision body, and the voting body. This loop captures the way in which society is governed.



2. The ‘social contract’, which is represented by the social wealth fund, the risk fund, the surplus fund and the way in which money is distributed. This part of the blueprint is meant to tackle social issues and problems of equitability in society.
3. The economic cluster (yellow) which incorporates commons-based and scarcity-based activity. This loop is responsible for the creation of value.

As is often the case with systems maps, the elements are not all linked by the same kind of connection. Hence, the three sections, viz. the elements they incorporate, do not share the same types of interaction in the blueprint. For the elements of the social contract, the arrows refer to a flow of effort. The value-creating cluster of the map is characterized by connections that represent the exchange of activity between economic models. The dotted arrows of the policy loop are meant to display the encompassing influence of governance on the system. Furthermore, the blueprint also

considers the influence of society on policy and governance, by incorporating ‘Historical context’ as a contributing factor, and through the factors in red. First, we explain how the policy loop is linked to the other sections of the map. Then, we describe how the social contract and the value-creating elements are connected. Together, these two aspects of the map highlight the most crucial features and values of the society portrayed.

5.2 Policy Loop

The use of ‘loop’ in this context does not really correspond to how loops are normally found in systems maps, viz. as ‘reinforcing loops’ or loops that have a dynamic of their own. In this policy loop, by contrast, the connections represent the flow of the signals from their capture until they have been integrated in a revision plan that is accepted by the voting body. If the voting body rejects the proposition, i.e. if more than a third of

the voting board refuses the revision plan, it is again submitted to the body that captures signals, effectively completing the feedback loop. The multitude of different bodies and the feedback loop ensure that a proposition to revise policy has been reviewed by many stakeholders and experts before being implemented. Hence, the policy system derives its resilience from the many checks and balances it incorporates.

The policy loop and its bodies are meant to be flexible and self-organizing, which enables society to quickly adapt to external influences. In practice, the bodies are resilient because they are composed of the citizens concerned, selected through lottery each time a new vote takes place.

Such a bottom-up approach to leadership and policy-making not only ensures more political representation for all stakeholders involved, but it also enables society to be informed of incipient problems as soon as they arise, thanks to knowledge acquired by otherwise unrepresented stakeholders and members of society, tackling the issue of inequality in the process. Nevertheless, the citizens are assisted by experts in policy-making, who play a mediating role between stakeholders in the discussion while ensuring that the process of decision-making proceeds smoothly and efficiently.

Directly or indirectly, the policy-making procedure influences virtually all of society, which is represented by the dotted arrows between the policy loop and the other essential components. It is safe to say that the opposite also applies: society exerts an influence on policy-making. This influence is accommodated by the structure of society in two ways. For one, individuals who were not selected to become political representatives, but who wish to report an issue or concern that escaped the signal-capturing body, can directly address the revision body. Secondly, the capturing body is directly affected by the element glossed 'historical context', which can be taken to correspond to the influence of culture on the system of governance.

5.3 Financial Freedom

Currently, it is necessary to have an income if one wants to escape poverty and the consequences thereof. As a result, individuals are coerced into unsatisfactory jobs through the dynamics of the job market. By contrast, respecting the fundamental freedom of the individual constitutes one of the core values of the society portrayed by the blueprint. This

principle is meant to prevent individuals being led by desperation due to their financial situation. Rather, the individual is free to dispose of his or her time as desired, leading to intrinsic motivation driving productivity, thanks to the Universal Basic Income and the Universal Basic Services. Both these components significantly reduce inequality in society, because they impart equal opportunities to all members of society, who are now able to devote themselves to an occupation that is fulfilling and that best suits their goals and abilities.

In the blueprint, this flexibility is embodied in the economic cluster of the map and its connections. Here, the arrows refer to flows of resources, i.e. monetary flows and the flows of activity in hours that are spent contributing to value-creating activity. The former type applies to arrows such as the one that links the commons-based and the scarcity-based economic models to the element named 'Taxes'. By contrast, the arrows that link both types of economic models represent a fluctuating complementary exchange between models with respect to economic activity, i.e. 'working' hours and investments spent in the respective economic models.

6 Gaps & Future Research

After grasping the complexity of the issues plaguing society, the research team sought to identify which mechanisms could be implemented to address and solve these wicked problems, which were then brought together in a schematic representation of what is designed to be a resilient and equitable society. Nonetheless, a number of topics and issues were not addressed in this study. Obviously, the ambitious goal of the study does not permit an in-depth treatment of all relevant aspects but, more importantly, there simply is no one-size-fits-all solution to any wicked problem: every initiative may have both intended and unintended consequences regardless of its intention.

Our research includes many gaps with respect to the implementation of the proposed alternatives, especially so with regard to the society's governmental and economic structure. Moreover, some of these mechanisms, among which the Universal Basic Income, the Social Wealth Fund, and a large-scale commons-centric economy, are yet to be tested empirically. While collaborative forms of value-production would thrive in a society that provides the necessary legal framework and legal protection, it

remains unclear how commons are to manufacture and distribute certain scarce products. Moreover, the question arises as to how the commons, which do not seek profit, would be stimulated to satisfy demand; or whether the commons should be taxed, provided they have a revenue. Due to the spread of collaborative production, research will probably address these blind spots in the near future.

As for the UBI, many academics and economists have discussed its potential benefits and drawbacks, yet there is still a distinct lack of real world examples: to our knowledge, only one program comes close to satisfying the conditions of UBI.³⁷ Therefore, many questions relating to its implementation and the consequences it may have remained unanswered. More specifically, the effects of a large-scale implementation of the UBI on productivity and motivation cannot be predicted with certainty. By extension, the same applies to social wealth funds.

Whereas the former gaps are intrinsically linked to research on wicked problems, the complexity of the issue and the limited scope of the study resulted in a second source of topics on which the team lacked information. For example, while we discuss economic reforms and policy programs at length, there is little attention for social issues,³⁸ and only indirect consideration of environmental factors.³⁹ Discussions on international policy, by contrast, do not figure in this study altogether.

Yet, these aspects equally contribute to the complex issue at hand. Therefore, our modular approach to an equitable and resilient society is highly simplified, as it focuses on a domestic scenario. Nevertheless, this paper hopes to represent an important step towards designing a future society that is both equitable and resilient. As mentioned in the opening section, no single field of expertise can single-handedly tackle any wicked problem, especially one that involves designing a society from scratch. Nonetheless, the challenge from which the incentive to research this topic derives will stimulate a different transdisciplinary team of graduate students to pick up where we left off and to keep improving our utopian model of society in future years.

Supplementary Materials

- 1) Original Challenge Document “BANK OF TRANSDISCIPLINARY CHALLENGES”,

KULeuven Transdisciplinary Challenge submission form

- 2) Symposium Presentation: Transdisciplinary Insights Challenge, “Our Current Predicament”, 4 July 2018.

Notes

- 1 Full title in Latin *De Optimo Reipublicae Statu deque Nova Insula Utopia*.
- 2 Originally *Dutch Utopisch Alfabet: honderd toekomstvisies*.
- 3 Wicked problems are defined as problems that “defy complete definition and cannot be solved using existing modes of inquiry and decision making. Moreover, no final solutions for such problems are possible since any resolution generates further issues.” (Bernstein, 2015)
- 4 “Transdisciplinarity” should not be confused with “multidisciplinarity” or “interdisciplinarity”, which do not involve as much exchange between the disciplines involved.
- 5 Programs of study: Philosophy, International Business, Linguistics, Digital Humanities, Criminology, Physics, International and European Law, and Biomedical Sciences.
- 6 Kim Becher and Philippe Vandebroek are part of the core team at ShiftN and work on a wide range of projects as researchers, facilitators, and systems thinkers.
- 7 Contrary to the customary actor constellation game, there was no role-playing involved.
- 8 For more information see: <https://www.demain-lefilm.com/en/film>
- 9 The books read are the following: A. Atkinson, *Inequality. What can be done?*; A. Rand, *Capitalism: The Unknown Ideal*; D. Van Reybrouck, *Against Elections*; J. Rifkin, *Zero Marginal Cost Society*; T. More, *Utopia*; N. Georgescu-Roegen, *The Entropy Law and the Economic Process*; P. Van Parijs, *Just Democracy: The Rawls/Machiavelli Programme*; Plato, *The State*; T. Sedlacek, *Economics of Good and Evil*
- 10 <https://www.kumu.io/>
- 11 Jef Peeters is Emeritus Professor Social Philosophy Ethics at the KU Leuven, Anne Snick is freelancer at SAPIRR, board member of Club-of-Rome EU Chapter, and founding member of Arne Loosveldt Fonds.
- 12 For more information see: <http://www.ldf.gov.mw/ldf-programmes/led/>
- 13 For more information see: <https://apfc.org/>
- 14 For more information see: <https://www.regjeringen.no/en/topics/the-economy/the-governmentpensionfund/id1441/>

- 15 For more information see: <http://www.futurefund.gov.au/>
- 16 See references for websites.
- 17 Thomas Paine, 'Agrarian Justice' pamphlet published in 1797
- 18 The unemployment trap occurs when being unemployed is more advantageous than working a low-paid job, which leads to people trying to remain unemployed for as long as they can (https://en.wikipedia.org/wiki/Welfare_trap)
- 19 See Richard Pereira, 'Financing Basic Income: Addressing the Cost Objection' for an elaborate discussion on this topic.
- 20 See Damon Jones & Ioanna Marinescu, 'The Labor Market Impacts of Universal and Permanent Cash Transfers: Evidence from the Alaska Permanent Fund.' for further discussion on this topic.
- 21 Win for Life is a Belgian lottery game. As the title implies, winning guarantees a life-long income (<https://www.nationale-loterij.be/nl/onze-spelen/win-for-life>).
- 22 Experiments running in 2018 are: Ontario Canada, 6000 participants receive up to 17000 dollars per year on a monthly basis; In the Netherlands cities (Groningen, Wageningen and Tilburg) make social benefits unconditional; In the USA a Silicon entrepreneur, Sam Altman, plans to give 1000 people 1000 dollars a month for a five year period; In Kenia there is a village whose inhabitants receive cash payments from charity organisation Give directly; in Finland the Kela experiment.
- 23 See www.kela.fi for more information.
- 24 If the participants know that in two years they must again seek work for fear of poverty and lack of a sustaining income, it is perhaps more likely that they see the experiment as a short-term opportunity for an easy income, since they cannot truly devote themselves to their non-lucrative vocations over two years' time if they know that they will ultimately wind up on the job market again.
- 25 Admittedly, there may be reasons other than the fear of poverty or precarity that may drive people to work against their will. For instance, stigmatisation may still affect those who wish not to contribute, so that they are again pressured into working against their will. However, our society addresses the problem of stigmatization in other ways. Therefore, I assume that intrinsic motivation is the main cause of contributions.
- 26 Admittedly, fewer traditional money-accumulating firms directly entail fewer taxes and consequently less capital in the Social Wealth Fund. However, this is not per se problematic since the decrease of firms
- 27 The Doha Declaration on TRIPS and Public Health (cited in Vaidhyanathan 2017: p. 65-66) declares that governments already have the right to produce cheap versions of necessary drugs when they are unaffordable. Examples are drugs that treat HIV, tuberculosis and malaria. See http://www.who.int/medicines/areas/policy/doha_declaration/en/ for more information.
- 28 In addition to promoting the importance of healthy eating, another such skill would be literacy or basic mathematics, which is aimed at bettering the chances of disadvantaged communities.
- 29 It is beyond the scope of this paper to discuss how a classification of signals can best be made, but this can be arbitrary: categorizing the signals is a matter of methodology and must not necessarily have any empirical foundation.
- 30 For additional information see: <https://www.citizenlab.co/blog/cases/hasselt/>
- 31 The legislative power "makes" the law, the executive power covers its implementation, and the judicial power controls and regulates the execution of the law.
- 32 "People in the thirteenth century arguably had stronger legal rights to subsistence and survival than people do today. Thanks to Magna Carta and its companion document, the Charter of the Forest, people had guaranteed legal access to the forest to gather firewood, water for drinking and planting, acorns for their pigs, the right to hunt wild game and collect fruit, and much else" (Bollier, 2015).
- 33 For further information see: <https://creativecommons.org/about/>
- 34 Another example is Stallman's idea of open source software and the creation of the General Public Licence.
- 35 In theory, there are 4 types of property regimes: (i) private property, which is said to belong to a private instance; (ii) common property, which belongs to everybody equally, like sunlight or the air we breathe; (iii) public property, i.e. goods and products monopolized by public authorities; and finally (iv) open-access property, which refers to things that have no owner yet, such as wild animals (Guerin, 2014).
- 36 "Value-creating elements" would roughly correspond to whatever elements currently produce economic activity. However, 'value' is currently tied to monetary value and for an activity, product or service to be considered valuable, there must often be an economic profit to it (see Section 4.4 on the commons-centric society).
- 37 This is the Alaska Permanent Fund Dividend, created in 1982 (Van Parijs, 2004)

- 38 This includes issues of racial, gender, and sexual orientation discrimination and bias, police brutality, women's reproductive rights, domestic violence, etc.
- 39 While global warming was mentioned as part of the problem, and some initiatives will likely have positive effects on this aspect of the problem there are outstanding concerns related to climate change related migration.

References

- "A respectable result for the Sovereign Money Initiative." *Vollgeld-initiative*, 10 June 2018. Retrieved from: <https://www.vollgeld-initiative.ch/english/>
- Abicht, L., Absillis, K., & Aelberts, J. *Utopisch alfabet: honderd toekomstvisies*. De Bezige Bij Antwerp, 2011.
- "About basic income." *Basic Income Earth Network*, 2018. Retrieved from: <https://basicincome.org/>
- "About the Licenses." *Creative Commons*, 2017. Retrieved from: <https://creativecommons.org/licenses/>
- Achterhuis, H. *Het rijk van de schaarste*. Utrecht: Ambo. 1988.
- Aslam, A. & Shah, A. "Taxation and the Peer-to-Peer Economy." *International Monetary Fund*, no. 17/187, 8 Aug 2017. Retrieved from: <https://www.imf.org/en/Publications/WP/Issues/2017/08/08/Taxation-and-the-Peer-to-Peer-Economy-45157>
- Atkinson, A. *Inequality. What can be done?* Cambridge, Massachusetts: Harvard University Press, 2015.
- "Australia's Sovereign Wealth Fund." *futurefund*, 2018. Retrieved from: <http://www.futurefund.gov.au/>
- Bauwens, M. *De Wereld Redden: Met peer-to-peer naar een postkapitalistische samenleving*. Antwerpen/ Utrecht: Houtekiet, 2013.
- Bauwens, M. *PEER-TO-PEER: Manifest voor een commons transitie*. Brussel: Oikos, 2017.
- Beck, U. *Risk Society: Towards a New Modernity*. Translated by Ritter, M. SAGE, 1992.
- "Benoeming Cédric Frère in Regentenraad was beslissing van regering: 'Politiek gekonkel van pure machtspartij'." *HLN*, 26 April 2018. Retrieved from: <https://www.hln.be/nieuws/binnenland/benoeming-cedric-frere-in-regentenraad-was-beslissing-van-regering-politiek-gekonkel-van-pure-machtspartij~a339fdee/>
- Bernstein, J. H. "Transdisciplinarity: A review of its origins, development, and current issues." *Journal of Research Practice*, 11(1), Article R1. 2015. Retrieved from: <http://jrp.icaap.org/index.php/jrp/article/view/510/412>
- Beyens, K. & Vanhamme, F. "Onderzoek naar rechtspreken als sociale praktijk." *Tijdschrift voor Criminologie*, vol. 51, no. 4, 2008, pp. 350–360.
- Bollier, D. "The Commons as a Tool for Sharing the Wealth." *Commons Strategies Group*, 21 Oct 2015. Retrieved from: <http://commonsstrategies.org/the-commons-as-a-tool-for-sharing-the-wealth>
- Bregman, R. *Gratis geld voor iedereen*. Amsterdam: De correspondent, 2014.
- Briony, H. "What is a sovereign wealth fund." *World Economic Forum*, 13 Oct 2017. Retrieved from: <https://www.weforum.org/agenda/2017/10/what-you-need-to-know-about-sovereign-wealth-funds/>
- Brown, C. "The Construction of a 'Realistic Utopia': John Rawls and International Political Theory." *Review of International Studies*, vol. 28, no. 1, 2002, pp. 5–21. Retrieved from: www.jstor.org/stable/20097776.
- Bruenig, M. "A Simple Fix for Our Massive Inequality Problem." *The New York Times*, 30 Nov 2017. Retrieved from: <https://www.nytimes.com/2017/11/30/opinion/inequality-social-wealth-fund.html>
- Carette, A. *Herstel van en vergoeding voor aantasting aan niet-toegeëigende milieu bestanddelen*. Antwerp: Intersentia, 1997.
- "Citizens' Jury." *Scottish Health Council*, 2018. Retrieved from: http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/citizens_juries.aspx
- Coleman, E. A. & Liebertz, S. S. "Property Rights and Forest Commons." *Journal of Policy Analysis and Management*, vol. 33, no. 3, 6 May 2014, pp. 649–668. <https://doi.org/10.1002/pam.21766>
- Deboosere, P. P. "Demographic Challenges of the 21st Century." *VUB*. 2018. Retrieved from: <http://www.vub.ac.be/en/demographic-challenges-21st-century>
- Demain*. Directed by Mélanie Laurent and Cyril Dion. 2017.
- EC. "Collaborative Economy." *European Commission*. 2018, June 29. Retrieved from: http://ec.europa.eu/growth/single-market/services/collaborative-economy_en
- Elser, J. "Comment on van der Veen and Van Parijs." *Theory and Society*, vol. 15, no. 5, 1986, pp. 709–721.
- Espejo, R. "Cybernetic Argument for Democratic Governance: Cybersyn and Cyberfolk." *Cybernetics: State of the Art*, edited by Werner, L. C., Universitätsverlag der TU Berlin, 2017, pp. 34–57.
- Espinoza, O. "Solving the Equity–Equality Conceptual Dilemma: A New Model for Analysis of the Educational Process." *Educational Research*, vol. 49, no. 4, 2007, pp. 343–363. DOI: 10.1080/00131880701717198
- Foqué, R., Orshoven, P. V., Van Gerven, W., Raymaekers, B., & Vandeurzen, J. "Debat: De scheiding der machten." *Ethische Perspectieven*, vol. 19, no. 4, 2009, pp. 346–373. Georgescu-Roegen, N. *The Entropy Law*

- and the Economic Process. Massachusetts: Harvard University Press, 1971.
- Goodwin, M. "New Report: The Rise of Populist Extremism in Europe." *Chatham House*. 2018. Retrieved from: <https://www.chathamhouse.org/media/news/view/178303>
- Graeber, D. *Bullshit Jobs: A Theory*. New York: Simon & Schuster, 2018.
- Graeber, D. *Debt: The First 5,000 Years*. New York: Melville House Publishing, 2011.
- Guerin, K. "Property Rights and Environmental Policy: a New Zealand Perspective." *New Zealand Treasury*, 1 March 2003, pp. 1–42.
- Gupta, S., Brown, D. & Gingerich, C. "Episode 13: Building the Caring Majority (w/Sarita Gupta)." *The Next System Project*, 6 Dec 2017. Retrieved from: <https://thenextsystem.org/learn/stories/episode-13-building-caring-majority-w-sarita-gupta>
- Harari, Y. N. *Sapiens: A Brief History of Humankind*, London: Vintage Books, 2011.
- Hardin, G. "The Tragedy of the Commons." *Science*. vol. 162, 1968, pp. 1243–1248. doi:10.1126/science.162.3859.1243
- Hayashi, M. "Japan's Fureai Kippu Time-banking in Elderly Care: Origins, Development, Challenges and Impact." *International Journal of Community Currency Research*, 16 Aug 2012, pp. 30–44. <http://dx.doi.org/10.15133/j.ijccr.2012.003>
- Hayward, T. "Global justice and the distribution of natural resources." *Political Studies* (54), 2006, pp. 349–369.
- IMF. "IMF Fiscal Monitor: Tackling Inequality, October 2017." *International Monetary Fund*. 2017, October. Retrieved from: <http://www.imf.org/en/Publications/FM/Issues/2017/10/05/fiscal-monitor-october-2017>
- International Forum of Sovereign Wealth Funds*. IFSWF, 2018, <http://www.ifswf.org>.
- Investopedia. "Sovereign Wealth Fund - SWF." *Investopedia*, 2018. Retrieved from: https://www.investopedia.com/terms/s/sovereign_wealth_fund.asp
- IPCC. *Climate Change 2014: Synthesis Report*. 2014. Retrieved from: https://www.ipcc.ch/pdf/assessment-report/ar5/syr/SYR_AR5_FINAL_full_wcover.pdf
- Jansen, T. R. "To Save on Rent, Some Dutch College Students Are Living in Nursing Homes." *The Atlantic*, 5 Oct 2015. Retrieved from: <https://www.theatlantic.com/business/archive/2015/10/dutch-nursing-home-collegestudents/408976/>
- Kim, B. & Belza, B. "Toward an Equitable Society for Every Generation." *Journal of Gerontological Nursing*, vol. 43, no. 11, 2017. doi:10.3928/00989134-20171012-01.
- Lansley, S. "How Social Wealth Funds Could Help Tackle Inequality." *The Political Quarterly* (86.4) 2015, pp. 563–572.
- Lennartz, C. & Ronald, R. "Asset-based Welfare and Social Investment: Competing, Compatible, or Complementary Social Policy Strategies for the New Welfare State?" *Housing, Theory and Society* (34.2), 2017, pp. 201–220.
- Lietaer, B. & Dunne, J. *Rethinking Money: How New Currencies Turn Scarcity into Prosperity*. San Francisco: Berrett-Koehler Publishers, 2013.
- "Making Money and Banking Work for Society." *Positive Money*, 2018. Retrieved from: <http://positivemoney.org/>
- Mason, P. *Postcapitalism: A Guide to Our Future*. London: Allan Lane Publishers, 2016.
- Mathys, Eric. Personal interview. 12 Dec 2017.
- Marx, K. & Engels, F. *The Communist Manifesto*. The Floating Press, 2009.
- Marx, I. "Zou jij nog werken met een basisinkomen?" *YouTube*, uploaded by Universiteit van Vlaanderen, 23 Apr 2018, <https://www.youtube.com/watch?v=Pu1tdoMk3Zg>.
- Mccann, D. "7 Principles for a Sovereign Wealth Fund." *New Economics Foundation*, 25 May 2017. Retrieved from: <http://neweconomics.org/2017/05/7-principles-sovereignwealthfund/>
- Middelkoop, W. *Als de dollar valt. Alles over de kredietcrisis*. Amsterdam: Nieuw Amsterdam, 2007.
- More, T. *Utopia*. Translated by Adams, R. M. Cambridge: Cambridge University Press, 2016.
- Nozick, R. *Anarchy, State, and Utopia*. New York: Basic Books, 1974.
- OECD. "Ten Steps to Equality in Education." *Organisation for Economic Co-operation and Development*, Jan 2008. Retrieved from: <https://www.oecd.org/education/school/39989494.pdf>
- Paine, T. *Agrarian Justice*. New York: Simon & Schuster, 2013.
- Paul, J. *Thomas More*. Cambridge: Polity Press, 2017.
- Piketty, T. *Capital in the Twenty-First Century*. Translated by Arthur Goldhammer. London: The Belknap Press of Harvard University Press, 2014.
- Plato, *The Republic*. Translated by Griffith. Cambridge: Cambridge University Press, 2000.
- Pogge, T. "Eradicating Systemic Poverty: brief for a global resources dividend." *Journal of Human Development* (2.1), 2001, pp. 59–77.
- Pohl, C. & Hadron, G. H. "Methodological challenges of transdisciplinary research." *Nature Sciences Sociétés*, vol. 16, 2008, p. 111–121. doi: 10.1051/nss:2008035
- Pohl, C., Krütli, P. & Stauffacher, M. "Ten reflective steps for rendering research societally relevant." *GAIA-Ecological Perspectives for Science and Society*. 2017, 26(1), p. 43–51. Polis, H. (ed.) *Utopisch Alfabet. Honderd toekomst visies*. Antwerpen: De Bezige Bij, 2011.

- Ports, J., Reed, H., & Percy, A. "Social Prosperity for the Future: A proposal for Universal Basic Services." *Social Prosperity Network*, Institute for Global Prosperity, 2017. Retrieved from: https://www.ucl.ac.uk/bartlett/igp/sites/bartlett/files/universal_basic_services__the_institute_for_global_prosperity_.pdf
- Rand, A. *Capitalism: the Unknown Ideal*. New York: Signet, 1967.
- Rawlings, L., Sherburne-Benz, L. & van Domelen, J. *Evaluating Social Funds: a Cross-Country Analysis of Community Investments*. Washington: The World Bank. 2004.
- Rawls, J. *A Theory of Justice*. Harvard University Press, 1971.
- Richard, M. "Norway fund blocked from private equity investment." *Financial Times*, 14 Apr 2018, p.11. Retrieved from: www.ft.com/content/2092083c-3cb5-11e8-b7e0-52972418fec4
- Rifkin, J. *The Zero Marginal Cost Society*. New York: Saint Martin's Press, 2014.
- Roberts, J. "Local action on health inequalities: Improving health literacy to reduce health inequalities." *Public Health England*, September 2015. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf
- Rousseau, J. J. "Ideal Empires and Republics. Rousseau's Social Contract, More's Utopia, Bacon's New Atlantis, Campanella's City of the Sun." Washington: M. Walter Dunne. 1901. Sedlacek, T. *Economics of good and evil*. Oxford: Oxford University Press, 2011.
- Sørensen, J. et al. "Health literacy and public health: A systematic review and integration of definitions and models." *BMC Public Health*, vol. 12, no. 1, 2012.
- "Stichting Ons Geld." *Ons Geld*, 2018. Retrieved from: <https://onsgeld.nu/over/ons>
- Sundararajan, A. "The Future of Work." *International Monetary Fund*. 2017. Retrieved from: <http://www.imf.org/external/pubs/ft/fandd/2017/06/sundararajan.htm>
- Troncoso, S. "Universal Basic Services." *Institute for Global Prosperity*, 16 Feb 2018. Retrieved from: <https://blog.p2pfoundation.net/universal-basic-services-could-work-better-thanbasicincome-to-combat-rise-of-the-robots/2018/02/16>
- UN. "Report on the World Social Situation 2011." *United Nations Department of Economic and Social Affairs*. 2011.
- Vaidhyanathan, S. *Intellectual Property: A Very Short Introduction*. Oxford University Press, 2017.
- van der Meer, T. W. G. "Political Trust and the "Crisis of Democracy"." *Oxford Research Encyclopedia of Politics*. 2017 Jan 25. Retrieved from: <http://politics.oxfordre.com/view/10.1093/acrefore/9780190228637.001.0001/acrefore9780190228637-e-77>
- Van De Velde, Antoon. Personal interview. 14 Dec 2017.
- Van Parijs, P. "Basic Income: A Simple and Powerful Idea for the Twenty-First Century." *Politics & Society*. Sage Publications, vol. 32, no. 1, March 2004, pp. 7–39.
- Van Parijs, P. *Just Democracy: the Rawls-Machiavelli Programme*. Colchester: ECPR Press, 2011.
- Van Parijs, P. "Why Surfers Should be Fed: The Liberal Case for an Unconditional Basic Income." *Philosophy and Public Affairs*, vol. 20, no. 2, 1991, pp. 101–131.
- Van Reybrouck, D. *Against Elections: The Case for Democracy*. Translated by Liz Waters. New York: Seven Stories Press, 2016.
- Van Reybrouck, D. *Tegen verkiezingen*. Amsterdam/Antwerpen: De Bezige bij, 2017.
- Vande Moere, Andrew. Personal interview. 8 Dec 2017.
- Varoufakis, Y. *And the Weak Suffer What They Must?: Europe, Austerity and the Threat to Global Stability*. London: The Bodley Head, 2016.
- Walker, J. "The viable systems model: A guide for co-operatives and federations." *ICOM*, 1998. Retrieved from: http://www.scio.org.uk/resource/vsmg_3/pdf/vsmg_2_2.pdf
- "We Want to Democratize Money." *International Movement for Monetary Reform*. 2018. Retrieved from: <https://internationalmoneyreform.org/>
- Zeddies, L. "Money Creation and Inequality An Underexposed Topic for Monetary Reformers." *International Movement for Monetary Reform*, 6 January 2018. Retrieved from: <https://internationalmoneyreform.org/news/2018/01/money-creation-inequalityunderexposed-topic-monetary-reformers/>

BANK OF TRANSDISCIPLINARY CHALLENGES

SECTION 1 OF 5 (BANK OF TRANSDISCIPLINARY CHALLENGES)

Dear,

Welcome to the Bank of Transdisciplinary Challenges!

This is an initiative where people concerned about the future translate their concern into a scientific challenge. The challenge typically revolves around a specific society, environment, and/or business problem or opportunity that you want to be addressed by a transdisciplinary research team.

Are you concerned about a specific theme or topic for the future?

We invite you to be part of this initiative by filling out this [form](#) and sharing your challenge with our academic team and other stakeholders.

We will inform you if your challenge is taken up by our research team, and of any further activities. Hope to hear from you soon.

The Bank of Transdisciplinary Challenges.

SECTION 2 OF 5 - BEFORE INFORMING US ABOUT YOUR CHALLENGE, WE WOULD LIKE TO KNOW A BIT MORE ABOUT YOU.

First Name: Kim

Last Name: Becher

E-mail Address: kb@shiftn.com

Affiliation:

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

If you are affiliated to an organization, please fill in its name here: shiftN You can also include some contact details of your organization. www.shiftn.com @shiftNGroup De Hoorn Creative Minds, Sluisstraat 79, 3000 Leuven Would you like to receive updates about this initiative? YES/NO

SECTION 3 OF 5 – ABOUT YOUR CHALLENGE-

ABOUT YOUR CHALLENGE

Name of the challenge:

“Develop a systems map as a blueprint for a future, resilient and equitable society”

Specific challenge:

To produce a ‘causal loop diagram’ that shows how a new societal value creation model can be connected to a new social contract, including access to basic rights and the provision of new redistribution mechanisms.

Objectives:

- To get a clear systemic view of the various obstacles (legal, architectural, economic, social, health care related) blocking the adoption of a new societal value creation model that would be more in line with the criteria of sustainability, social equity and community building than the current model.
- To get a clear systemic view of the (untapped) resources and possibilities (legal, architectural, economic, social, health care related) that would facilitate the creation of a new societal value creation model as described in the previous point, connecting it with a new social contract.
- Final objective: to build a causal loop model that visualizes the new societal model.

Context and relevance to a transdisciplinary team:

As shiftN, we often work in transdisciplinary settings. Our team brings in various disciplinary and methodological backgrounds, ranging from biology, philosophy, design, engineering to urban planning, psychology and organization development. In our assignments, we often deal with complex, ‘wicked’ problems, which demand multidisciplinary and transdisciplinary approaches. As part of our methodology, we invite scientists and stakeholders to think beyond the limits of their specialisms and integrate different ideas and perspectives into their thinking.

shiftN’s interest in the topic of post-capitalism stems from our observation that the current late-capitalist system is unsustainable, not only from a monetary and economic point of view, but also from a social, environmental, cultural, psychological, medical and governance perspective.

Since the big credit crunch of 2008, no serious structural reforms have been undertaken to remedy the system’s deficiencies. Governments have imposed austerity measures on their populations in order to save the banking system, but without taking the necessary steps to avoid a similar or worse kind of economic cataclysm in the future. In the meanwhile, many layers of society are suffering from the consequences of precarity and poverty. Public services are being cut down, inequality is mounting, trust in authorities and the political realm is eroding, populism and extremism are on the rise.

In the past, capitalism always found a way out of the big crises, mainly through technological innovation. However, as Paul Mason points out in his book “Postcapitalism”, the information and network based technologies that have boomed over the last 25 years are not compatible with capitalism. Capitalism is based on scarcity, whereas info-technologies are abundant by nature. They work best when they’re free and shared.

With the advent of new information technologies, a different path has opened up: that of collaborative production. Goods, services and production methods are emerging that no longer fit into the logic of the market or managerial hierarchy. Developments like the shared economy, commons based peer production, cooperative currencies, all point towards a new paradigm, in which individual interests are tied to the common good and vertical hierarchies are being replaced by more open, horizontal types of collaboration. This not only requires different forms of organization, but also new ways of learning, creating, thinking and living.

Although collaborative structures are proliferating everywhere, there are still many obstacles preventing them to develop their full potential. Many legal and administrative provisions run counter to the fundamental principles and ethos of the cooperative economy, such as pay scales that are based on age or academic background.

In the decades following the 2nd World War, a welfare state came into being in many Western countries, based on the creation and extension of social policies and social security structures. A social contract was agreed upon, based on

the acceptance of capitalism as the ruling economic system in return for redistribution mechanisms that would guarantee the viability of the welfare system. The last decades have seen a gradual erosion of the welfare state under neoliberal rule. The time has come to think about a new social contract, which is more in sync with the value creating models of the New Economy.

One of the main questions regarding such a new social contract is whether it would continue to be based on the same old redistribution mechanisms. These are conceived as a compensation for labor and calculated on the basis of salary. But Info-technologies, however, reduce the need for work, blur the edges between work and free time, and loosen the relationship between work and wages (see Paul Mason, “Postcapitalism”). Could a Universal Basic Income be part of the solution?

Relevance to a transdisciplinary team

For this challenge, we would like the transdisciplinary team to think of how a new societal value creation model could be developed, taking a systemic view on the interaction between variables that are relevant to building such a model, including new legal frameworks ensuring social equity and wellbeing.

This challenge relates to various disciplines: architecture/urban planning, medicine, the cooperative economy, community building and new legal frameworks.

The methodology

The focus of the systems work in this challenge is to present an evidence-based, richly layered, qualitative model of a future, resilient and equitable society. We refer to this general approach as “systems thinking”, and embodiment of this thinking in visual form as “systems mapping”.

In order to further differentiate this work from other systems-oriented activities, we propose informal definitions of often-used terms such as system thinking, mapping and modelling:

“System thinking” refers to the activity of (more or less rigorously) using systems principles and systems-oriented heuristics in structuring our thinking about complex, problematic situations (examples of these are the System’s Iceberg, Donella Meadows’ Systemic Ladder, system dynamics archetypes and the notion of a system’s root definition).

“Systems mapping” denotes the activity of working towards a coherent visual representation of a system.

“Systems modelling” aims at the construction of formal, quantitative models to obtain hopefully accurate predictions about a system’s future state.

Qualitative systems maps do not have formal predictive power. They are used in a variety of ways in supporting sense-making and decision-making in complex environments:

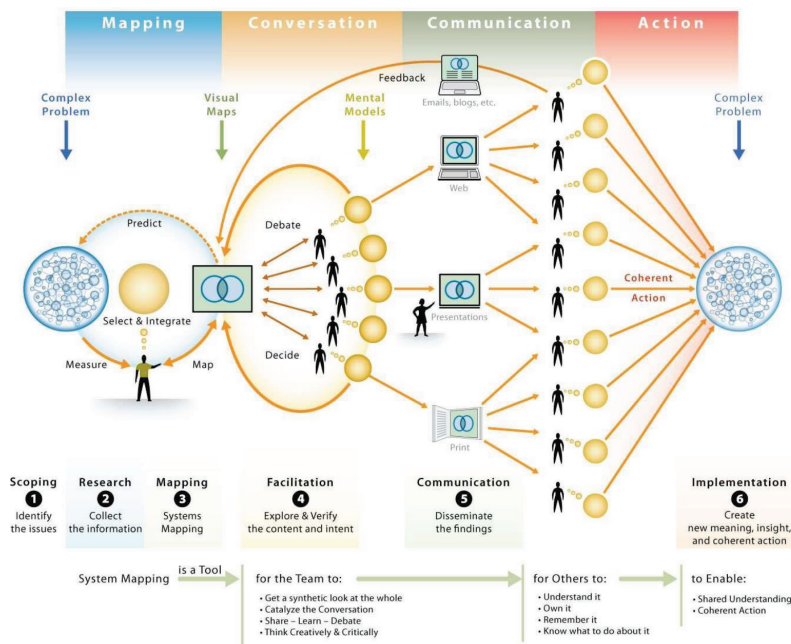
As heuristic tool: to support meaningful conversation amongst experts and professionals; to invite new questions and hypotheses for data gathering and theory building.

As a knowledge management tool: to organise available knowledge in an integrative way.

As a diagnostic tool: to identify potential gaps in current policy approaches.

As an operational tool: to identify “leverage points” in the land system as a starting point for policy interventions.

The process of systems mapping can be structured in a number of phases: scoping, research, mapping, facilitation, communication and implementation. We suggest that the present challenge encompasses at least the first three phases.

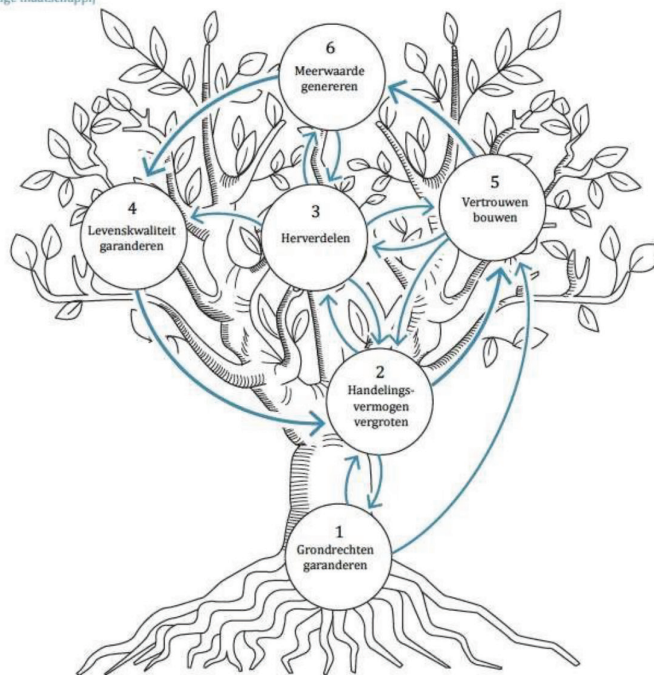


The transdisciplinary team for this project will be invited to participate for free in shiftN's systems mapping and Kumu course. shiftN will also seek to connect this challenge with our internal 'Beyond Capitalism' project and with other elements in the shiftN academy.

Phasing of the research

Phase I - We propose to start with a critical investigation of an embryonic ('core') systems model that shiftN (in collaboration with Namahn) developed in the framework of a recent assignment. The model is a very simple one that includes only a handful of variables. This is a back-of-the-envelope model that is not based on rigorous research. But it is a useful starting point for a systemic reflection. Research will focus on the nature of the variables included and the strength and validity of interconnections.

6 hefboomen voor een veerkrachtige maatschappij



shift^o namahn

Phase II – As a result of this initial phase of research, the team will amend, expand the core model to a more encompassing model. The questions listed below (by discipline) may provide fruitful directions for research. The revised model will be implemented and documented in Kumu.

Phase III – The team will produce the desired deliverables (abstracts).

Transdisciplinary context:

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

Domain of Humanities and Social Sciences:

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

Domain of Science, Engineering and Technology:

- Architecture
- Bioscience Engineering
- Engineering Science
- Engineering Technology
- Sciences
- Other: _____:

Domain of Biomedicine:

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

Economics and business:

- How can we foster the development of business models that are based on social and environmental responsibility and are centered around collaborative production? For example, ‘reciprocity based licensing’ is a model in which capital is not only granted to shareholders, but also to employees. This way, profits and power are distributed in a more equitable way (see Michel Bauwens from the P2P Foundation: ‘Fair Shares’).
- Could complementary currencies that link unmet societal needs to unused human potential be part of the solution? (See proposals from Bernard Lietaer).

- Or what about an entire new monetary system, as proposed by Stichting Ons Geld (NL), Positive Money (UK) and Vollgeld-Initiative (CH), which would reverse the roles of private banks and government and restore the privilege of money creation to the state.
- Could a universal basic income be a solution, as a first step to de-link salary from work and tackle the problem of unemployment in a highly automated society? (proposal by Paul Mason in his book ‘Postcapitalism’).
- One could take this even a step further and introduce a ‘universal basic dividend’, which wouldn’t be financed by taxation, but through capital returns yielded by automation.
- What are the main obstacles that impede the upscaling and further development of the cooperative economy? Which available resources can be used to support it?

Law:

- Basic rights: should we guarantee a universal basic income to every citizen? Or a universal basic dividend? (see above).
- How can we assure the right to universal access to quality health care in the future? (See shiftN scenarios on drug pricing).
- Towards a new paradigm of freedom? Our current notion of freedom is heavily influenced by Roman Law: individual rights must be respected by others, but also involve the right to destroy one’s own property. How does this match with social and environmental responsibility?
- What about intellectual property? Are IP-rights compatible with a collaborative economy and peer-to-peer production?
- Central Banks have a monopoly on money creation. They’ve used this monopoly in the past to abolish cooperative currencies, even though these currencies proved to be successful in tackling unemployment and social dislocation. Should this monopoly be challenged?

Philosophy

- Reflection on our current notions of autonomy, liberty and property: to what extent do they match with the notions of social and environmental responsibility and with conceptual frameworks of cooperative production, including notions as the commons, shared economy, open source, P2P?
- Our monetary system is based on scarcity and therefore stimulates competition rather than cooperation. On the other hand, oil pollution contributes to a higher BNP, whereas voluntary work to clean up the oil spill is not rewarded financially. What models of value creation can we create to contribute to a more sustainable and equitable solution?
- Could one think of a more horizontal, relational view of freedom, the possibility to enter into meaningful relationships with others and work together to create personal and social wellbeing?

Social sciences

- How can institutions of collective action (commons, initiatives from civil society) contribute to a new, more equitable and resilient societal model?
- Which models/theories in social sciences can be applied to enhance the cooperative economy?
- Which models/theories in social sciences can be used to enhance community building?
- Can examples from the past be used as an inspiration to new cooperative models?

Medicine

- How to promote an “ecological” view of medicine: recognizing the connections between the health of ecosystems, populations, communities and individuals?
- Which elements of the cooperative economy could contribute to a better access to health care, lower drug prices, better quality of care, community-based health care.

- How to guarantee solidarity and access in the context of extremely expensive medicines, in particular for rare diseases? (See shiftN scenarios on drug pricing).
- Community health care: reflection on the strengths and weaknesses, opportunities and risks. E.g. can we speak of communities in urban contexts where neighbors don't know each other and communities are built along social, religious or racial lines? How can we tackle these issues?

Architecture

- Promoting ecological health in urban contexts, including composting, recycling, energy efficiency.
- Promoting urban agriculture to provide food, create green areas, create new jobs and strengthen the city's resilience to climate change.
- Improving access to everyone, in particular the poor and disabled.

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

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

Terms and Conditions

1. Stakeholders (Students, University, Government, Industry, Society, and Non-profit Organizations) are invited to submit their challenges and also to share their insights to help address specific challenges, structured programs of analysis and knowledge sharing to address specific questions around societal or global problems faced by people and planet based on transdisciplinary interactions. This may be in the form of Stakeholders providing background for the challenge, publishing articles, posting comments in online discussions, participating in in-person events, or in other ways sharing their expertise.
2. If a submitted challenge is selected for further research, the academic team could modify the submitted contents for formatting in a scientific frame
3. Stakeholders should ensure that they own the intellectual property rights or have secured the necessary permissions to content or ideas they share as part of a Challenge
4. Intellectual property rights over content shared by a Stakeholder as part of a Challenge will remain with the original owner of the intellectual property.
5. Stakeholders that submit or contribute to a challenge will not be entitled to any payment or reward for contributing content to a challenge.
6. The intellectual property rights of final Challenge outputs, such as, but not limited to reports, papers, abstracts, videos, conferences, will belong solely to the "Transdisciplinary Insights Course" based on the Honors program regulated by the terms and conditions of the KU Leuven. These outputs will be made available in an open access "Transdisciplinary Insights e-Journal". Any other form of knowledge dissemination of the challenge output can be negotiated with the Academic team. Stakeholders agree that Challenge outputs can draw on content and ideas shared by them during the course of the Challenge, or shared on the "Transdisciplinary Insights e-Journal" or at a "Transdisciplinary Insights Course"-related event. Stakeholders agree to place no restrictions on the content that they share and grant permission to the "Transdisciplinary Insights e-Journal" to draw on or reproduce or publish this content, with appropriate attribution, in producing the Challenge outputs.
7. Challenges are funded by supporters. Supporters' names and/or logos will be acknowledged by the "Transdisciplinary Insights e-Journal"
8. "Transdisciplinary Insights Course" reserves the right to change or update these T&Cs from time to time without prior notice to you.

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

SECTION 4 OF 5 – SUPPORT, PARTNERS & SHARING-

How would you like to support that challenge?

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

Other:

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

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

The range of stakeholders affected by this challenge is potentially very large and encompasses all segments of society. We propose to provide the transdisciplinary team with access to a number of experts or resource persons who are able to contribute to a systemic reflection on broad societal transitions towards sustainability. These experts could be involved in personal interactions (via interviews, or team coaching sessions) or as a group (in a workshop format). To be decided.

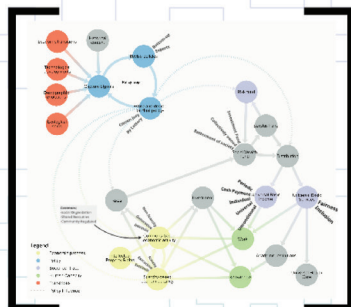
How can we introduce your challenge to other stakeholders?

- By using your name.
- By using your name and your affiliation
- By using only your affiliation
- Anonymously

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

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

Blueprint for an Equitable and Resilient Society



Questions for Further Thought

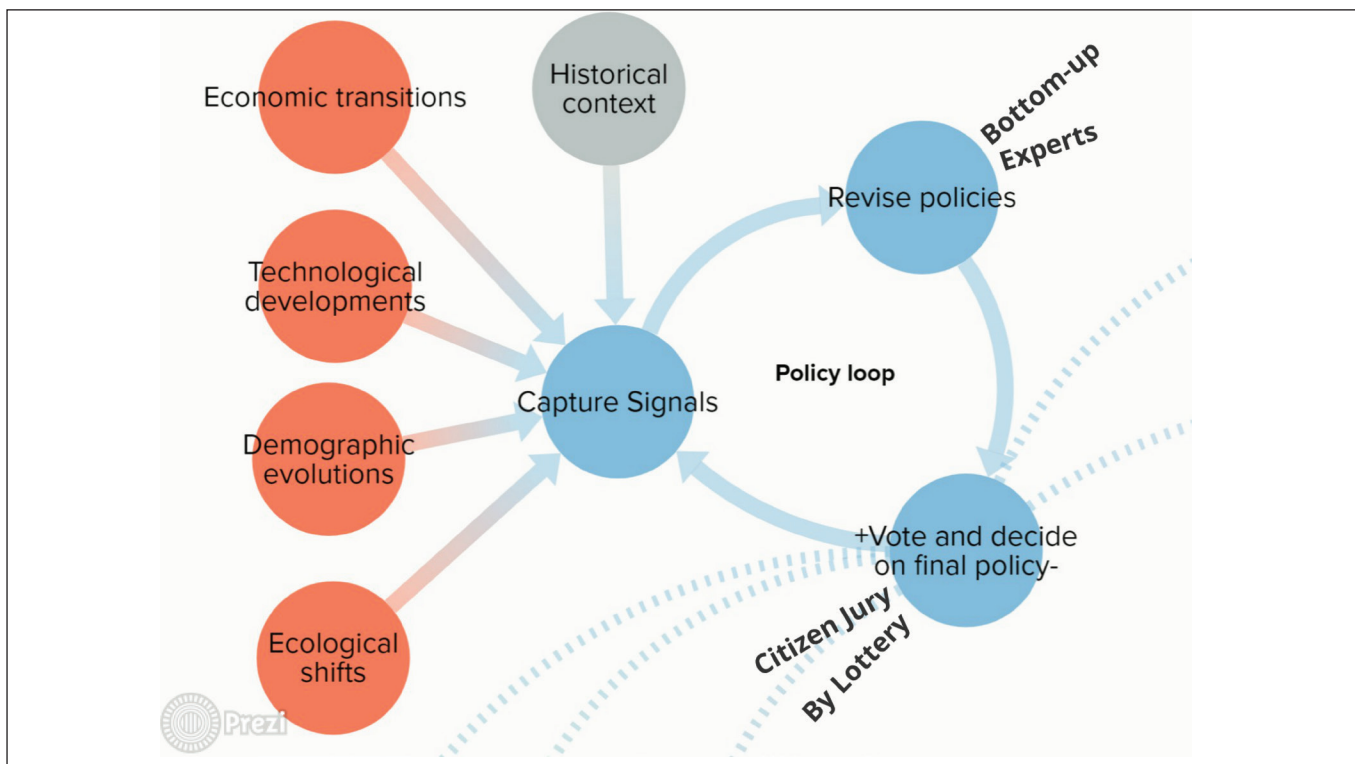
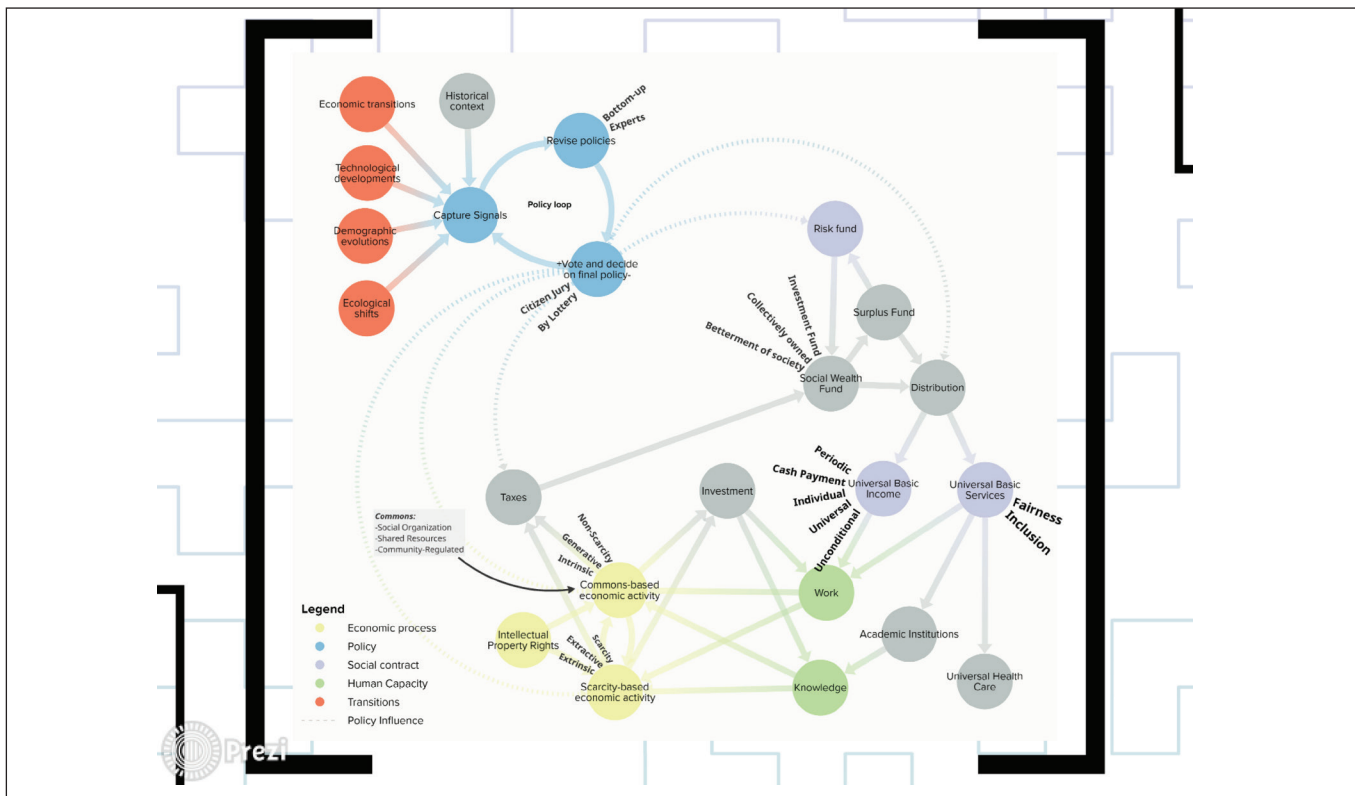
- How do we adjust supply & demand?
- Does intrinsic motivation suffice to ensure productivity?
- What is the position of artificial intelligence & its relationship towards labour?
- How do we cope with individual profit seeking in a commons-based society?

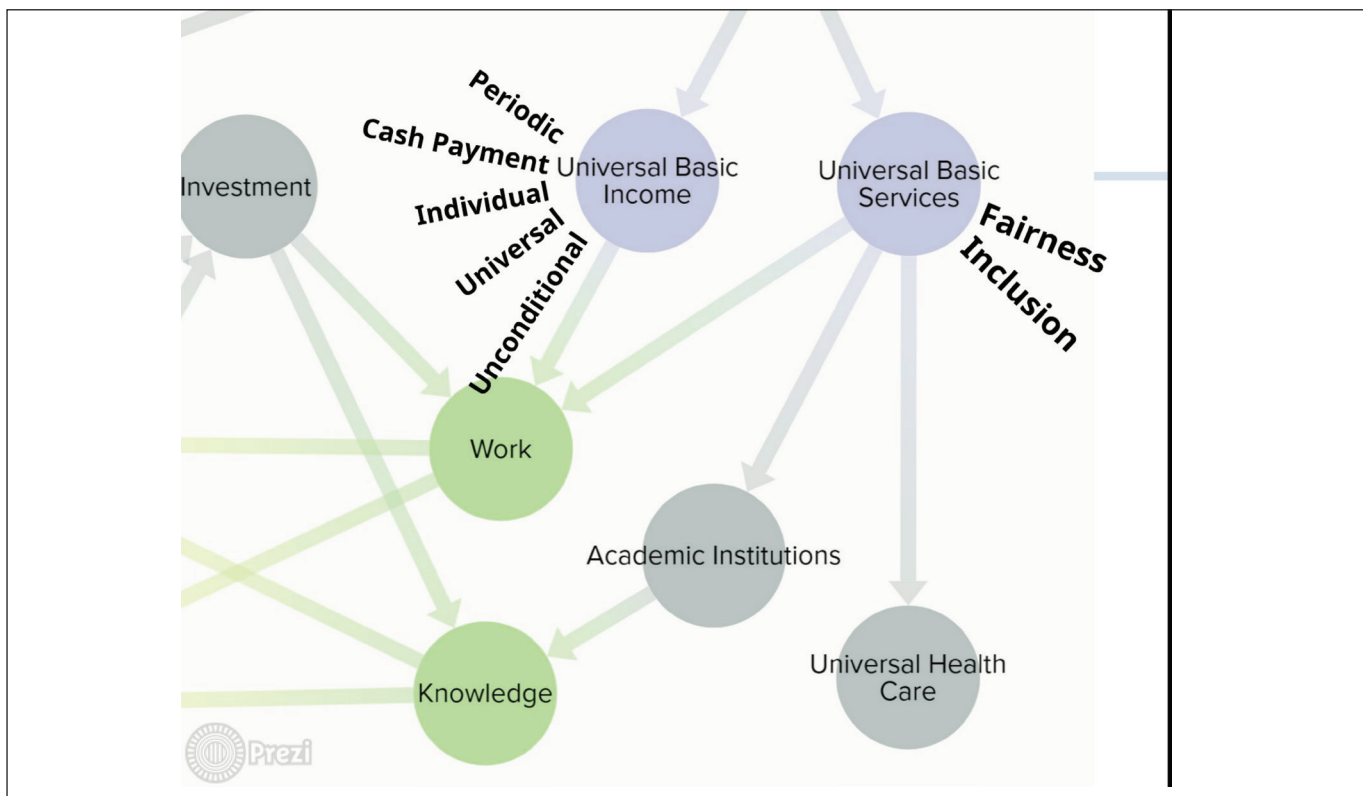
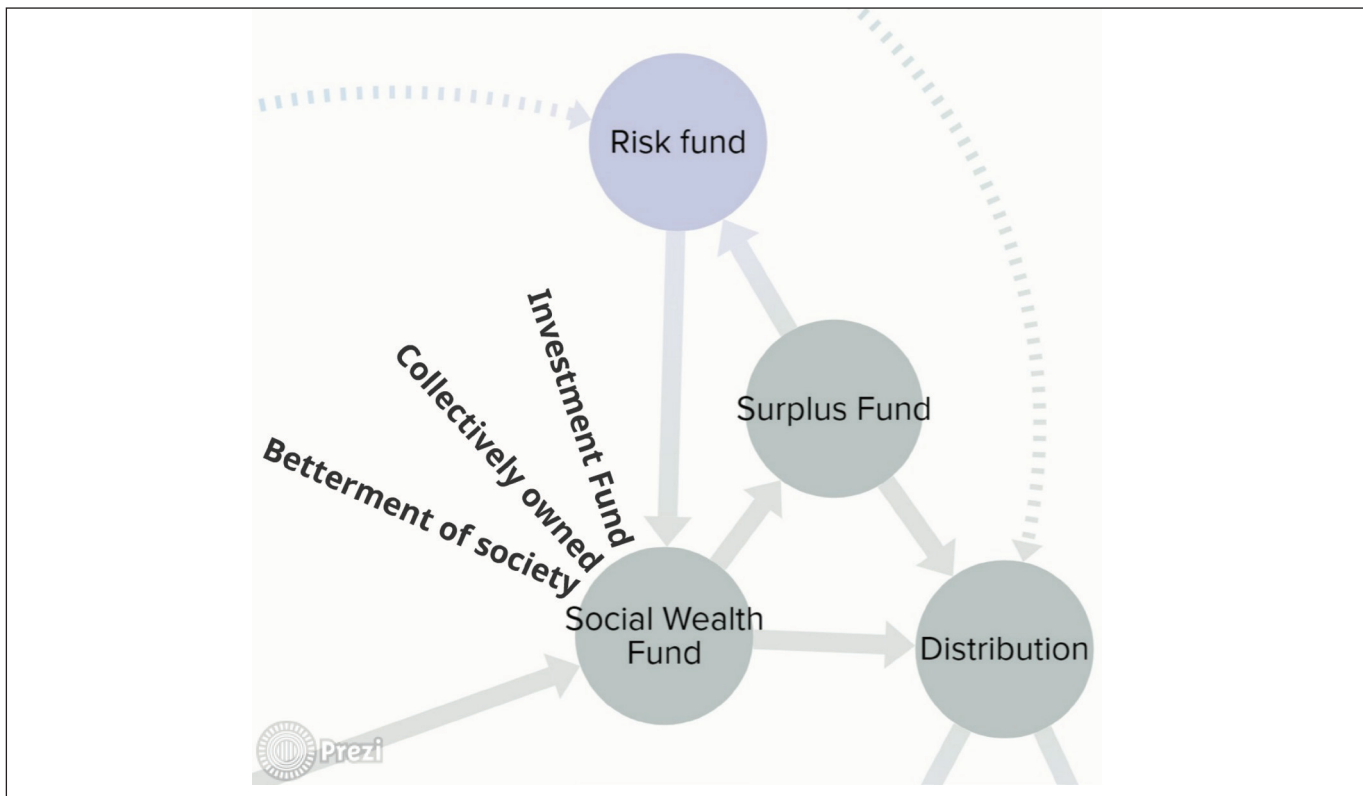
Thank you for your attention!



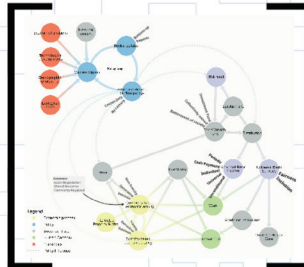
OUR CURRENT PREDICAMENT







Blueprint for an Equitable and Resilient Society



Questions for Further Thought

How do we adjust supply & demand?
Does intrinsic motivation suffice to ensure productivity?
What is the position of artificial intelligence & its relationship towards labour?
How do we cope with individual profit seeking in a commons-based society?

Thank you for your attention!





Down to Counsel: Towards A Transdisciplinary Toolbox for Non-directive Counseling in Prenatal Screening for Down Syndrome

**Laura Costan^{1,2} Matthew J. Devine^{1,3}
Maud van Dinther^{1,4} Louise Hendrickx^{1,5*}
Job Meijer^{1,6*} Nynke van Uffelen^{1,7*}
Eline Zenner^{1,8*}**

1 KU Leuven – University of Leuven, Honours Programme Transdisciplinary Insights, Leuven, Belgium;

2 KU Leuven – University of Leuven, Master student European Studies, Leuven, Belgium;

3 KU Leuven – University of Leuven, Research Master student Philosophy, Leuven, Belgium;

4 KU Leuven – University of Leuven, Master student Medicine, Leuven, Belgium;

5 KU Leuven – University of Leuven, Master student Drug Development, Leuven, Belgium;

6 KU Leuven – University of Leuven, Master student Philosophy, Leuven, Belgium;

7 KU Leuven – University of Leuven, Master student Philosophy, Leuven, Belgium;

8 KU Leuven – University of Leuven, Faculty of Arts, Quantitative Lexicology and Variational Linguistics (QLVL) Unit, Brussels, Belgium;

*These authors contributed equally to the work.

§Email: Eline.Zenner@kuleuven.be

Abstract

Since the introduction of non-invasive prenatal testing (NIPT) in Belgium in 2013, expectant parents have had

access to a new efficient and reliable test for genetic abnormalities, including trisomy 13, 18 and 21. In 2017, the Belgian government decided to cover over 95% of the cost for all women who choose to take this test. In this context, a diagnosis of trisomy 21 (Down syndrome) presents an especially challenging decision for parents: it is impossible to tell the severity of impairment prenatally, and although several medical risks are involved in the condition, many individuals with Down syndrome live a long, happy, and relatively independent life (Shakespeare, 1998; Scott et. al., 2014). Expectant parents face a very difficult situation: how to decide whether or not to terminate a pregnancy? It appears that termination is becoming the routinized outcome of the clinical encounter during which a diagnosis is delivered.

The intricacy of the matter, and the fact that many actors are involved, lead to the necessity of a transdisciplinary methodology when scrutinizing the future of prenatal counseling. However, medical professionals tend to approach Down syndrome from an exclusively medical perspective (Skirton and Barr, 2010), leaving aside the economic, social and psychological dimensions of living with Down syndrome. This may result in unbalanced information; some (perhaps precipitously) refer to this phenomenon as ‘nudging practices’ (Hippman et. al., 2012; Reid et. al., 2009). In order to address this imbalance, we adopt a stakeholder approach in this project: we consulted

experts with diverse backgrounds and fields of expertise. Through this transdisciplinary approach, we hope to bring about a more transdisciplinary perspective directly within the offices of gynecologists and GPs. More specifically, we aim to find ways to provide GPs and gynecologists with direct access to information about the aforementioned dimensions of Down syndrome.

The next step is to define a strategy to achieve this goal. Given the fact that medical professionals often lack both time and easy access to concise information about Down syndrome to present a nuanced perspective (Ahmed et al., 2007), but are still the first in the prenatal screening process, the output of this project is the idea of an online tool 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 expectant 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.

Key words

Prenatal screening, Down syndrome, non-directive counseling, non-invasive testing, informed decision making.

Challenge Statement

Strategies for non-directive counseling in prenatal screening for Down syndrome

Introduction

In the past decades, prenatal screening and reproductive technology have advanced rapidly. One of the latest and most widespread of these innovations is the non-invasive prenatal test (NIPT). In the past, prenatal screening for fetal abnormalities was performed by a non-invasive combination test, which consisted of an ultrasound scan measuring the nuchal translucency and a blood test of the mother resulting in an odds ratio for chromosomal disorders. This would be followed by an invasive (and hence not risk-free) amniocentesis or

chorion villus biopsy in case of a probability ratio of more than 1 out of 300 or 500 for disorders. Like the combination test, the new NIPT holds no risk of harming the fetus (Allyse et al. 2015), as it allows fetal trisomies to be detected through a blood test. However, it is at the same time notably more accurate: it delivers a binary outcome (positive/negative result) instead of an odds ratio. Additionally, the NIPT can be conducted at an earlier time in the pregnancy than the more reliable amniocentesis (Lewis et al. 2014). A positive NIPT is, however, not 100% conclusive, so it is still advised to conduct an amniocentesis after a positive screening result, although this advice is not always taken to heart (Chetty et al. 2013).

Because of the advantages of the NIPT, in 2017 Belgian Federal health minister Maggie De Block made the decision to reimburse almost the whole cost of it to every Belgian pregnant woman. This results in many pregnant parents facing difficult decisions, namely whether to screen or not and what to do after receiving a positive NIPT result. We choose to focus on Down syndrome in this project because, in the case of trisomy 21, the dilemma whether to terminate a pregnancy or not has an added complexity. There are three main reasons for this. Firstly, the chromosomal defect has the highest prevalence and visibility of the three trisomies that are detected with the NIPT. Therefore, prenatal screening for Down syndrome will reveal the condition itself; however, it will not reveal the severity of the associated impairment. Odds ratios on medical risks provide odds, not certainty. This is in contrast to the other conditions screened for with the NIPT, trisomy 13 or 18 (see Savva et al. 2010, 61), which are non-viable conditions. The multi-varied ways in which Down syndrome may manifest can only be known after birth and throughout the lifespan; termination therefore implies a life-long uncertainty and a lingering 'what if'. Secondly, most people with trisomy 21 can live a long and relatively care-free life (again, in contrast to people with trisomy 13 or 18, see Savva et al. 2010, 61), which increases the difficulty of the choice. Thirdly, society seems to have evolved to a point where termination has become an expected outcome of the decision-making process. These three points emphasize the importance of counseling in order to stimulate well-informed, autonomous decision-making. However, out of the annual 15-million-euro budget provided for the reimbursement of the NIPT, no funding has been made available for (multidisciplinary) counseling (De Block, 2017).

Despite the focus on Down syndrome, this project has a broader relevance: the need for thinking about autonomous decision-making grows as technology and science progress (Allyse 2015). Given these considerations, this project focuses on the following question: how can non-directive counseling be stimulated within the current Belgian healthcare structure to ensure free, well-informed decisions by parents concerning prenatal screening for Down syndrome?

Focal point

To tackle this question, we began by examining it closely in order to choose a focal point. As a first step, we scrutinized the original challenge as described by Eline Zenner (cf. supplement 1), which contained several assumptions that were in need of further research. A preliminary analysis (cf. supplement 2) showed that there were indeed important ethical questions at stake about the relationship between disability and society at large. At the same time, it would be naïve to try to free pregnant parents of all ‘nudging’ influences that stem from society’s perspectives on Down syndrome. Instead, we began by following an actor constellation game. As part of a transdisciplinary research approach, the purpose of this activity is to examine all the potential actors or stakeholders involved in such a challenge (e.g. individuals with Down Syndrome, parents, siblings, medical professionals, therapists, etcetera), think about how these actors are all involved, and thereby determine where our contribution could be most impactful, yet realistic (see supplement 11, and https://naturalsciences.ch/topics/co-producing_knowledge/methods/actor_constellation_final).

We directed the focus of this project on GPs and gynecologists. This move was motivated by the following considerations. Firstly, nowadays the NIPT is often offered as a ‘routine part’ of the prenatal care system; screening is often a taken for granted practice, rather than a subject of free choice (Birko et al. 2018, 5). It is important that medical professionals such as GPs and gynecologists are aware of the potential benefits and drawbacks of offering parents the conscious choice of whether or not to screen in the first place.

Secondly, GPs and gynecologists are often the first to deliver the NIPT-results to their patients. Although counseling is available through channels like genetic centers connected to the Flemish university hospitals and NGOs such as Fara, it is typically offered to parents

only after they receive the positive NIPT-result or when they explicitly seek advice. The way in which a medical professional presents a choice can influence the patient’s decision-making process (see for instance Gorin et al., 2017 for a definition and ethical use of ‘nudging’). Therefore, health-care professionals play a crucial role in the guidance of the decision-making process (Korenkomp et al., 2006). In other words: first impressions matter. It should, however, be added that nudging is not always or even most of the time an intentional practice of medical professionals, and we recognize that many medical professionals do support informed decision-making and a non-directive approach to counseling, but we still believe there is opportunity for improvement.

Thirdly, given their educational background, GPs and gynecologists often merely have a medical perspective on the matter. Therefore, they are inclined to focus on the medical aspects (and therefore mainly on the medical risks) of the condition, leaving out other substantial practical and emotional consequences of living with a child with Down syndrome. A one-sided perspective on the subject may (unintentionally) entail the danger of nudging, and this puts the autonomy of the patient(s) in question.

From these findings, we concluded that GPs and gynecologists are the authoritative and common factor in nearly every pregnancy, which makes them the most effective disseminators of information from diverse perspectives. As such, we see an opportunity to enrich these central actors with a transdisciplinary perspective. What is distinctive about a transdisciplinary approach is that it not only endeavors to work between several disciplines. It aims to work beyond these disciplines, involving academics from relevant disciplines, but also non-academic stakeholders with different but nonetheless crucial expertise (Choi et al. 2006, 356). Our hypothesis is that, when GPs and gynecologists embrace a broader view than the medical perspective alone (viz. providing more information on the condition than the purely medical one), the first crucial contact with their patients will be more nuanced and will stimulate free decision-making and/or seeking further, more transdisciplinary counseling – in the proper sense of the word – will be encouraged (see Hippman et al. 2012, who consider ‘balanced’ descriptions impossible, but instead strive for nonjudgmental terminologies, helping families evaluate possibilities in the context of ‘their own values, coping strategies and support networks’).

We acknowledge, however, that GPs and gynecologists often lack the time for in-depth counseling (Williams et al. 2002, 233; Sup 10). It therefore remains important to refer patients to the existing (transdisciplinary) institutes for counseling. A solution to the initial challenge must take these time constraints into account.

We propose the creation of an online tool, developed for GPs and gynecologists, where they can quickly find reliable and up-to-date information on prenatal screening, decision-making and living with Down syndrome. This information will be transdisciplinary: it will cover not only medical aspects, but also social implications, psychological dimensions, financial arrangements, education opportunities and so on. At the moment, no such tool is available in Belgium; tools for non-directive counseling do exist (see for example Reid et al., 2009 and Fransen et al., 2009 for research on these topics, and see Ahmed et al., 2007 for a description of the tool AnSwEr, developed by Tom Shakespeare), but they are not specifically adjusted to the Belgian context. Our tool is not confined to counseling alone; it aims for an overview of multiple perspectives, including for example educational opportunities and relevant labor or financial laws on Down syndrome. Once finished, we suspect that this tool will broaden the perspectives of medical professionals and therefore enhance their use, understanding of and referral to non-directive counseling, and we hope that it will ensure that non-directiveness is supported within the initial clinical encounter.

Stakeholder Approach

The next step is to decide on the shape and content of such a tool. The aim is to bring about a broader, more transdisciplinary view, and a transdisciplinary tool must be created in a transdisciplinary manner. The complexity of the challenge implies that many different actors are involved: there are many possible perspectives on Down syndrome. Therefore, we chose a stakeholder-approach. All related actors must be consulted in order to demarcate what they think is relevant content for the purpose of the tool, and to discern whether the basic idea of the tool is useful in the first place.

The selection of stakeholders from the initial list included in the challenge proposal (see supplement 1) was made based on considerations concerning the relevance of the subject field(s) and the variety of

different perspectives within the whole selection: interviews were held with people with medical, social, and individual stakes in the different dimensions touched upon by prenatal screening, including the general impact on society, prenatal counseling, and life with Down syndrome. These meetings provided us with valuable insights that helped us to define the content, outline and design of our proposition. The selection of who to meet was based on availability, accessibility, and ensuring a diversity of perspectives (e.g. academic, professional, lived-experience experts).

Firstly, via the organization Downsindroom Vlaanderen, we met with several people with Down syndrome and their family members (cf. supplement 4, 7, 8). This provided valuable information about everyday life with Down syndrome. For example, it became clear that experiences are extremely variable; it is impossible to provide a single, unified picture of what life is like with Down syndrome, which may complicate prenatal counseling. Moreover, by talking to parents we acquired valuable insights on experiences with the (current) medical system and counseling practices during and after the pregnancy. Numerous parents felt the necessity for better counseling, more information and a better referral process to institutions or organizations for counseling. These parents felt like they were on their own after receiving the diagnosis; they had to look for information and counseling by themselves, and some felt they needed to defend their decision to keep their child with Down syndrome during every interaction with medical professionals.

Secondly, we spoke with Jean Jacques Cassiman, professor of genetics at the KU Leuven (cf. supplement 9). The genetic perspective is vital because genetic centers are the prime location for innovations in genetic research and these centers strongly adhere to neutral counseling. Cassiman argued that, even though science defines the possible, society demarcates the boundaries of the acceptable. In his opinion, prenatal screening is progress. The NIPT is more and more becoming standard practice in the daily organization of peripheral hospitals; this could pose problems since there are no extra funds made available for the necessary counseling to counterbalance this push. It is far from unthinkable that our future is one where termination is the standard (or even obliged) outcome of positive NIP-tests.

Thirdly, we met with Fara, a nonprofit pregnancy-counseling organization that operates in Belgium

(cf. supplement 5). Fara endorses the model of nonjudgemental counseling and shared decision-making; they believe care providers have a responsibility to stimulate the parents to make conscious, well-considered choices. Fara's insights on counseling are of great value for our project. For example, they note that medical professionals sometimes tend to see Down syndrome as a 'problem' or something negative. Doctors screen for disabilities, while parents screen for assurance that their baby is healthy: however, a negative attitude could be contested in cases where a fetus is diagnosed with Down syndrome. Another important insight concerns the importance of anxiety and fear of the unknown. A diagnosis often goes hand in hand with odds ratios; it must be taken into account that people tend to count on the worst-case scenario. Fara stressed the factor of uncertainty: one will only know the reality when one chooses to keep the child, however hard it may be. When one chooses to terminate, a life-long 'what if' lingers. Lastly, Fara stipulated that the medical professional does not need to know what the best solution is for the patient, simply because he/she cannot know what it is. Counseling should not start with an answer set in stone.

Fourthly, we spoke with a member of Cozapo, a parent-to-parent organization that seeks to help alleviate the psychological repercussions suffered by those who terminate their pregnancies. The perspective of women who decided to terminate is indispensable. Firstly, the importance of consciousness of the 'life-long what if' was stressed again as a major consequence of terminating a pregnancy. Another important insight was that parents should be informed not only of the consequences of keeping the child, but also of the exact procedure that would be followed after they chose to terminate, since this is a very vulnerable time for parents.

Fifthly, genetic screening goes hand in hand with numerous ethical questions. This is why we chose to speak with Kasper Raus, bioethicist at the university hospital of Ghent (cf. supplement 6). Raus pointed to the fact that attention must be paid to the way information is conveyed. For example, an 80% chance of living has a different connotation than a 20% chance of dying. Also, he made us aware of the fact that there is no unified framework to facilitate counseling in Belgium, meaning that certain information might not reach prospective parents because it is assumed to have already been provided to them by other

healthcare professionals (where this is not necessarily the case).

Lastly, we met with Luc De Catte, gynecologist and professor at the KU Leuven (cf. supplement 10). Meeting the target group itself is essential, because it gives them (in this case, the gynecologists) the opportunity to co-create the content of the tool. This increases its quality and the odds that it might actually be used in practice. Also, this meeting gave important insights into how to tackle the more strategic questions linked to this project: what is the best way to enrich medical professionals with transdisciplinary perspectives, and how can we convince GPs and gynecologists to use this tool? De Catte agreed that the nature of the current curriculum for medical students is too medical. However, changing the curriculum is not realistic within this decade; it will not be realistic for our tool to gain an official place at the university of KU Leuven just yet. Also, he emphasized the importance of concise information about nonmedical aspects of Down syndrome that medical professionals can easily and quickly consult. This will increase the odds that the tool will actually be consulted.

Outline of the Online Tool

Meeting these stakeholders affirmed the need for a transdisciplinary online tool for GPs and gynecologists. Since they are often the first ones in contact with the patients when announcing the NIPT results, they can have a huge impact. We hope that non-directiveness will be encouraged in this initial contact when these medical professionals have a more comprehensive – in other words, not merely medical – perspective on Down syndrome.

As mentioned, there is a limited amount of time available for counseling and GPs and gynecologists tend to focus on the medical perspective. Therefore, to improve this crucial first interaction, these medical professionals must have easy access to concise information on Down syndrome from multiple perspectives. This is why we decided on a freely-accessible brief online course.

The tool, shaped as a Q&A format, must contain reliable and up-to-date information from every relevant involved perspective, gathered in a transdisciplinary manner. Especially the input from the gynecologists and GPs must not be forgotten: this way, the tool is co-created by its target group, which increases its quality and the odds that it will be used in practice.

The stakeholder insights also provided the outline of the content that must be covered (cf. supplement 3). The medical perspective is not the only possible one on Down syndrome; other perspectives are relevant to the parents, for example economic, social and psychological dimensions of living with the disability. Furthermore, the perspective of people with Down syndrome must not be forgotten. An example is the following question: 'What education possibilities are there for a person with Down syndrome?' This question would link to a page with a description of the possibilities and to relevant institutions. The website idea is meant to specifically tackle the situation in Belgium, which allows for the inclusion of information regarding government aid, types of schooling, relevant laws and so on.

In addition to its own content, the website would contain referrals to websites of organizations for counseling such as Fara. It should also include a feedback form so that information can be updated, adjusted or supplemented by the actors that visit the website. Also, to ensure GPs and gynecologists would notice the website, it would be good if known websites such as the 'Vlaamse Vereniging voor Obstetrie en Gynaecologie' (VVOG) contained a link to the tool.

Through this tool, the medical professional becomes aware of the fact that Down syndrome is more than a medical condition and an odds ratio; their view is broadened, which leads to a more nuanced perspective from which parents are informed about their prenatal testing results. We understand that we cannot expect physicians to counsel in the full sense of the word, but they can still ensure that all options are kept open to their clients, and this is more likely when other perspectives are taken into account. At the same time, the tool can help as a guide through counseling; it provides answers to parents' questions and contains a list of relevant institutions to refer them to.

Conclusions and Limitations

This website, as a last remark, would neither be a panacea for the general issues surrounding genetic screening, nor does it suggest to be exhaustive of all steps that could contribute to informed decision-making in the case of prenatal screening. Regarding genetic screening generally, it is paramount that further research is conducted into the role that disabilities play in society, effective ways of integrating ethical practice into medicine as technology opens up new possibilities,

and the practice of counseling itself. However, this website may set some precedent for counseling, and in that sense provide a baseline within medical practice to deal with the changing landscape of what childbirth is in society. Lastly, more research into the impact of the NIPT within Belgium is necessary.

Regarding informed decision-making, some further limitations of this project should be noted. After all, a fully transdisciplinary approach to prenatal screening would endorse collaboration from multiple experts as much as possible. This was our intention in collaborating with multiple academic, professional, and lived-experience experts. It may be argued that our decision to focus on physicians deviates from this collaboration. By focusing on physicians, we do not intend to narrow transdisciplinarity to one single actor. As mentioned in the paper, since prenatal screening is a process that begins within the medical sphere, physicians are the first point of contact for parents. The presence of such a website, for instance, could encourage the likelihood that news is delivered in a sensitive manner, without the use of derogatory language or language expressing pity, a conclusion of several studies that sought to understand the preferences of mothers in receiving news about a diagnosis of Down syndrome. (See Skotko et al., 2009). We nonetheless endorse physicians making appropriate referrals to organizations better equipped to provide fuller counseling. Indeed, we believe enriching physicians' awareness of the multidimensionality of Down syndrome will not only allow them to answer initial questions parents may have (for example during the delivery of the news), but also encourage them to make appropriate referrals to said organizations. Providing physicians with basic knowledge of other dimensions of Down syndrome is not intended to replace the role of other counseling resources.

In any case, our proof of concept might be a first step towards an approach to enriching medical professionals with a broader, more comprehensive view on the matter. GPs and gynecologists tend to have a medical perspective on Down syndrome, and they often lack the time to do in-depth counseling after parents receive a positive NIPT-result. We argue for the usefulness of an online tool in a succinct Q&A format that provides reliable, up-to-date information on Down syndrome from multiple perspectives. A broader, more comprehensive view will lead to more nuanced counseling. The importance of transdisciplinarity in complex

matters such as this one cannot be underestimated; therefore, the tool must be created in a transdisciplinary manner so that the outcome will be of the same nature. Through this tool, physicians can provide expectant parents with a more balanced, transdisciplinary view of Down syndrome, thereby enhancing their capability to make informed and autonomous decisions about their pregnancies. We hope that this project will be fully executed in the future and that it will successfully be put into practice.

Supplementary Materials

1. The original challenge document
2. Assumptions in the original challenge
3. Website table of content
4. Video fragment 1
5. Video fragment 2
6. Video fragment 3
7. Video fragment 4
8. Video fragment 5
9. Audio fragment 1
10. Audio fragment 2
11. Actor constellation game
12. 'Facing the Future' symposium presentation

References

- Ahmed S, Bryant L, and Hewison J. 'Balance' Is in the Eye of the Beholder: Providing Information to Support Informed Choices in Antenatal Screening via Antenatal Screening Web Resource. *Health Expectations*. 2007 Dec; 10(4): 309–320. <https://doi.org/10.1111/j.1369-7625.2007.00455.x>.
- Allyse M., Minear A. et al., Non-invasive prenatal testing: a review of international implementation and challenges, *Int J Womens Health*. 2015; 7: 113–126
- Birko, Stanislav, Marie-Eve Lemoine, Minh Thu Nguyen, Vardit Ravitsky. Moving Towards Routine Non-Invasive Prenatal Testing (NIPT): Challenges Related to Women's Autonomy. *OBM Genetics 2018*
- Chetty S., Garabedian M. J. and Norton M. E. (2013), Uptake of noninvasive prenatal testing (NIPT) in women following positive aneuploidy screening. *Prenat Diagn*, 33: 542–546.
- Choi, B.C K., Pak, A.W.P. Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. *Clinical Investigative Medicine*. 2006; 29(6): 351–364.
- De Block, Maggie, De Block betaalt NIP-test naar downsyndroom terug aan alle zwangere vrouwen die de test wensen, 29 May 2017, available at: <http://www.deblock.belgium.be/nl/maggie-de-block-betaalt-nip-test-naar-downsyndroom-terug-aan-alle-zwangere-vrouwen-die-de-test>, accessed on June 8, 2018
- Fransen Mirjan P., Wildschut Hajo, Vogel Ineke, Mackenbach Johan, Steegers Eric and Essink-Bot Marie-Louise, Information about prenatal screening for Down syndrome: Ethnic differences in knowledge. *Patient Education and Counseling*. 2009; 7(2): 279–288.
- Hill M, Barrett A, Choolani M, Lewis C, Fisher J, Chitty LS. Has noninvasive prenatal testing impacted termination of pregnancy and live birth rates of infants with Down syndrome? *Prenatal Diagnosis*. 2017; 37(13): 1281–1290. doi:10.1002/pd.5182.
- Hippman C, Inglis A, Austin J. What Is a 'Balanced' Description? Insight from Parents of Individuals with Down Syndrome. *Journal of Genetic Counseling*. 2012 Feb; 21(1): 35–44. <https://doi.org/10.1007/s10897-011-9417-2>.
- Korenromp MJ, Page-Christiaens GCML, van den Bout J, Mulder EJH, Visser GHA. Maternal decision to terminate pregnancy in case of Down syndrome. *Am J Obstet Gynecol* 2007
- Korenromp MJ, Page-Christiaens GC, van den Bout J, et al. Is there pressure from society to terminate pregnancy in case of a fetal anomaly? *Prenat Diagn* 2006; 26: 85–86.
- Lewis C., Hill M. et al., Non-invasive prenatal testing for trisomy 21: a cross-sectional survey of service users' views and likely uptake, *BJOG* 17 January 2014, 582.
- Maxwell S., Bower C., and O'Leary P. (2015) Impact of prenatal screening and diagnostic testing on trends in Down syndrome births and terminations in Western Australia 1980 to 2013. *Prenat Diagn*, 35: 1324–1330.
- Neyt M, Hulstaert F, Gyselaers W, Introducing the non-invasive prenatal test for trisomy 21 in Belgium: a cost-consequences analysis, *BMJ Open* 2014.
- Reid B, Sinclair M, Barr O, Dobbs F, Crealey G. A Meta-Synthesis of Pregnant Women's Decision-Making Processes with Regard to Antenatal Screening for Down Syndrome. *Social Science & Medicine*. 2009 Dec; 69(11): 1561–1573. <https://doi.org/10.1016/j.socscimed.2009.09.006>.
- Savva, G. M., Walker, K. and Morris, J. K. (2010), The maternal age-specific live birth prevalence of trisomies 13 and 18 compared to trisomy 21 (Down syndrome). *Prenat. Diagn.*, 30: 57–64.
- Scott M, Foley K R, Bourke J, Leonard H, and Girdler S. 'I Have a Good Life': The Meaning of Well-Being from the Perspective of Young Adults with Down Syndrome.

- Disability and Rehabilitation. 2014 July; 36(15): 1290–1298. <https://doi.org/10.3109/09638288.2013.854843>.
- Shakespeare T. Choices and Rights: Eugenics, Genetics and Disability Equality. *Disability & Society*. 1998 Nov; 13(5): 665–681. <https://doi.org/10.1080/09687599826452>.
- Skirton H, Barr O. Antenatal screening and informed choice: a cross-sectional survey of parents and professionals. *Midwifery*. 2010 Dec; 26(6): 596–602. doi:10.1016/j.midw.2009.01.002
- Skotko BG. Prenatally diagnosed Down syndrome: mothers who continued their pregnancies evaluate their health care providers. *Am J Obstet Gynecol* 2005; 192: 670–677.
- Skotko G., Capone G.T. and Kishnani P.S. Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News. 2009; 124(4): 751–758.
- Stanislav B., Lemoine M. et al., Moving Towards Routine Non-Invasive Prenatal Testing (NIPT): Challenges Related to Women’s Autonomy. *OBM Genetics* 2018; 2(2): 2018.
- UZ Leuven, Centre for Human Genetics, NIPT, 04–02–2017, available at: <https://www.uzleuven.be/en/nipt#reimbursed>, accessed on June 5, 2018.
- Verweij E. J., Oepkes D. and Boer M. A. (2013), Changing attitudes towards termination of pregnancy for trisomy 21 with non-invasive prenatal trisomy testing: a population-based study in Dutch pregnant women. *Prenat Diagn*, 33: 397–399.
- Williams C., Alderson P. and Farsides B. (2002), What constitutes ‘balanced information in the practitioners’ portrayals of Down’s syndrome? *Midwifery*, 18: 230–237.

Supplement 1: The Original Challenge document

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.

(Written by Eline Zenner on behalf of Downsyndroom Vlaanderen)

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 fewer risks for the fetus than an amnio (where a needle is guided through the abdominal wall and into the fluid sac), and can be conducted at a much earlier point in pregnancy. Without going into medical detail, the test isolates the fetus's DNA from a blood sample taken from the mother and offers a near-conclusive diagnosis (with more than 98% accuracy) for trisomy 13, trisomy 18, and trisomy 21.

On Monday, 29 May 2017 Belgian Minister of Social Affairs and Health Maggie De Block announced that 15 million euro would be made available to refund the NIPT to every Belgian pregnant woman. 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 provided. 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 long and relatively care-free lives (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 toward a world without Down syndrome?

The answer to this question is not what we as parents of a child with Down syndrome want to focus on. If future parents make a well-informed and well-considered decision following a prenatal diagnosis of Down syndrome to

terminate their pregnancy, then it is by no means our desire to stop them. No matter how dearly we love our children, we support a pro-choice vision on prenatal screening: every parent has the right to choose whether to terminate or to continue a pregnancy.

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 whether or not to continue a pregnancy, in essence defending their right to terminate. Because of this socio-political context, the decision to terminate a pregnancy is subsumed under the flag of a 'pro-choice' vision. It is however incorrect to equate a pro-choice vision with a pro-termination stance: we should be careful not to evolve to a point where, under certain conditions, allowing a woman to choose entails that we expect a woman to terminate. Under a true pro-choice approach, the choice for life and the choice for termination should at all times be measured with equal scales.

In the specific context of the NIPT, a pro-choice vision entails that future parents first and foremost make a conscious decision whether or not they want to screen for disabilities and abnormalities during pregnancy. Once they decide to screen, a second choice then is what to do with the outcome of such screenings. In this respect, society seems to be evolving to a point where screening is a given rather than a choice, and termination is the standard outcome of a positive diagnosis in prenatal screening. The parents in our network who have consciously decided to keep a child with a disability after positive results in prenatal screening find themselves faced with hostile comments and repeatedly have to defend their choice to others, including medical staff. Why bring a child into the world with a syndrome that no longer needs to be? The recent decision to refund the NIPT on a national level without mirroring this financial initiative with efforts concerning counseling further illustrates this termination-oriented climate.

As parents of a child with Down syndrome, who have joined forces in the Downsindroom Vlaanderen voluntary association, 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 with 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 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 issue from a transdisciplinary scientific framework, but we also and more importantly need to come up with a strategy to disseminate insights on the matter to a wide audience.

On the broader level of genetic screening, the question is how we can (re?)introduce fair play in the public debate on prenatal decisions, how we can contribute to a correct perception of life with (a child with) a disability?

On the more specific level of screening for Down syndrome, the question is two-tiered. First, we need to find out how we can provide non-directive information on Down syndrome to all future parents. How can we make sure that up to date information on the possible impact of Down syndrome on a child's and a family's living conditions finds its way to future parents, ideally even before they decide to undergo prenatal screening? As we see that centers for human genetics typically already undertake efforts in this respect, we secondly want to question the position of GPs and gynecologists in providing this information. Which tools, data, approaches 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 cannot 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?

Additionally, we question the role of the media in the debate. Currently, the media frequently offer broad platforms to individuals who have strong opinions on prenatal screening, but do not necessarily have any notable actual experience with people with Down syndrome. Several individuals for instance make public assessments on the 'unbearable suffering' that is tied to trisomy 21, often relying on old and colored terminology (calling people with Down syndrome *mongooltjes* – a term that was abandoned by WHO in the 1960s). Although this assessment may hold for a number of people with Down syndrome, it most surely does not apply to all. Public opinion on the genetic condition is however greatly colored by such mediatized debate. 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 that they decide on screening without ever having met a person with Down syndrome: the information shared in the media (in terms of both form and content) hence is of crucial importance for future parents' perception of Down syndrome.

The issues we raise here are hard to tackle in their own right, but political and economic concerns further complicate the debate. 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?

Several objectives can be derived from this overview. From our perspective as parents, we would like to prioritize the most practical ones:

- How can we provide **future parents** with non-directive information on all aspects of life with a child with Down syndrome as an a priori for prenatal screening? Downsyndroom Vlaanderen would be thrilled with a tool (a script for a video that might go viral, for instance) that allows doctors to communicate about prenatal screening and decision processes to young parents, ideally tailored to the NIPT and Down syndrome.
- How can we provide **medical teams** with strategies for counseling: how can we provide medical teams with specific strategies to counsel future parents on the topic of prenatal screening, ensuring that screening is provided from a multidisciplinary perspective? Downsyndroom Vlaanderen would be very grateful for a concrete proposal for a training session for doctors (GPs, gynecologists etc.) on (i) current living standards and possibilities of life with Down syndrome; (ii) existing organizations that can be addressed for instance in non-directive communication.
- How can we sensitize **society at large** concerning the ideologically colored and relatively outdated discourse on people with disabilities in general and people with Down syndrome in particular?

In the next section of this proposal, we sketch precisely how this challenge could be addressed by a properly trans-disciplinary 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. 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:

- opposing genetic progress against ethical progress;
- 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;
- counseling and prenatal diagnosis: from GPs over gynecologists to centers of human genetics;
- how will care for people with disabilities improve in the future, and how could that influence the decision making?

Arts & Social Sciences:

- in-depth analysis of current public discourse and medical counseling;
- lexical variation and ideology: revealing connotations and stigmatization attached to *mongooltje* (vis-à-vis *een baby met downsyndroom*);
- communication on disabilities in a general societal context: how to ensure that people acquire a realistic perspective on the potential of people with a disability;
- communication in the 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;
- intercultural communication: how to provide information to people with different cultural backgrounds;
- cultural history: the background to the pro-life vs. pro-choice debate, complemented with an analysis of the reasons for abortion (psychosocial reasons, medical reasons, ...), and how we can use these insights for the future. What is the distinction between these reasons and how can we tease them apart?

Economic Sciences:

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

Law:

- human rights at play in prenatal screening (see the UN Convention on the Rights of Persons with Disabilities);
- linking counseling and refunding of prenatal screening in the Belgian system: prevention is located at the regional level, but healthcare is organized on a federal level.

LUCA (Associatie KU Leuven):

- people with Down syndrome often have great artistic abilities: what is the value of this for society?
- Psychology & Pedagogy:
- psychological factors involved in the process of making life-changing choices;
- psychological factors of normality and differences;
- living with a family member with Down syndrome;
- sharing 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);
- 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 counseling 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 stakeholders 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.

CMEs: The centers 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 research and at the same time have always strongly adhered to neutral counseling. The CMEs 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 follows: '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 CMEs 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 in being involved in this project. Also marek.wojciechowski@telenet.be from UZA can be contacted as a 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 CMEs for advanced testing. Hence, it is crucial to include VVOG as stakeholder in this project. The organization agrees to operate as stakeholder for the project. VVOG can be contacted by e-mailing doctor Van Keirsbilck via joachimvankeirsbilck@hotmail.com.

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 counseling 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 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 counseling 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.

Grip vzw: GRIP (Equal Rights for Each Person with a Disability) is a Flemish civil rights organization for people with disabilities. Patrick Vandelanotte has described 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 its 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 manner in which people with a disability are treated (from exclusion over segregation to participation), but indicate where there is room for improvement. They take it to heart to show the value of people with an intellectual disability, and underline their right to 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@inclusievlaanderen.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 DVDs 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, were future midwives, 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 go to Professor De Dijn (KU Leuven) and Doctor Kasper Raus (UGent) for their useful comments on earlier versions of this proposal.

Notes

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.

Supplement 2: Assumptions in the Original Challenge

This document lists several assumptions in the original challenge, or assumptions that are relevant for our project. These assumptions are divided into six categories, plus we include a seventh paragraph with several assumptions that are also relevant for our research but that are not included in the original document. This was an assignment in an early stage of our project. Therefore, each assumption is accompanied by a preliminary analysis of it, aiming for possible angles for our project and further research.

1. ASSUMPTIONS CONCERNING PEOPLE WITH DOWN SYNDROME

The first assumption is the following: ‘People with Down syndrome are people.’ Who decides the standard for personhood? Should capabilities and functioning have a role to play in this? A capabilities approach is philosophically weak; why should capabilities take precedent in defining personhood? The capability standard in defining personhood is a normative standard we can attack.

Secondly, it is often assumed that people with Down syndrome are happy. This is true according to a qualitative study (Alderson 2001), in which the author examined the lives of several people with Down syndrome. However, the author expressed some reservations regarding the methodology used: it is possible that the participants that are chosen for such studies are more high-functioning and therefore happier. So, we cannot simply assume that Down syndrome comes with happiness. Also, it is common knowledge that measuring happiness is very hard. So, a conclusion may be that studies on the happiness of people with Down syndrome are not very reliable. However, when it comes to people with Down, we can learn from what they tell us. Qualitative research also shows that they can articulate whether they are happy or sad and point out the things in their lives they are happy or unhappy about. They describe hopes, dreams, aspirations as well as difficulties and things they would like to be different in the world.

Another assumption states that people with a disability have a valuable position in society that gives them the ‘right to live’. However, why should there be a standard of value or contribution to society in order to obtain that right? A lot of literature looks at whether people with Down syndrome can indeed work and fulfil basic contributions to society in capitalistic terms, but we must ask why this is a requirement at all.

Also, the challenge states that ‘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’. This seems to assume that segregation in schooling is a bad thing. However, this is a controversial claim, and disability activists themselves are not in full agreement. On the one hand, inclusion suggests equal opportunity for participation. On the other hand, segregation sometimes is more conducive to providing environments for developmentally disabled individuals to receive proper and individualized support, as opposed to being inadequately included in mainstream settings which may not be adequately supportive.

2. ASSUMPTIONS WITH REGARD TO PARENTS WHO HAVE A CHILD WITH DOWN SYNDROME

In the document, it seems to be an assumption that parents of a child with Down syndrome see something good when they look at their children. ‘When we look at our children, we see people. We see people with hopes and dreams, fears and desires, hands, fingers, toes, favourite food, bath time rituals, bubbles and images of the life we share.’¹ However, it is hard to generalize the viewpoints of parents like that. It may be possible that not all parents view their children like this.

A second assumption can be formulated as following: ‘Having a child with Down syndrome does not necessarily cause more suffering than not having it.’ This, of course, depends on a comparison of the ‘suffering’ of having a child with Down syndrome on the one hand with the ‘suffering’ of not having the child on the other hand. This comparison

can never be made, and it surely cannot be generalized. However, it is worth investigating the risks of ‘suffering’ in both cases – keeping in mind that risks are risks, and not harm.

Thirdly, the challenge states the following: ‘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.’² The truth of this assumption depends, firstly, on your definition of ‘life-shattering’; is this meant on a financial, medial, social, emotional or psychological level? Thereby, Down syndrome comes with higher risks of certain disabilities such as autism and Syndrome of West. In severe conditions it might be ‘life-shattering’, given certain possible definitions of the term. Overall, it might be true that Down syndrome is not the most life-shattering condition; but there are certainly exceptions to the rule.

3. ASSUMPTIONS CONCERNING SOCIETY AND TAX PAYERS

Firstly, it is assumed that society sees Down syndrome as something bad, due to medical complications. Indeed, when we look at the literature about the medical, psychological, nursing and ethical aspects of Down syndrome, it has negative referrals such as ‘not treatable’, ‘the most common form of severe mental retardation’ linked to ‘precocious dementia’, associated by mid-adulthood with high levels of (frequently undiagnosed) severe sight and hearing loss, heart and lung disease (often following untreated infections and heart defects), loss of cognitive abilities, epilepsy, serious behavioral problems and ‘poor communication or confusion due to Alzheimer disease’. Some pediatric texts mention Down syndrome only with reference to prenatal screening or emphasize severe pathology as if everyone with Down’s is very adversely affected. Psychometric research often concentrates on negative issues, such as anxiety, depression, stress and blame, thus tending to present negative reports about Down syndrome. The many surveys of raised anxiety among pregnant women during screening implicitly reinforce assumptions that Down syndrome is something to be very anxious about (Alderson 2001).

Secondly, the challenge suggests that society will hold it against people who (consciously) decide to have a baby with Down syndrome that they cost taxpayers money, or to blame them for high tax costs when parents refuse prenatal testing. These are assumptions that still need more investigation.

Thirdly, the challenges pose the following question: ‘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)?’ Prenatal medical prevention is the logical solution to non-treatable genetic/biological causes of suffering, whereas social/emotional suffering is resolved and prevented by changes in social attitudes and structures toward making societies more inclusive, reforms which are undermined by national prenatal screening programs. Prenatal screening is an effort to reduce the ‘costs of life-long care’; however, it may propagate attitudes which restrict independence and employment opportunities of people with Down syndrome (Alderson 2001). For years now, there has been no money from Riziv for refunding speech therapy for children with an IQ lower than 85, for refunding multidisciplinary consultations, for refunding behavioral therapists, or for the expansion of rehabilitation centers. All this support is very valuable for children with Down syndrome and often highly necessary. But suddenly 15 million euros is available for refunding a prenatal screening test for Down syndrome. With this decision, the government seems to give a clear message: ‘If you really want a child with Down syndrome, go ahead, but you’ll have to manage everything by yourself.’ If the government does not provide an equal alternative, it pushes people in the direction of termination. Having a child with Down syndrome might become a possibility only for the rich. So this assumption may turn out to be true.

4. ASSUMPTIONS CONCERNING THE CHOICE FOR TERMINATION OF THE PREGNANCY OR NOT

There are several assumptions concerning the question whether we can make a real choice or not. Some examples of possible assumptions are the following: ‘Parents choose termination of their child with Down syndrome under pressure of society’s desire for perfection’; ‘Parents have a right to choose under all circumstances whether or not

to have a child'; 'Parents can make that choice, because they have "free will"; 'Parents are able to come to a unified choice' and 'Society seems to be evolving to a point where screening is a given rather than a choice'.

The problem of free will itself is already an issue, since nowadays a good section of both neurologists and philosophers have cast serious doubt on the ability of free will to exist. Nonetheless, we must argue that a certain assumption of free will should be made. We are trying to find a method of counseling people on screening for Down syndrome without directing them toward a certain decision. If any method is to be found that entails actual counseling, it must necessarily assume that people have autonomy in making that decision, which means that one must allow for the assumption that they have an autonomous will that can direct itself toward a choice. To challenge this means either to deny the existence of free will as a political necessity, in which case they should not be consulted at all, a mere governmental directive being sufficient, or to deny people autonomous choice up to a certain point. In this last case, which coincides with the second assumption ('Parents have a right to choose under all circumstances whether to have a child or not'), one is dealing with absolutes. The options are, as far as we can tell, fivefold (although more may be thought of):

- The child can be seen as sacred from the beginning, even if it has a condition.
- The child may live if it can live a life in which it will not wish to die by default.
- The transhumanist/eugenic argument, namely that it is incumbent upon society to ameliorate the genetic structure of its citizens or to eliminate pathological elements from the genetic inheritance. Especially now that technology starts to allow for this. The absolute here is that there is no inherent sacredness tied to genetic essence.
- That only those conditions should be kept which either allow for a positive contribution to society, like with certain forms of society, or are unlikely to put an undue burden on society. The absolute being that society should only bring about things to its immediate benefit and has a right to cancel out anything it can that goes against that maxim.
- That society has a duty to minimize the suffering of its citizens, including both children who, if born, would be faced with an enormous disadvantage and parents who are faced with the task of bringing up a child in this situation.

This does not, of course, describe the full scope of the issue, but it suffices for our current purposes. The maxims here described all provide grounds to limit the choice of the parents to give birth to the child or not. And here, at least, decisions must to be made by us and by society at large.

On what basis should parents make their choice? This expresses the worry in the assumption that parents choose for the termination of their child with Down syndrome under pressure of society's desire for perfection. The decision may not be motivated through a healthy philosophical position, but through a rather pathological desire engendered through the culture at large. Should we make people aware of this and, if so, how?

In the decision process, several important considerations must be taken into account. Firstly, it is far from obvious that both parents will come to the same conclusion. This is something that must be taken into account. Also, there is the question of initiating this counseling before or after screening. If it is done after screening, it is debatable whether enough time can be taken to reach a decision. Proper counseling before screening, however, would entail a huge effort, since every pregnancy would entail counseling. Also, in this stage, people may not yet be ready to be confronted with this issue.

Questions concerning free will pose further questions, for example whether genetic screening should be made available to all and what the influence of the government refunding the NIPT test means as imperative to avoid 'abnormal' children. These are questions that would also need further investigation.

5. ASSUMPTIONS CONCERNING NON-DIRECTIVE COMMUNICATION

The first assumption here is the following: 'There is such a thing as non-directive communication.' This is a very controversial assumption, with opposite opinions from different perspectives. Most people in the field of communication

seem to think that it is nearly impossible to really be non-directive while communicating (Clarke 1991, Pennacchini & Pensieri 2011). Everyone has their own frame of reference built up through life and when we communicate, our own reference will influence what we say and even why we say things. Also, even with the communication of only facts, there will be a nonverbal component: it is hard to hide body language, and this may also show one's feelings about the topic. The nonverbal component is at least as important as the verbal component in communication (Pennacchini & Pensieri 2011). On the other hand, other people say: 'Let's communicate only in facts and it will be non-directive anyhow.' This is of course not necessarily true: a selection of the facts to be disclosed must be made. Moreover, it has turned out that giving out merely facts will lead to less understanding of the topic. People seem to understand and remember more of the given information when this information is put into perspective and made more practical (Pennacchini & Pensieri 2011). But of course, when we do this the communication will become more and more directive. A study shows that the great majority of women are being influenced by health professionals in deciding whether or not to continue with an affected pregnancy (Marteau & Dormandy, 2001). There is also a study that shows that parents are more likely to terminate pregnancies affected by a sex chromosome anomaly when counseled by an obstetrician than by a geneticist or a specialist pediatrician (Marteau et al. 2002). Another study shows that information provided on conditions such as Down syndrome is generally more negative when it is given to those considering prenatal testing than to those considering testing at other times or to parents who have already received a positive test result (Marteau & Dormandy 2001). This shows that our communication is influenced not only by our own frame of reference, but also by the frame of reference of the people we are talking to.

'The medical practice is the location where such communication should be provided.' This is a second assumption concerning non-directive communication that is important in our research. Ever since prenatal testing has been offered in medical practice, it has seemed to be most logical that communication about it is also provided here. After all, so-called informed consent is needed for every medical act. This means that people should have been given sufficient information by the doctor about the procedure itself and the reasons for it, so that people can make a conscious decision on the matter. Since this principle is there by law, it is mandatory that such communication happens in medical practice. Moreover, information collected in medical practice is seen as reliable: it is often taken seriously by the population. However, one can argue that the government should select and organize the information that is provided, based on the view that prenatal screening is provided as some kind of public health issue. Also, when there are unexpected results or when a certain condition such as Down syndrome is diagnosed, it is argued that the communication should not be done merely by health professionals, but also by professionals in counseling.

Thirdly, a possible assumption is that 'screening for Down syndrome is merely the beginning of a general societal tendency to screen for conditions'. To a great extent, the NIPT test is developed to screen for Down syndrome and other trisomies (trisomy 13 and 18). Now that a way to analyse the DNA of the fetus without any risk for the fetus has been found, it is very likely that researchers will search for other genetic defects such as mendelian deviations, and in the further future even multifactorial conditions. Right now, the NIPT can screen for Down syndrome, fragile X-syndrome, SMA, cystic fibrosis and Edwards' syndrome, and when testing is done after 15 weeks gestation even for neural tube defects and abdominal wall defects. Screening increases, both in the number of tests taken and in the number of conditions that can be screened for (this is an insight acquired in a meeting with Prof. Cassiman). Incentives for this come from the parent(s) who want to be prepared, from the fact that it is possible to do so, and there may also be an important role of commercial companies that find a new way of making money with the offering of these kinds of possibilities to screen for more conditions.

Fourthly, we should investigate whether the claim that centers for human genetics typically make efforts to provide non-directive counseling holds. This assumption seems to be true: indeed it seems clear that centers for human genetics typically have much better knowledge about the conditions which we screen for such as Down syndrome in comparison with GPs or gynecologists. Therefore, these centers can provide more information and details about the conditions and the risks of repetition in a next pregnancy (this is an insight we acquired through our meeting with Prof. Cassiman). Generally, in these centers, more time is provided per consultation to give a detailed explanation than in consultation at the gynecologist's office. In the limited time gynecologists have available per consultation,

prenatal screening is only one of the many topics that must be discussed. So, centers for human genetics probably can provide better counseling, but future parents are usually sent there only when there already is a suspicion or confirmation of a condition.

Lastly, it must be investigated whether communication in the gynecologist's offices is indeed, as suggested in the original challenge, too idiosyncratically tied to specific profiles. Unfortunately, there is little data revealing how genetic counselors communicate about disabilities in the context of prenatal setting. A study on topic reveals that most counselors (95%) focus on the physical aspects of disability, while fewer (27%) discuss the social aspects. In addition, few genetic counselors (38%) asked patients about personal experiences with disability. When discussing possibilities, most genetic counselors mention termination (86%) while fewer mention the continuation of the pregnancy (37%) or adoption (13%). Only half of the genetic counselors ask if the future mom had thought about how she might use the results of prenatal screening (Farrelly et al 2011). In another study by Leonard et al., parents of families containing children with cystic fibrosis, phenylketonuria, and Down syndrome were asked questions designed to discover their understanding of the genetic counseling that they received. Although all the families had been counseled, about 1/2 had a good grasp of the information given, 1/4 gained something, and 1/4 learned very little. This variation is probably due to differences in the contexts in which the counseling was provided, including variable skills of the physicians who provided it, but it is also associated with the knowledge of biology and the perception of the usefulness of the counseling that the parents brought to it (Leonard et al. 1972). There is also a study available that indicates that gynecologists in general have a lack of interdisciplinary knowledge to offer the right counseling to pregnant women (Harris et al. 2005). Another explanation for the inadequate counseling could be that gynecologists spend less time in providing information to women with an a priori low risk in comparison with women with a high risk.

6. ASSUMPTIONS CONCERNING (SOCIAL) MEDIA

There are lots of assumptions visible about the (social) media, such as the following: '(Social) media have an important role in the dissemination of stereotypes and public opinion on Down syndrome', and 'Risk and harm are confused in the public debate on Down syndrome.' This paragraph explores the role of social media in the perception of Down syndrome.

If we look at social media, we observe that they have become a platform for interaction, discussion, the sharing and consuming of information and the production of political information. This way of exchanging information has an impact on political participation, perceptions of opinion leadership, attempts at political persuasion (Brian 2017).

Looking at previous studies, we observe that media consumption affects social interactions. Bryant & Zillmann stated that media effects are social or psychological changes that occur in consumers of media messages because they are exposed to those messages: they process them or even act on them (Bryant & Zillmann 2009, pp. 9–18).

When we ask ourselves what kind of information we acquire through the media, we find that most of what people know comes to them from the mass media or from other people (Lang & Lang 1966, p. 466). The mass media force attention to certain issues. They build up public images of political figures, they are constantly presenting objects suggesting what individuals should think about, know about, have feelings about (Lang & Lang 1966, p. 468). Adapted to our research question, Goethals argues that 'the mass media are a useful source of information about current and historical norms and values, public opinions and attitudes on disability' (Goethals 2017).

There are only a small number of studies that systematically explore the media representations of people with Down syndrome. What these studies show, is that what is depicted in the media is not an exact representation of the realities of disability identities in society (Goethals 2017, p.52). This is also the case on social media. Many initiatives such as *T21 Mum Australia* have their own Facebook page to connect moms and provide support by the organization of online and real-life events. For the month of October, which is World Down Syndrome Awareness Month, *T21 Mum Australia* denounced the negative stigma associated with Down syndrome: 'Children with Down syndrome are not lazy, stubborn, and definitely not always happy. Children with Down syndrome don't always like hugs or naturally like

music. These are all stereotypes associated with the diagnosis. Children with Down syndrome are just children. They are individuals with ranges of abilities, interests and personalities.'

Another aspect that should be taken into consideration when looking at stereotypes is the language used in media content related to Down syndrome. The language used in media can shape our view on people with Down syndrome. Several associations have published a guide to suggest the use of adequate language for Down syndrome-related issues in the media. 'Language choice can empower people' is a statement found in the media guide offered by *Down syndrome Victoria* in Australia. The guide proposes to 'try not to portray people with a disability as objects of pity or as brave' and comes up with a list of words which are to be favored over misused terms. 'The key consideration is to always put the person first, not the disability.' In Dutch, for example, the correct term is '*iemand met Down syndroom*', not '*mongooltje*'.

The A&E reality show *Born this way* portrays a group of young adults having Down syndrome in their everyday lives in the US. The series also shows their parents and the joys and challenges that they encounter in supporting their children. The channel had a coverage of 81.6 per cent of households in 2015, so the series had great potential to reach out to a wider public. The image given to the audience is overall very positive, the characters pursue their dreams and careers just like people without Down syndrome. The website of the TV show also provides a language guide and a viewing guide with further information on Down syndrome to encourage discussions at college level as well as for general audiences. Evana Sandusky, who is a language speech therapist for children, mother of a child with Down syndrome and author of *The Mighty* (a blog on health and parenting issues), complains that people with Down syndrome who appear in the media are certainly not those who struggle the most: 'Support comes from all directions celebrating those with Down syndrome with extra-special talents who seem to meet the world's view of success.'

A study conducted in New Zealand in 2014 on the media portrayal of Down syndrome observed that recent mixed media coverage of the topic is critical, complex and socially inclusive of people with Down syndrome: it seems to be politically correct. Although the quality of life for people with Down syndrome was represented as slightly negative, the study showed no strong directional reporting. Most of the time, articles in New Zealand's media focused on issues of society, government and care rather than genetics, screening and testing (Wardell et. Al 2014, 242-250).

According to Goethals, 'there is a complex relationship between media coverage and the public, the media have a powerful influence on the way "disability" as a phenomenon is perceived and on the process of attitude formation.' Her analysis conducted between January 2003 and December 2012 showed that there is very little coverage on people with disabilities or even a 'total lack of representation in certain media sources' (Goethals 2017).

In any case, media representation is of major importance: Tsfaty argues that stigmatization of minority groups in mainstream media makes minority members more likely to feel alienated. (Tsfaty 2007, pp. 632–651.)

7. ASSUMPTIONS THAT ARE MISSING IN THE ORIGINAL CHALLENGE DOCUMENT

Other assumptions, related topics and research questions that might be worthwhile exploring are for example:

- Are people capable of deciding the criteria for prenatal screening?
- Are parents capable of fully assessing what parenthood is all about, prior to becoming parents?
- Are fetuses people? Do they have rights?
- Is communication about Down syndrome (or generally about the disability you are screening for) more important than communication about screening in general?
- Should society make sure that people with disabilities make up a relevant proportion of society and maintain a certain position within it?
- What role do personal experiences play in the decision-making process, and what role should it play? What roles should personal experience, the media and doctors have within the process?
- Pharmaceutical companies (and other private companies) have their own gain in making the test widely available; is this a good thing?

Notes

- ¹ Original challenge document, p. 45.
² Original challenge document, p. 46.

References

- Alderson, P., 'Down syndrome: cost, quality and value of life'. *Soc Sci Med* [Internet]. 2001;53(5):627–38. Available from: <http://www.sciencedirect.com/science/article/pii/S0277953600003658>
- Brian E., 'Online Influence? Social Media Use, Opinion Leadership, and Political Persuasion'. *International Journal of Public Opinion Research* Vol. 29 No. 2 2017.
- Bryant, J., & Zillmann, D. 2009. 'A retrospective and prospective look at media effects'. In L. R. Nabi, & M. B. Oliver (Eds.), *The sage handbook of media processes and effects*, 9-18.
- Claire O. Leonard, Gary A. Chase, A. & Childs, Barton, 1972, 'Genetic Counselling: a Consumer's View', in *The New England Journal of Medicine*, 287, 433-439.
- Clarke, Angus, 1991, 'Is Non-directive Genetic Counselling Possible?'. In *The Lancet*, 338, 998-1001.
- DADA Study Group comprising Marteau, Theresa M, Irma Nippert, Sue Hall (writing committee), Caroline Limbert, Margaret Reid, Martin Bobrow, Alan Cameron, Martina Cornel, Mariet van Diem, Bernd Eiben, Sixto García-Minaur, Janine Goujard, Donna Kirwan, Karen McIntosh, Peter Soothill, Corien Verschuuren-Bemelmans, Catherine de Vigan, Stephen Walkinshaw, Lenore Abramsky, Frank Louwen, Peter Miny and Jürgen Horst, 2002, 'Outcomes of pregnancies diagnosed with Klinefelter syndrome: the possible influence of health professionals' in *Prenatal Diagnosis*, 22: 562–566.
- Farrelly et al., 2011 'Genetic Counseling for Prenatal Testing: Where is the Discussion About Disability'. In Farrelly, Ellyn, Mildred K. Cho, Lori Erby, Debra Roter, Anabel Stenzel & Kelly Ormond. 2012. Genetic counseling for prenatal testing: Where is the discussion about disability? *Journal of Genetic Counseling* 6: 814-824.
- Goethals, Tina, 2017, 'Inclusion of persons with disabilities in Flanders. A "participatory" research project on personal narratives, the representation of persons with disabilities in the media and political participation of persons with an intellectual disability' (PhD Thesis).
- Harris, Rodney & Lane, Beverley & Paris, Hilary & Williamson, Paula & Dodge, John & Moddell, Bernadette & Ponder, Bruce & Rodeck, Charles & Alberman, Eva, 2005, 'National Confidential Enquiry into counselling for genetic disorders by non-geneticists: general recommendations and specific standards for improving care', in *An International Journal of Obstetrics and Gynaecology* <https://doi.org/10.1111/j.1471-0528.1999.tb08364.x>.
- Lang, Kurt & Lang, Gladys Engel, 'The Mass Media and Voting'. In Bernard Berelson and Morris Janowitz, eds., *Reader in Public Opinion and Communication*, 2d ed., New York, Free Press, 1966, p. 466.
- Marteau, Theresa M & Dormancy, Elizabeth, 2001, 'Facilitating Informed Choice in Prenatal Testing: How Well Are We Doing?' In *American Journal of Medical Genetics* (Semin. Med. Genet.), 106, 185-190.
- Pennacchini, M. & Pensieri, C., 'Is non-directive communication in genetic counseling possible?'. In *Clin Ter*, 162, 141–144.
- Tsfati, Y., 2007. 'Hostile media perceptions, presumed media influence, and minority alienation: The case of Arabs in Israel'. *Journal of Communication*, 57, 632-651.
- Wardell, S. et. al., 2014, 'A qualitative and quantitative analysis of the New Zealand media portrayal of Down syndrome'. *Disability and Health Journal* 7, 242–250.

Supplement 3: Website table of content

This supplement section provides a detailed table of contents for the website downtocounsel.weebly.com which is currently in the making. Each thematic section is associated with questions covering many elements of counseling. One example of such a question is provided for each section in the table of contents.

The answers and information listed in the proposed table of content are of course nonexhaustive. To keep the information up-to-date and as close as possible to our users' needs, we seek to cooperate with medical staff using our website. The information provided on downtocounsel.weebly.com can be completed with the help of users through online feedback, which will be accessible on the website. The form to be used can be found on the last page of this section.

INTRODUCTION

Medical bias

- *How can I provide a transdisciplinary approach to counseling?*

SCREENING

Consequences of NIPT

- *What does the NIPT change regarding the choices that people face?*

Medical timeline

- *How do I communicate about the medical timeline?*

Choosing to screen

- *In what way can I present the choice of whether to screen without diminishing either the medical value of screening or the personal free choice of my patient regarding the matter?*

Future developments

- *What future developments can I expect?*

Screening & free market

- *How should I address free market options when my patient brings them up?*

THE DECISION-MAKING PROCESS

Well-informed decision-making

- *What makes decision-making so difficult for prospective parents?*
- *What if counseling from organizations does not help?*
- *What should parents realistically expect from counseling?*

Non-directive counseling and nudging

- *Which organizations can I refer to for decisionmaking support after a positive result has been disclosed?*

Stigmas and stereotypes

- *What language should be used in talking about Down syndrome in counseling?*

Individual factors influencing decisions (age, gender, ethnicity)

- *What social factors influence the decisionmaking process?*

Post-decision counseling: guilt and other obstacles

- *What if parents need help coping with their decision?*

LIVING WITH DOWN

Independent life

- *To what extent can people with Down syndrome have an independent existence?*

Therapy and support

- *What support can be given to people with Down syndrome in the current society in Flanders, and by what organizations?*

Everyday life: from kindergarten to professional life

- *Can people with Down syndrome go to a normal school?*
- *What job opportunities are there for people with Down syndrome?*

Family life: ASS or pattern-proof? Practical aspects: bathing, cleanliness, food, transport, vacation, life stages (transition to adulthood, growing old with Down)

- *What are practical concerns that should be taken into account when you have a child with Down syndrome?*

Social aspects (integration)

- *What can I do if a child with Down syndrome faces exclusion?*
- *How far does having a child with Down syndrome affect my own social life?*
- *What implications does having Down syndrome have for your social life?*

Subjective experiences of living with Down syndrome

- *What does it mean to have a sibling with Down syndrome?*

Financial aspects

- *What are the financial implications of living with a child with Down syndrome?*
- *What financial aid is there currently available in Flanders?*

International/historical perception of Down syndrome

- *In what aspects does the current situation in Flanders differ from that in other regions or countries with regard to education, job opportunities, financial aid and so on?*
- *In what aspects does the current situation in Flanders differ from that in the past?*
- *What organizations strive for progress or emancipation for people with Down syndrome?*

Supplements 4-10: Description of the video and audio fragments

SUPPLEMENT 4 (VIDEO FRAGMENT 1)

This supplement concerns a video of a mom of a child with Down syndrome we met. In this video she tells about her experiences during her pregnancy with her child. This video shows that counseling in a non-directive way is extremely important. Negative and discouraging counseling should be avoided. This fragment is an extract from a five-minute interview.

SUPPLEMENT 5 (VIDEO FRAGMENT 2)

During our one hour talk with Fara, we talked about counseling for prenatal screening. Fara is an organization that counsels women and couples about choices in pregnancy, among which are choices regarding termination of pregnancy in case of a prenatal diagnosis of a fetal condition. This one-minute extract concerns the weight that can be felt by parents either by choosing to terminate or to keep the child and therefore the importance of the decision-making process.

SUPPLEMENT 6 (VIDEO FRAGMENT 3)

In this extract of a one and a half hour talk with Dr. Raus, he tells us about nudging in healthcare and the importance of how to convey information to parents. Dr. Raus is a bio-ethicist at the University of Ghent.

SUPPLEMENT 7 (VIDEO FRAGMENT 4)

In this extract you can see two parents with their little daughter, who has Down syndrome. The father tells us what convinced him to make the choice of keeping his daughter. This is an extract of twelve minutes from the talk.

SUPPLEMENT 8 (VIDEO FRAGMENT 5)

This extract shows the mother of a child with Down syndrome. She tells us about her experience with the doctors after she received the positive NIPT result. This video is an extract of six minutes during the talk.

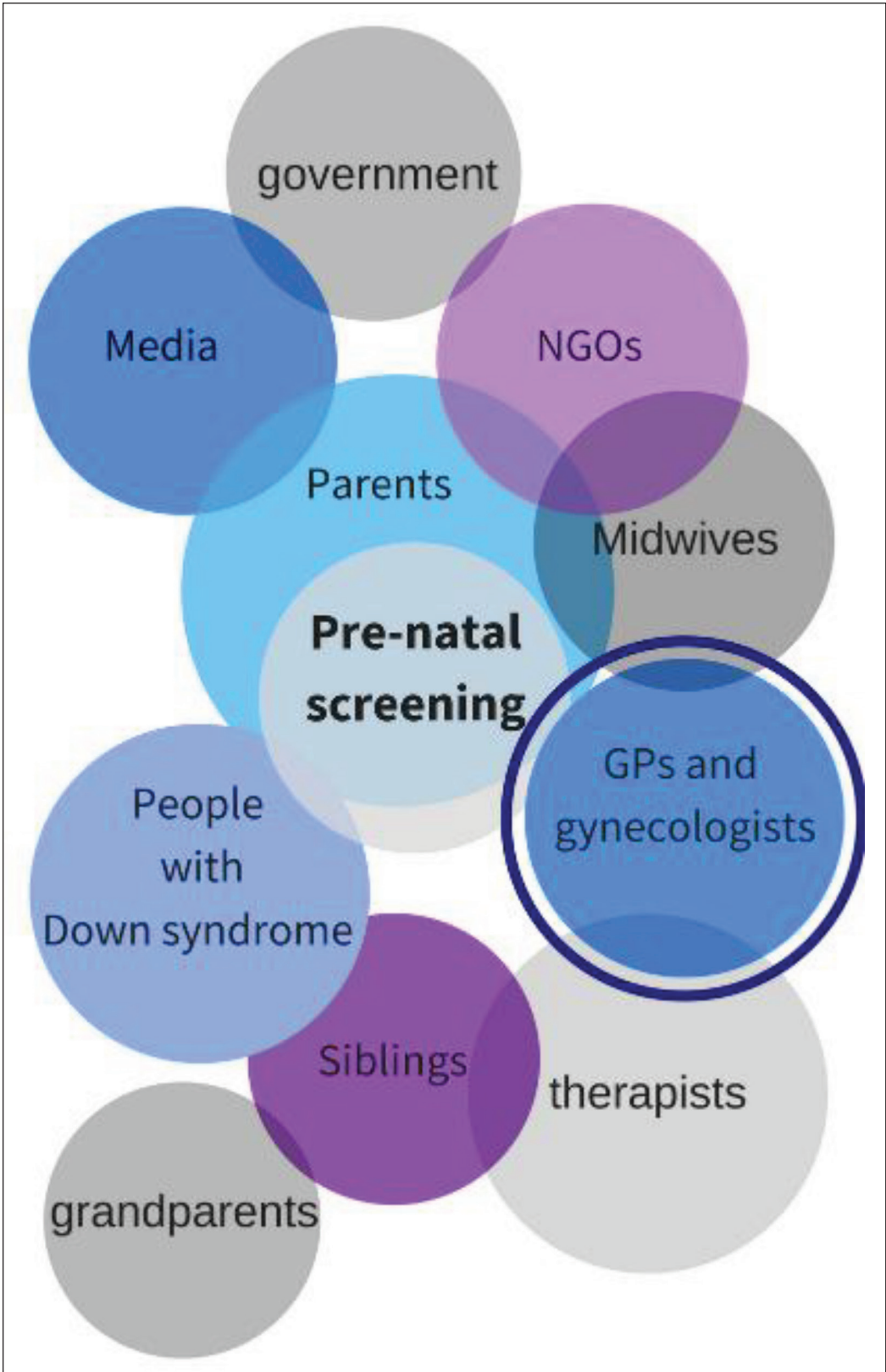
SUPPLEMENT 9 (AUDIO FRAGMENT 1)

This audio fragment is from a one-hour meeting with Professor Cassiman, one of our stakeholders. He is a geneticist at the KU Leuven. In this meeting we obtained a lot of information about the genetics of Down syndrome, the details of the NIPT and the counseling performed at the centers for human heredity. This selection of audio fragments of the meeting with Professor Cassiman represents our main insights from the session.

SUPPLEMENT 10 (AUDIO FRAGMENT 2)


This audio fragment concerns a selection of fragments of a one and a half hour meeting with Prof. De Catte. He is a gynecologist at UZ Leuven and specialized in prenatal screening and diagnosis. Most of all he gave us important insights into the best way to reach a gynecologist and how to present our information to them. This selection of audio fragments of the meeting with Professor De Catte represents our main insights from the session.

Supplement 11: Actor constellation game




Supplement 12: Facing the Future Symposium Presentation



Laura Costan, Matthew J. Devine, Maud van Dinther,
Louise Hendrickx, Job Meijer, Nynke van Uffelen, Eline
Zenner



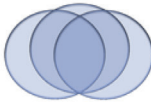
Non-Directive Counselling in Prenatal screening for Down's Syndrome



TRANSDISCIPLINARY INSIGHTS 2017 - 2018



TRANSDISCIPLINARY INSIGHTS 2017 - 2018





BACKGROUND

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



The Government

2017 Reimbursement of the NIPT

TRANSDISCIPLINARY INSIGHTS 2017 - 2018

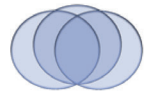




The Government

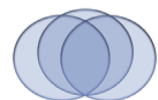
BUT... what about funds for counselling?

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



CHALLENGE

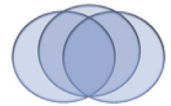
TRANSDISCIPLINARY INSIGHTS 2017 - 2018





How do we provide potential parents with balanced information in order to make a **free and well-informed decision?**

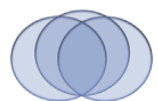
TRANSDISCIPLINARY INSIGHTS 2017 - 2018

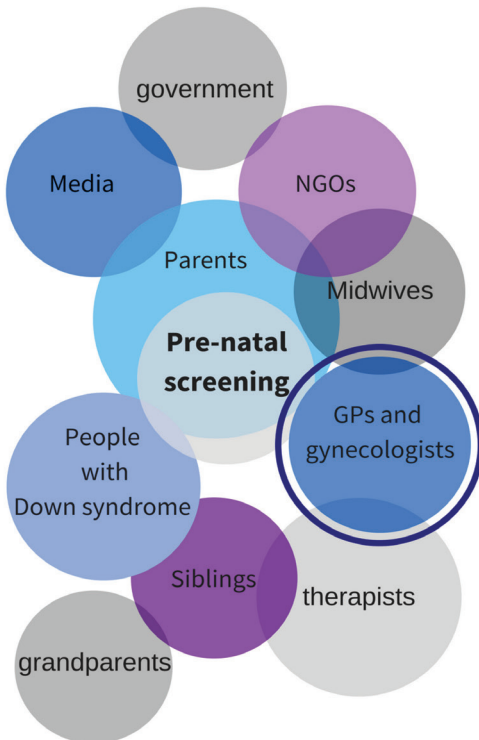


METHOD

STEP 1: Actor constellation game

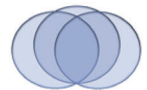
TRANSDISCIPLINARY INSIGHTS 2017 - 2018





The Focal point : GPs and Gynecologists

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



Obstacles

- Purely medical perspective - need for a transdisciplinary perspective
- Time issues

TRANSDISCIPLINARY INSIGHTS 2017 - 2018

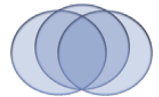




METHOD

STEP 2: Stakeholder approach

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



Each story is different

What if...?

It is important to feel prepared before and after your decision



Sindy Helsen (psychology)

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



Honours
KU LEUVEN

KU LEUVEN

Prof. Jean Jacques Cassiman (genetics)
Prof. Luc De Catte (obstetrics)

No unified framework for counselling

importance of concise information

Screening is progress

UNIVERSITEIT GENT

Dr. Kasper Raus (bio-ethics)

TRANSDISCIPLINARY INSIGHTS 2017 - 2018

Honours
KU LEUVEN

OUR PROOF OF CONCEPT

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



DOWN TO COUNSEL

HOME

COMMUNICATING ABOUT PRENATAL SCREENING

THE DECISION MAKING PROCESS

LIVING WITH DOWN SYNDROME

REFERENCES AND FURTHER READING

DOWN TO COUNSEL

- Q & A format
- Small bursts of info, concise and well-structured.
- Flanders specific
- Applicable to other genetic disorders

The Content

Introduction

1. Communicating about Prenatal Screening
2. The Decision-Making Process
3. Living with Down Syndrome

References and Further Reading

A Feedback/Contact Form



The Content

Introduction

- 1. Communicating about Prenatal Screening**
2. The Decision-Making Process
3. Living with Down Syndrome

References and Further Reading

A Feedback/Contact Form



The Content

Introduction

1. Communicating about Prenatal Screening
2. The Decision-Making Process
- 3. Living with Down Syndrome**

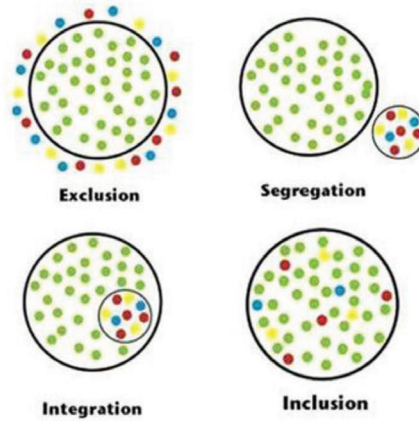
References and Further Reading

A Feedback/Contact Form



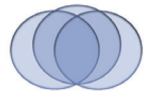
DOWN TO COUNSEL

HOME
COMMUNICATING ABOUT PRENATAL SCREENING
THE DECISION MAKING PROCESS
LIVING WITH DOWN SYNDROME
REFERENCES AND FURTHER READING
RESOURCES TO SHARE WITH PARENTS



What education possibilities are there for a person with Down's Syndrome?

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



The Content

Introduction

1. Communicating about Prenatal Screening
2. The Decision-Making Process
3. Living with Down

References and Further Reading

A Feedback/Contact Form





RESOURCES FOR PARENTS

DOWN TO COUNSEL

HOME

COMMUNICATING ABOUT PRENATAL SCREENING

THE DECISION MAKING PROCESS

LIVING WITH DOWN SYNDROME

REFERENCES AND FURTHER READING

Fara: <https://www.fara.be/>

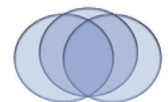
Cozapo: <https://sites.google.com/cozapo.org/welkom/welkom>

VVOG : <https://www.vvog.be/>

Down's Syndroom Vlaanderen: <http://downsyndroom.eu/>

Inclusie Vlaanderen: www.inclusievlaanderen.be

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



FURTHER READING

DOWN TO COUNSEL

HOME

COMMUNICATING ABOUT PRENATAL SCREENING

THE DECISION MAKING PROCESS

LIVING WITH DOWN SYNDROME

REFERENCES AND FURTHER READING

Alderson, Priscilla. "Prenatal Screening, Ethics and Down's Syndrome: A Literature Review." *Nursing Ethics* 8, no. 4 (2001): 360–374.

Sheets B., Kathryn et. al. "Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis of Down Syndrome: Recommendations of the National Society of Genetic Counselors." *Journal of Genetic Counselling* 20: 432–441. (2011). DOI 10.1007/7810897-011-9375-8.

Reid, Bernie et. al. "A meta-synthesis of pregnant women's decision-making processes with regard to antenatal screening for Down syndrome". *Social Science & Medicine* 69 (2009) 1561–1573.

Vanstone, Meredith, et al. "What Is "NIPT"? Divergent Characterizations of Non-invasive Prenatal Testing Strategies." *AJOB Empirical Bioethics*, vol. 6, no. 1, 2015, pp. 54–67.

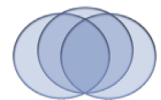
TRANSDISCIPLINARY INSIGHTS 2017 - 2018





NEXT STEPS

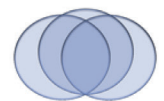
TRANSDISCIPLINARY INSIGHTS 2017 - 2018



From prototype to reality




TRANSDISCIPLINARY INSIGHTS 2017 - 2018





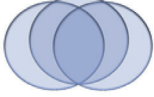
Honours
KU LEUVEN

TRANSDISCIPLINARY INSIGHTS 2017 - 2018



Honours
KU LEUVEN

TRANSDISCIPLINARY INSIGHTS 2017 - 2018





HIV-positive men as a key population for fighting HIVDR in Africa

**Jennifer Herrmann^{1,2*}, Jenny Lushaba^{1,3*},
Lotte Michielsens^{1,4*}, Nicklas Quirós^{1,3*}, Robbe
Saesen^{1,5*}, Coenie Louw⁷, Michael R Jordan^{8,9},
Anne-Mieke Vandamme^{1,6,10}, Astrid Van den
Eede¹, Anneleen Kiekens^{1,6,§}**

¹KU Leuven – University of Leuven, Honours Programme Transdisciplinary Insights, Leuven, Belgium;

²KU Leuven – University of Leuven, Master student Biomedical Sciences, Leuven, Belgium;

³KU Leuven – University of Leuven, Master student Philosophy, Leuven, Belgium;

⁴KU Leuven – University of Leuven, Master student Medicine, Leuven, Belgium;

⁵KU Leuven – University of Leuven, Master student Pharmaceutical Sciences, Leuven, Belgium;

⁶KU Leuven – University of Leuven, Department of Microbiology and Immunology, Rega Institute for Medical Research, Clinical and Epidemiological Virology, Leuven, Belgium;

⁷Gateway Health Institute, Pretoria, South Africa;

⁸Tufts University School of Medicine, Boston, USA;

⁹Tufts Medical Center, Boston, USA;

¹⁰Center for Global Health and Tropical Medicine, Unidade de Microbiologia, Instituto de Higiene e Medicina Tropical, Universidade Nova de Lisboa, Lisbon, Portugal.

*These authors contributed equally to the project;

§Email: anneleen.kiekens@kuleuven.be.

Abstract

This article is concerned with transdisciplinarity as a framework for addressing the wicked problem of rising HIV drug resistance (HIVDR) rates in Africa and its implications. According to data published by the Joint United Nations Programme on HIV/AIDS (UNAIDS), even though the number of AIDS-related deaths has declined by 48% between 2005 and 2016, this significant decrease is now threatened by a rise in resistance of HIV to antiretroviral drugs in several regions, including Africa. Through the application of transdisciplinary research methods, the team identified various factors with an impact on HIVDR, of which they found adherence to be the one most reasonable to address in the context of their research project. Subsequently, the team sought to characterise factors influencing non-adherence among HIV+ individuals. By identifying the current state of the problem, existing gaps in knowledge needed to tackle the issue and stakeholders with a pronounced impact on HIV+ individuals' adherence and beliefs, non-governmental organisations and community health workers were established as particularly important actors. As a result of discussions with external experts and a review of the literature, the poor health-seeking behaviour of men, who represent a group particularly challenging to engage, became the focal point of the project. Eventually, investigating the possibility of setting up a health helpline providing

peer-to-peer support to men living with HIV in South Africa was agreed upon as a concrete objective of the project in collaboration with Dr. Coenie Louw of the Gateway Health Institute. The attributes such a helpline would need to be useful and attractive to its target audience will be explored further in the near future by means of interviews with local community health workers as well as through focus group discussions with male HIV+ individuals in South Africa. A transdisciplinary approach to the problem of HIVDR facilitated the sharing of knowledge across multiple disciplines, which in turn facilitated the exchange of thoughts and ideas between students from different academic backgrounds and various stakeholders with expertise relevant to the project.

Key words

HIV, HIVDR, Drug resistance, HIV-positive men, Transdisciplinary methodology, Health helpline, Stakeholders, Stigma, Community health workers

Challenge Statement

A way to understand and prevent HIV drug resistance in Africa

Introduction

Note: *the authors have deliberately chosen to avoid labelling people infected with HIV as ‘patients’ throughout this article, opting instead for the terms ‘HIV+ individuals’ or ‘people living with HIV’. Thereby, they hope to contribute in part to reducing the stigma accompanying positive HIV status by refraining from automatically associating it with disease and suffering.*

Over the past decades, countless initiatives have been undertaken in order to optimise testing, treatment and care for those infected with human immunodeficiency virus (HIV). As a result, the number of deaths attributable to AIDS declined by 48% worldwide in just over a decade, from about 1.9 million in 2005 to 1.0 million in 2016 [1]. Antiretroviral therapy (ART) is a key contributor to this progress, with 60% of HIV+ individuals receiving ART in Eastern and Southern Africa in 2016 [1]. Due to the relatively low costs associated with their use and their sufficient availability, antiretroviral drugs belonging to the class of non-nucleoside reverse transcriptase inhibitors (NNRTI) are currently being used extensively in the first-line treatment of

HIV in a number of African countries [2]. As a result of the occurrence of corresponding mutations in the HIV genome during replication, however, viral resistance to antiretroviral drugs of all currently available classes, commonly referred to as HIV drug resistance (HIVDR), can arise [2], potentially resulting in insufficient viral suppression [2]. In the 2016–2030 period, HIVDR could thereby be responsible for an additional 16% of AIDS-related deaths and an additional 9% of new HIV infections ([3]). In 2017, the World Health Organization (WHO) carried out a systematic review of the literature [2] in order to estimate the prevalence of resistance to NNRTIs amongst adults who had never been exposed to antiretroviral drugs before, also referred to as ‘pre-treatment drug resistance’. Besides, the review described the evolution of pre-treatment drug resistance over the preceding 16 years in resource-limited settings. Over time, significant increases in pre-treatment drug resistance were observed across all low- and middle-income countries, with a particularly alarming estimated annual increase of 29% (95% CI 17–42) and 23% (95% CI 16–29) in Eastern and Southern Africa, respectively. Non-adherence to ART is an important factor contributing to the development of HIVDR. A systematic review of adherence to antiretroviral drugs in Sub-Saharan Africa covering the period between 2002 and 2014 found an average adherence rate of merely 72.9% among HIV+ individuals ([4]). Adherence rates of between 70% and 89% are strongly associated with the occurrence of HIVDR ([5]). Despite its relevance for the problem at hand, the factors contributing to a lack of adherence to antiretroviral therapy remain insufficiently understood.

The pronounced annual increase in the prevalence of HIVDR in several countries, including Eastern and Southern Africa, and its devastating consequences on both individual and public health illustrate the urgent demand for an improved understanding of the causes of HIVDR, including lack of adherence, and for immediate appropriate actions.

In a response to the aforementioned report of the WHO ([2]) and under the assumption that a complex problem such as HIVDR would benefit from a radically novel research approach, Dr. Michael R. Jordan provided a challenge document entitled “A way to understand and prevent HIV drug resistance in Africa.” (*Supplement 1*) to the Honours Programme Transdisciplinary Insights at KU Leuven. In this document, he specifically mentioned adherence to ART

as an important factor in the context of HIVDR. Subsequently, a research team involving students with backgrounds in medicine, biomedical sciences, pharmaceutical sciences and philosophy was put together in order to address the problem in a transdisciplinary manner over a period of 8 months. Thereby, the team built upon the work of the preceding year, during which another student research team had worked on a similar challenge in the context of the Honours Programme Transdisciplinary Insights at KU Leuven. This team had explored the value and acceptability of peer support groups in Dar-es-Salaam, Tanzania, in order to improve HIV treatment adherence [15].

The research undertaken by the student team and presented herein therefore had three main objectives. First of all, the team explored the potential of addressing the problem of HIVDR in a transdisciplinary manner. In this context, the significance of working in a team of students with different backgrounds and of applying established transdisciplinary methodologies to a complex problem such as HIVDR should be analyzed. Secondly, the different factors relevant in the context of HIVDR, including adherence to antiretroviral therapy, should be identified and their potential impact on HIVDR and on each other should be characterized. Thirdly, the team should develop an approach towards the problem of HIVDR based on one or more of the factors previously identified as relevant and targetable.

Methods

During the first 3 months of the project, the team was trained in transdisciplinarity and complexity through various workshops and exercises [15]. Over the course of eleven sessions, the students developed a shared understanding of the HIVDR challenge, identified the latest state of the problem and worked towards parsing its complexity. The aim was to narrow the scope of research down to a particular subtopic by the end of the third month, in order to be able to create an output for the challenge after the 8 months designated for the project.

In what follows, a timeline of the Honours Programme Transdisciplinary Insights and the respective accomplishments is provided. A summary of the process can be found in *Figure 1*, and the different aspects of this figure are described in more detail below.

In session 1, the team members were introduced to each other and to the challenge as submitted by the stakeholder, Dr. Michael R. Jordan. In session 2, the

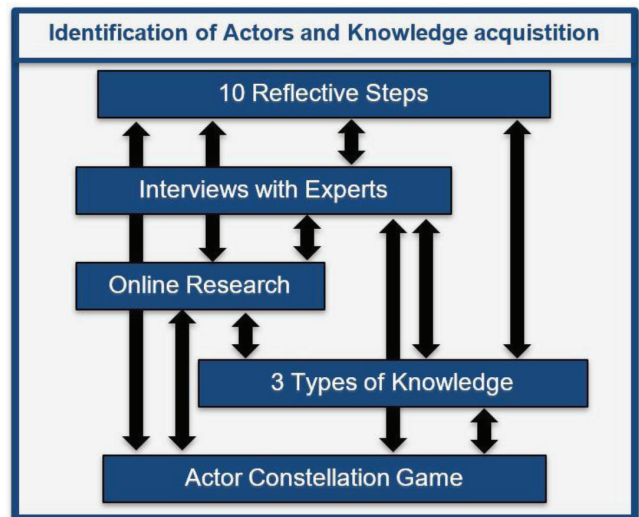


Figure 1: Schematic representation of the process of actor identification and knowledge acquisition.

team attended the ‘Co-creation of Knowledge’ workshop by Professor Marc Craps, a Belgian organisational psychologist and anthropologist, who lectures at KU Leuven and has experience in multi-actor collaboration and transdisciplinary research. The purpose of this session was to introduce the students to the principles of transdisciplinarity and to the idea of wicked problems ([6]). In session 3, the team interviewed Dr. Michael R. Jordan and Moses Supercharger over Skype. Dr. Michael R. Jordan is an American physician in the Division of Infectious Diseases and Geographic Medicine at Tufts Medical Center, an assistant professor of medicine at Tufts University School of Medicine and a consultant for the World Health Organisation. The team contacted him to discuss the submitted challenge and to determine his expectations towards and his precise role in it. Moses Supercharger is a Ugandan musician living with HIV, who uses music to raise awareness and aims at de-stigmatising people living with HIV. The purpose of this interview was to enable the team to develop a better understanding of what it is like to live with HIV in a sub-Saharan society today. In session 4, the team discussed the existing literature on HIVDR. Moreover, the students were formally introduced to systems mapping as a way to visualize complex problems and to the exercise of the ‘10 Reflective Steps’ (cf. *infra*) ([7]). Subsequently, the students were given a list of potential stakeholders relevant in the context of the challenge and were invited to research which experts they would like to interview.

In session 5, the ‘Actor Constellation Game’ ([8]) was carried out; this is a tool useful for defining the most important actors influencing a certain wicked problem. First, the team agreed on a central question. Subsequently, potential actors were written down on labels and positioned around this central question. The closer the labels were thereby placed to the question, the more influence the respective actors were deemed to exert in the framework, while the distance between two labels reflected the strength of the underlying association. At the end of the session, various actors were assigned to the students for them to conduct online research on those actors. In session 6, a second round of the Actor Constellation Game was performed. At the same time the team conducted an online phone interview with Dr. Fausta Mosha and Dr. Raphael Z. Sangeda. Dr. Mosha is a Tanzanian medical microbiologist and epidemiologist working for the Tanzanian Ministry of Health and Social Welfare. She has also been the director of the National Public Health Laboratory since 2010. Dr. Raphael Z. Sangeda is a Tanzanian bioinformatician and senior lecturer in the Department of Pharmaceutical Microbiology at the Muhimbili University of Health and Allied Sciences. The purpose of the interview was to provide the students with an insight into the epidemiology of HIVDR and its implications on public health. The students also asked for Dr. Mosha’s and Dr. Sangeda’s expert opinion on potential solutions to tackle HIVDR. Ultimately, the students were invited to discuss the ‘10 Reflective Steps’ ([7]) online, which challenged the students to analyse their work up to that point.

In session 7, the team discussed the usefulness of narrowing their scope of research down to non-governmental organizations (NGOs) and community health workers (CHWs) as a result of their preceding research (see results). They attended a presentation on the ‘3 Types of Knowledge’ and were invited to perform the corresponding exercise ([9]). The purpose of this exercise was twofold: on the one hand, it was supposed to shed light on the team’s current position with regard to the project; on the other hand it was meant to support the team in reaching a decision about suitable next steps. In session 8, the team discussed the results of the research the individual team members had carried out in the context of the exercise on the ‘3 Types of Knowledge’. Afterwards, they conducted an interview with Prof. Eric Van Wijngaerden, Rita Verstraeten and Dr. Marie-Pierre de Béthune. Prof. Van Wijngaerden is a Belgian

infectious disease specialist and a professor of medicine at KU Leuven. Mrs Verstraeten is a Belgian specialized nurse at the AIDS reference centre of the University Hospital Leuven. Dr. de Béthune is a Belgian HIV virology consultant. The interviewees shared their experiences with health care provider-patient relationships in the context of HIV and African societies. They supported the students in understanding the problem of HIVDR from a patient’s perspective. In session 9, the team attended a lecture on the societal impact of social mass media by Prof. Steven Eggermont. The content of the session invited the team to reconsider the role of social media when tackling the problem of HIVDR. In session 10, the team attended a workshop on systems mapping, during which the students were familiarized with tools used to visualize complex problems. In session 11, the team discussed the progress achieved over the past months and possible ways to proceed.

In the fourth month of the project, two members of the team conducted interviews with experts in South Africa:

- Prof. Tulio de Oliveira: South African bioinformatician, director of the KwaZulu-Natal Research and Innovation Sequencing Platform (KRISP), professor at the University of KwaZulu-Natal (UKZN) and at the Centre for the Aids Programme of Research in South Africa (CAPRISA);
- Prof. Salim Abdool Karim: South African infectious disease specialist, epidemiologist, professor of global health at Columbia University and Pro Vice-Chancellor (Research) at the University of KwaZulu-Natal (UKZN);
- Prof. Deenan Pillay: Director of the Africa Health Research Institute and professor of virology at University College London (UCL);
- Dr. Coenie Louw: South African physician, founder of the NGO Gateway Health Institute.

The transcripts of these interviews were passed on to the entire team and enabled the team to further narrow down their scope of research and to identify a subtopic of HIVDR, which was subsequently addressed primarily through literature research for the remainder of the project.

Results

Through online research, discussions with experts and exercises in transdisciplinary thinking, a myriad of

different and interconnected factors mutually influencing both the rise of HIVDR in Africa as well as each other were identified, a non-exhaustive list of which is provided in *Table 1*. The embeddedness of the problem of HIVDR into this dynamic network of factors thus indeed renders it a ‘wicked problem’ ([6]). Problems of this type are inherently difficult to formulate, as a thorough understanding of them can be reached only once all potential solutions are considered. To identify, for example, the relevance of stigmatization to the rising rates of HIVDR requires widening of the scope of the problem, and with each proposed effort to reduce stigmatization the issue of HIVDR becomes clearer in return. Tackling one issue contributing to a wicked problem can thereby actually magnify it via underlying interdependencies with other causes. For instance, if one were to try to solve the problem of HIVDR by launching public awareness campaigns to increase the knowledge about its potential health repercussions, this could result in new-found feelings of animosity towards people living with HIV among the general population, thereby worsening stigmatization. Wicked problems like HIVDR have no straightforward solutions, and there is no clear-cut way to assess the impact of measures intended to mitigate them. This

also implies that there is no point at which one can reasonably state that the problem is solved. Solutions are never all-encompassing and due to time and/or budget constraints, one often has to settle for a solution that is simply ‘good enough’.

In the present case, poor adherence to treatment was finally identified as the most feasible factor for the team to address meaningfully within the foreseen timeframe of the challenge. By their very nature, wicked problems span many different fields of expertise, and therefore require a transdisciplinary approach.

Actor Constellation Game

The final outcome of the Actor Constellation Game demonstrated that the team should focus on NGOs and CHWs, a lay group of (mostly) volunteers who provide basic healthcare to their community. CHWs represent the direct connection between formally trained and remunerated healthcare staff at specialized centres and the people living with HIV in rural areas. Other actors that were taken into consideration were nurses, doctors and media. With regard to nurses and doctors, the team concluded that they were already suffering from a heavy workload and

Infrastructure	
Drug Stock-Outs	Insufficient transport systems undermining a consistent supply of medication in rural areas
Insufficient Access to Care	Large distances between clinics and homes of HIV+ individuals and insufficient time for visits to clinics due to employment
Healthcare System	
Drug Stock-Outs	Poorly funded and/or organized healthcare systems unable to provide sufficient medication
Insufficient Availability of Medical Staff	Severe shortage of medical professionals, resulting in overworked doctors and nurses lacking time to provide sufficient information to patients
Awareness and Personal Behavior	
Lack of Education	Insufficient public knowledge and awareness about HIVDR
Illusion of Being Well	Refusal of HIV+ individuals to take medication due to absence of obvious symptoms
Absence of Safe Sex	Low use of safe sex methods facilitating the spread of drug resistant viruses
Psychosocial Factors	
Stigmatization	Avoidance of or discontinuation of treatment due to feelings of shame and/or fear of becoming an outcast
Lack of Trust	Distrust in conventional medicine paralleled by deeply rooted trust in traditional healers
Association with Homosexuality	Reluctance of governments to address HIVDR due to its association with (morally condemned or illegalized) homosexuality

Table 1. Selection of factors relevant in the context of HIVDR.

that it would be neither feasible nor desirable to further expand their scope of work. With respect to media, recent literature ([10]) suggests that the public is already fed up with the myriad of messages and campaigns aiming at boosting HIV awareness. Therefore, the media are not likely to constitute an effective channel to reach out to communities. In the discussion with Dr. Marie-Pierre de Béthune, one of the team's external experts, she stressed the importance of working with an already existing local partner or structure, which was a clear affirmation of the outcome of the results of the Actor Constellation Game.

10 Reflective Steps

The results of the '10 Reflective Steps' exercise are shown in *Figure 2*. In a first step, the team divided the research question into four separate questions:

- What are the different **factors** influencing HIVDR?
- What are the **relationships** between those factors (i.e. mutually reinforcing, counteracting, etc.)?
- How could one **support** HIV+ individuals in taking their drugs properly?
- What is the relevance of **stigmatization** in HIV drug resistance and how can one contribute to reducing it?

1. Formulate your research question.

- What are the different **factors** influencing HIVDR?
- What are the **relationships** between the factors (i.e. mutually reinforcing, counteracting, etc.)?
- How could we support HIV+ individuals in taking their drugs properly?
- What is the relevance of **stigmatization** in HIV drug resistance and how can we reduce it?

Is the research basic, applied or transdisciplinary?

This is a **transdisciplinary** research question, as it deals with a **societally relevant wicked problem** requiring input from many different fields of knowledge (biomedicine, sociology, human behaviour...). We will tackle it as a student team with different academic backgrounds.

2. Formulate the societal problem you want to help solve.

The bigger picture: What is the **impact** of increasing HIV drug resistance in general?

We attempt, firstly, to understand, and secondly, to solve the problem of **stigmatization**, given the increase in HIV drug resistance (HIVDR). HIVDR can develop because of bad adherence to drugs. Bad **adherence** is a societal problem. On the other hand, the development of severe HIVDR might lead to the societal problem of having a lot of hard-to-control HIV cases, which will put a huge burden on public health.

3. Specify the stage of the policy cycle.

- **Problem framing:** What exactly has an influence on HIV+ individuals who do not take their drugs properly? How can we act upon these different (f)actors?
- **Policy development:** Create a **complexity map** with the different (f)actors influencing drug adherence. Develop a differentiated model of care to act upon these (f)actors.
- **Implementation:** Implement differentiated model of care.
- **Evaluation:** Does the implementation of the differentiated model of care improve drug adherence among people living with HIV?

We are still in the 'problem framing' and to a certain extent also the 'policy development' stage. Research around this topic all seems to be quite recent and there does not appear to be a general consensus among different groups in society about how the problem should be defined, let alone which kind of solution should be implemented. For example, HIV+ individuals feel that their doctors do not explain the consequences of taking drugs incorrectly enough, while the doctors themselves will probably tell you there is not enough time to do this and the responsibility should be transferred to someone else.

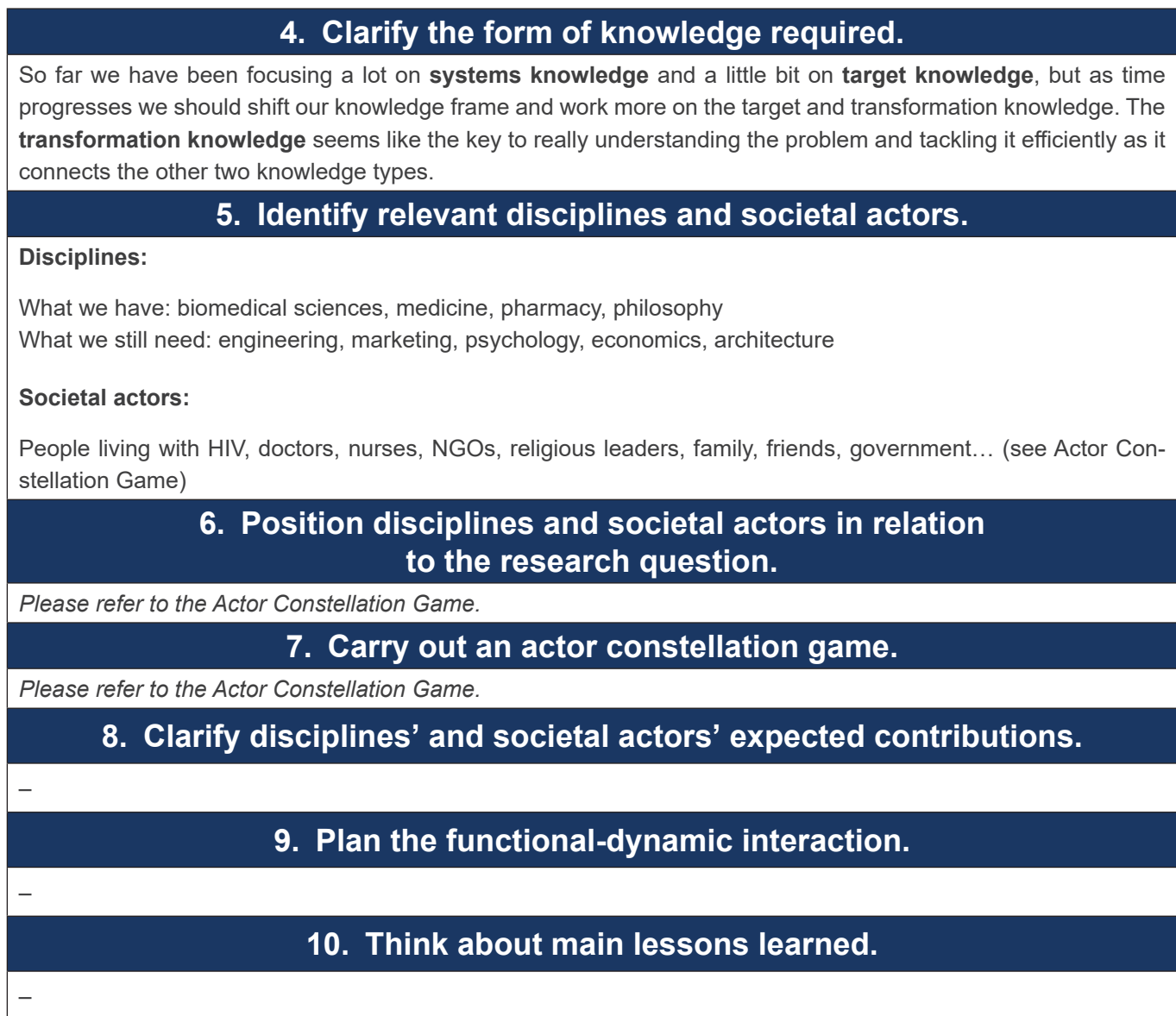


Figure 2: 10 reflective steps and state of progress after the first semester. Steps 8, 9 and 10 were not discussed by the team and are thus left blank.

Additionally, they characterized the type of research required to address HIVDR as transdisciplinary, since the rise of HIVDR in sub-Saharan Africa can be considered a wicked problem, as explained before. Wicked problems by definition cover many different areas of knowledge and thus suggest a transdisciplinary approach.

The concrete societal problem the team intended to contribute towards solving was further explored in the second step. By focusing on stigmatization and bad adherence to therapy, the team assumed it would be able to contribute towards resolving the issue of rising HIVDR rates in sub-Saharan Africa during the limited time frame of the project.

The third step involved thinking about the problem in terms of the four stages of the policy cycle. In the first stage, the problem could be framed with regard to the factors that may help to explain why some people living with HIV would not take their medication properly. In the second stage, a complexity map of these factors could then be made and a differentiated model of care could be developed in order to act upon them. The third and fourth stages, both of which relate to the question of how to actually implement and evaluate the said model, could not be described in detail yet at the respective point in time.

Step 4 pertained to the '3 Types of Knowledge' (cf. infra). The team discovered that until that point they

had mainly been gathering systems knowledge, i.e. knowledge about the problem as it presents itself at the present time. They also realized that target knowledge, referring to knowledge about the problem as it should be, would become more important to them as the challenge progressed. Transformation knowledge, which allows the bridging of the gap between the other two types of knowledge, was identified as the key to understanding and approaching the problem.

In step 5, the team reflected on the disciplines and societal actors they would require in order to be able to tackle the problem efficiently. They concluded that, while some disciplines (philosophy, biomedical sciences, medicine, pharmacy) were well represented within the group, they still lacked input from other disciplines (engineering, marketing, psychology, economics, architecture). The relevant societal actors were further analysed

during the previously described Actor Constellation Game (step 6 and step 7). The team left out the final three steps at the time of performing this exercise.

3 Types of Knowledge

The results of the ‘3 Types of Knowledge’ exercise are shown in *Figure 3*. As discussed above, three different types of knowledge relating to the problem can be distinguished. The team reflected on each of them in the context of the two stakeholders they had deemed most feasible to engage with during the remainder of the project, namely NGOs and CHWs. For each type of knowledge several questions were formulated, which would allow the group to acquire the knowledge needed from the respective stakeholders. These questions can be found in *Figure 3*.

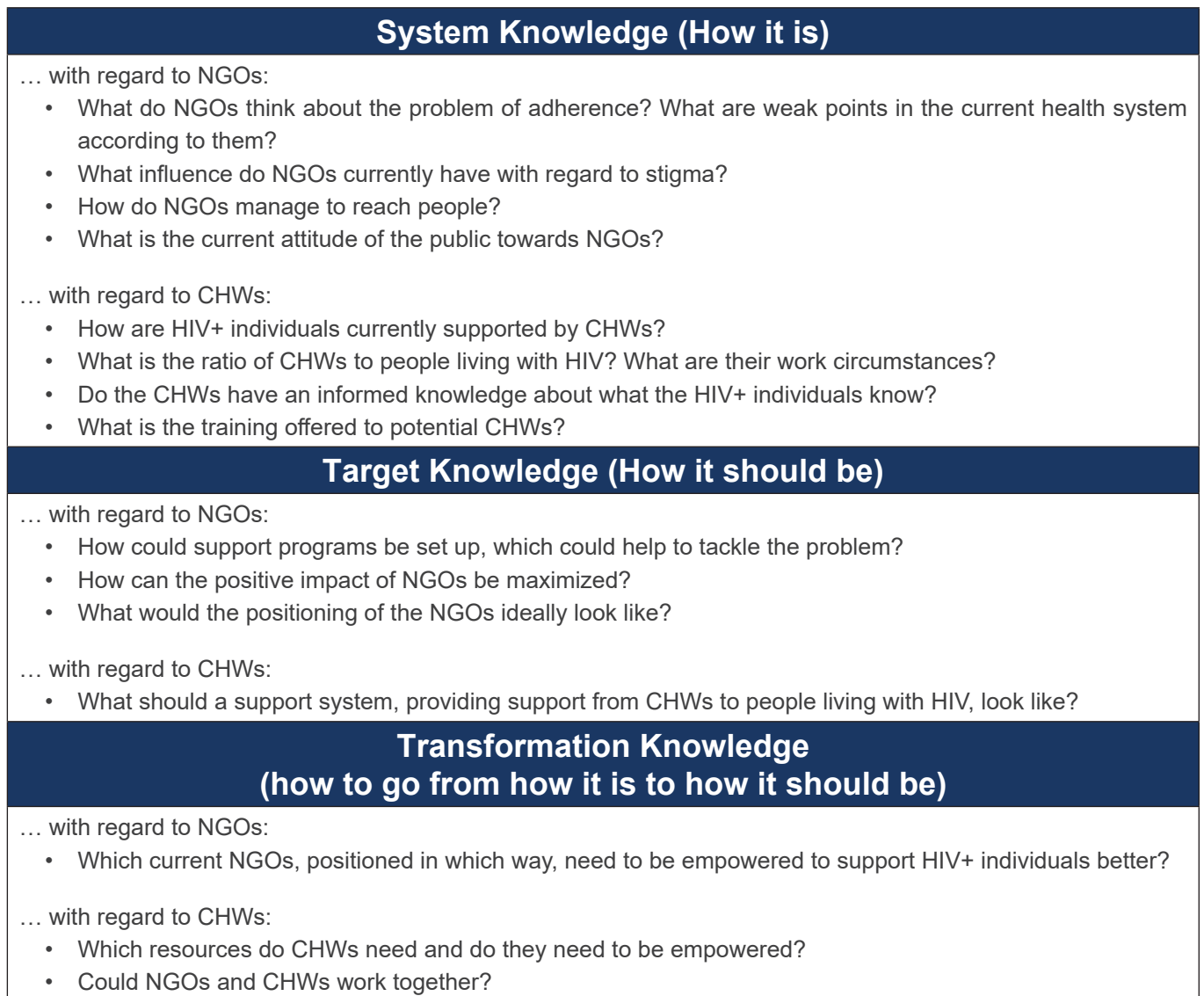


Figure 3: 3 Types of Knowledge and state of progress after the first semester.

Further research and formulation of hypothesis

Following the ‘Actor Constellation Game’ and the exercises on the ‘10 Reflective Steps’ and the ‘3 Types of Knowledge’, the team researched what local NGOs in Africa were concerned with and how they contribute towards improving adherence to ART. Of particular importance was the finding that the majority of NGOs were mainly or exclusively focusing on women. Women face a particularly high burden of HIV, with the rate of infection among girls and young women being twice as high as that among age-matched boys and men ([11]). In addition, the rate of pre-treatment drug resistance without ever having been exposed to antiretroviral therapy is twice as high among women than men ([2]). These findings resulted in the team’s hypothesis that next to resistance resulting from taking ART as prevention of mother to child transmission, a considerable proportion of HIV-positive women might have become infected with an already resistant virus.

Literature research and discussions with multiple stakeholders and experts suggested that men have a higher tendency than women to be in denial about their HIV status and frequently blame their female partners for their infection ([12]). They seek treatment late and consequently often present with advanced disease ([13]). Therefore, men are not only less likely to receive timely HIV treatment in the first place, but also tend to adhere poorly to their prescribed therapeutic regimen. Keeping in mind the study of Sethi et al. (2003), which draws attention to the bell-shaped relationship between adherence and resistance development ([5]), the team hypothesised that male HIV+ individuals could be an important carrier population for drug-resistant HIV.

Future perspectives

In January 2018, after 4 months of working on the project, the team got in contact with Dr. Coenie Louw and his associates at the Gateway Health Institute in South Africa. Dr. Louw is working on a health helpline targeting girls and young women who are disproportionately affected by HIV ([14]). When the team’s research topic was presented to Dr. Louw, the conclusion was reached that it would be valuable to look into the possibility of setting up peer-to-peer support via

phone for HIV+ men in particular. Such a call service could answer any questions they might have about HIV and encourage them to seek medical care and to stick to their prescribed treatment. The group committed to researching the recommended attributes a health helpline would need to have in order for it to be attractive and useful from the point of view of male HIV+ individuals by conducting qualitative research by means of interviews with CHWs and via focus group discussions with men living with HIV in South Africa. The results of this research will be published in a second abstract.

Discussion

By tackling the problem of HIVDR in a transdisciplinary way, the team was able to combine the ideas of students from different academic backgrounds with the expertise of various stakeholders and societal actors. As the ‘wicked problem’ of HIVDR is an issue with many underlying complexities, this approach made it possible effectively to frame and analyse the problem by connecting established knowledge on the development of HIVDR with the practical experience of HIV+ individuals and healthcare professionals.

By employing a transdisciplinary methodology, the team was able to identify a variety of factors potentially relevant in the context of HIVDR and to narrow the scope of its research to factors deemed relevant, targetable and desirable to be targeted. As a result, it decided to focus its efforts around NGOs and CHWs in Africa. Furthermore, through online research and discussions with experts, it became evident over the course of the project that men living with HIV represent a key population for efforts to curb the development of HIVDR and are also particularly difficult to reach. As a result of the knowledge the team had acquired during the course of the project, it was able to link this finding with an idea for a potential partial solution to the problem of HIVDR. Through a collaboration with the Gateway Health Institute in South Africa, the team will finally contribute to the evidence-based design of a health helpline aiming at reaching male HIV+ individuals.

Supplementary materials

Supplement 1: Dr Michael R. Jordan. 2017. “A way to understand and prevent HIV drug resistance in Africa.”

Supplement 2: Video of the project presentation at the 'Facing the Future' Symposium

References

1. Joint United Nations Programme on HIV/AIDS (UNAIDS). UNAIDS Data 2017. 2017. URL: http://www.unaids.org/sites/default/files/media_asset/20170720_Data_book_2017_en.pdf (accessed on 25th of April 2018).
2. HIV drug resistance report 2017. Geneva: World Health Organization, 2017. Licence: CC BY-NC-SA 3.0 IGO.
3. Phillips, A. N., Stover, J., Cambiano, V., Nakagawa, F., Jordan, M. R., Pillay, D., Doherty, M., Revill, P. & Bertagnolio, S. 2017. Impact of HIV Drug Resistance on HIV/AIDS-Associated Mortality, New Infections, and Antiretroviral Therapy Program Costs in Sub-Saharan Africa. *The Journal of Infectious Diseases*, 215(9): 1362–1365.
4. Heestermans, T, Browne, JL, Aitken, SC, Vervoort, SC, Klipstein-Grobusch, K. Determinants of adherence to antiretroviral therapy among HIV-positive adults in sub-Saharan Africa: a systematic review. *BMJ Glob Health*. 2016 Dec 30;1(4):e000125. doi: 10.1136/bmjgh-2016-000125.
5. Sethi, AK, Celentano, DD, Gange, SJ, Moore, RD, Gallant, JE. Association between adherence to antiretroviral therapy and human immunodeficiency virus drug resistance. *Clin Infect Dis*. 2003 Oct 15;37(8):1112–8.
6. Rittel, HWJ & Webber, MM. Dilemmas in a General Theory of Planning. *Policy Sciences*, 1973 June;4(2):155–169.
7. Pohl, C, Krütli, P, Stauffacher, M. Ten Reflective Steps for Rendering Research Societally Relevant. *GAIA - Ecological Perspectives for Science and Society*, 2017;26(1):43–51(9).
8. Sciences Switzerland powered by Swiss Academy of Sciences (SCNAT). Actor constellation. URL: https://naturalsciences.ch/topics/co-producing_knowledge/methods/actor_constellation_final_ (accessed on 14th of October 2018).
9. Sciences Switzerland powered by Swiss Academy of Sciences (SCNAT). Three types of knowledge tool. URL: https://naturalsciences.ch/topics/co-producing_knowledge/methods/three_types_of_knowledge_tool (accessed on 14th of October 2018).
10. Chalk, S. 2014. HIV and Stigma: The Media Challenge. URL: https://www.ippf.org/sites/default/files/ippf_ibt_hivstigma_final_060814.pdf (accessed 25th of October 2017).
11. World Health Organization. 2016. Global Health Sector Strategy on HIV 2016–2021 - Towards ending AIDS. URL: www.who.int/hiv/strategy2016-2021/ghss-hiv/en/ (accessed on 28th of March 2018).
12. Kahamba, JS, Massawe, FA, Nombo, CI, Jeckoniah, JN. 2017. Working Paper: How Gender Affects Adherence to Antiretroviral Therapy in Tanzania.
13. Gateway Health Institute. 2018. URL: <http://gateway-healthinstitute.org/index.php/what-we-do/technology/124-technology-mhealth> (accessed on 13th of May 2018).
14. Marconi, VC, Wu, B, Hampton, J, Ordonez, CE, Johnson, BA, Singh, D, John, S, Gordon, M, Hare, A, Murphy, R, Nachega, J, Kuritzkes, DR, del Rio, C, Sunpath, H, South Africa Resistance Cohort Study Team Group Authors. 2013. Early Warning Indicators for First-Line Virologic Failure Independent of Adherence Measures in a South African Urban Clinic. *AIDS PATIENT CARE and STDs*, 27(12): 657–668.
15. Dehens, J, de Hemptinne, M, Galouchka, M, Sajud, A, van Otzel, RP, Vanhoorebeeck, C, Wyszowska, M, Mosha, F, Sangeda, RZ, Bernard, EJ, Thompson, M, Kiekens, A, Baert, S, Nova Blanco, JR, Jordan, MR, Vandamme, AM. Exploring the value and acceptability of peer support in the process of improving adherence to HIV antiretroviral drugs in Tanzania, Dar-es-Salaam. *Transdisciplinary Insights, Volume 1*, 2017, 9–32. <https://doi.org/10.11116/TDI2017.1.2>

Supplement 1: Revised Challenge document

In 2016, the “original” challenge was researched by a team of students of this same honours programme, and their insights were published (Dehens et al., 2017). As a result of those efforts, the here listed “revised” challenge document was submitted in 2017. It is this revised challenge document that was the start of the efforts of the new team in 2018, whose results are published in this report.

Revised Challenge 2017

15th September 2017

Challenge Submitter: Dr. Michael Jordan and Anneleen Kiekens based on (Dehens et al., 2017)

Name of the Challenge: A way to understand and prevent HIV drug resistance in Africa

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

This challenge focuses on HIV drug treatment in Africa. As of December 2016, 19.5 million people are receiving antiretroviral therapy (ART) for the treatment of HIV infection. Some level of HIV drug resistance (HIVDR) is inevitable and expected to emerge and be transmitted in populations infected with HIV and receiving ART. However, recent data suggest an increase in levels of HIVDR to a point that there may be increased mortality and or morbidity. In recent documents, WHO reports that in Africa, the continent most heavily affected by HIV, levels of HIVDR are increasing (WHO, 2017a). This may be in part due to drug stock outs; difficulty in programs in retaining the patients; problems in communication due to low quality of patient-provider relationship, amongst other reasons. WHO also states that increasing HIVDR may jeopardize the success of HIV treatment and the broader HIV response (WHO, 2017b).

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

Such evidence of poor adherence to therapy as described above is indeed a major factor associated with the development of HIVDR. Of note is the finding that the adherence-resistance-development curve is bell-shaped, with peak selection for resistance to ARV between 70%–89% adherence rates (Sethi et al., 2003). This means that no resistance develops in individuals whom either have very poor adherence or have excellent adherence ($\geq 95\%$) (Harrigan et al., 2005). In spite of that, average adherence rates of only 72.9% are reported (Heestermaans et al., 2016). The rate of development of HIV drug resistant strains through suboptimal adherence has been shown to be different for each class of drugs (Kan et al., 2017). These findings suggest the need to aim for nothing less than excellent adherence.

However there is more to HIVDR than low therapy adherence and all its related factors. For example the types of drugs that are available, the specifics of the local health care approach and even factors that are at first sight unrelated, like religion, can play a role in HIVDR (Sangeda, 2013; Moshia, 2014). As many of these factors leading to HIVDR are not known yet, it might be interesting to identify them and determine their interaction with each other. Through the creation of a HIVDR complexity map the true nature of the problem might become more visible, facilitating the solution searching process.

To increase adherence and availability of ART some studies have developed a 'differentiated model of care' (Decroo, 2017). Any change in health care approach leading to less work load for the doctors and/or centering the care around the patients themselves can be seen as a differentiated model of care.

Differentiated care models can vary from the patient simply skipping the long waiting line when going for a drug refill, to patients joining a peer support group where they can give each other psychological and logistic support. Several forms of differentiated care models have been implemented in different locations in Africa, in a way that patients have the choice to follow or not follow the alternative model available in their treatment center. However ideally, a differentiated model of care should offer several options so that the patient can choose the one closest to his or her needs and expectations, leaving room for change when the patient's situation changes over time. Moreover such a model should be adaptive to change in, for example, drug landscape, or economic situation, in order to be sustainable overtime.

Would you like to add some objectives to that challenge?

The research group is asked to identify the factors influencing HIVDR and how they are connected to each other. For this purpose causal loop diagrams or other visualization tools might be appropriate. The group will conduct a case study in Dar es Salaam, Tanzania, with local people to characterize factors influencing HIV drug resistance and ways to improve them. Through a series of case studies and conversations with patients, doctors, nurses, health care providers, general public and community members, the group should suggest steps that can be taken to prevent HIV drug resistance in the form of an adaptive model of care.

The way to progress from here would be to study the existing differentiated models of care to analyse their strengths and weaknesses, and how principles of resilience can be built into such models of care. The group could search for reports on ways to implement differentiated models of care, especially in the context of HIV in Africa. The group project could proceed by adapting such a differentiated model of care based on the HIVDR complexity map. Ultimately, the adaptive model of care case-study will no doubt be helpful in seeking to find new and innovative ways to prevent HIV drug resistance and to identify previously unknown factors that can be implemented in the HIVDR complexity map.

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

WHO has drafted a 2017–2021 action plan to reduce HIV drug resistance in developing countries, outlining a collective strategy, including surveillance activities, service delivery interventions, diagnostic strengthening, and enabling mechanisms. These cover several disciplines in various domains of science. This action plan outlines the problems, the goals and the possible steps to take. However, this action plan is not detailed with regard to specific local situations that can vary widely. Though the WHO action plan describes local enabling mechanisms, it would be interesting to see these mapped for a particular case study, and whether what WHO described is possible and sufficient for that particular case study. For this purpose, the transdisciplinary research team could make a significant contribution.

References

1. Decroo, T. (2017) 'Community-based ART in sub-Saharan Africa: lessons learnt from Community ART Groups in Tete province, Mozambique'.
2. Harrigan, P. R. *et al.* (2004) 'Predictors of HIV Drug-Resistance Mutations in a Large Antiretroviral-Naive Cohort Initiating Triple Antiretroviral Therapy', pp. 8–11.
3. Heestermans, T. *et al.* (2016) 'Determinants of adherence to antiretroviral therapy among HIV- positive adults in sub-Saharan Africa: a systematic review', *BMJ Global Health*, 1(4).
4. Kan, W. *et al.* (2017) 'Predictors of HIV virological failure and drug resistance in Chinese patients after 48 months of antiretroviral treatment, 2008–2012: a prospective cohort study', *BMJ Open*, 7. doi: 10.1136/bmjopen-2017-016012.
5. Sangeda, R. Z. (2013) 'Challenges for monitoring HIV-1 therapy response in resource-limited settings'.

6. Sethi, A. K. *et al.* (2003) 'Association between Adherence to Antiretroviral Therapy and Human Immunodeficiency Virus Drug Resistance', *Clinical Infectious Diseases*. Oxford University Press, 37(8), pp. 1112–1118. doi: 10.1086/378301.
7. Mosha, F. *et al.* (2014) 'Socio-Demographic Factors associated with Success of Antiretroviral Treatment among HIV Patients in Tanzania'.
8. WHO (2017) *Hiv drug resistance report 2017*.
9. World Health Organization (2016) 'HIV drug resistance. *Global report on early warning indicators of HIV drug resistance*', (July). Available at: <http://apps.who.int/iris/bitstream/10665/246219/1/9789241511179-eng.pdf>.
10. World Health Organization (2017) *Global Action Plan For HIV Drug Resistance 2016–2021, WHO Guidelines*. Available at: http://apps.who.int/iris/bitstream/10665/204518/1/WHO_HIV_2016.02_eng.pdf (accessed April 07, 2016).

Supplement 2: Video of the project presentation at the ‘Facing the Future’ Symposium (9th of May 2018)

The Honour Programme organized a symposium on 9 May 2018, during which all teams were presenting their results so far. This video was made during the presentation of the team that worked on the here presented HIVDR challenge.



How Storytelling Can Combat Vaccine Hesitancy: a Transdisciplinary Approach

**Jacobs Laura^{1,2*}, Kattumana Tarunjose^{1,3*},
Konnova Angelina^{1,4*}, Obasa Mojisola^{1,5*},
Smlatic Enisa^{1,6*}, Vandendriessche
Valentine^{1,7*}, Voragen Fleur^{1,8*},
Boey Lise⁹, Vandermeulen Corinne^{10,\$}**

¹KU Leuven – University of Leuven, Honours Program Transdisciplinary Insights, Leuven, Belgium;

²KU Leuven – University of Leuven, Master Student, Pedagogical Sciences, Leuven, Belgium;

³KU Leuven – University of Leuven, Masters Student Research, Philosophy, Leuven, Belgium;

⁴KU Leuven – University of Leuven, Master Student, Biomedical Sciences, Leuven, Belgium;

⁵KU Leuven – University of Leuven, Master Student, Bioethics, Leuven, Belgium;

⁶KU Leuven – University of Leuven, Master Student, Pharmaceutical Sciences, Leuven, Belgium;

⁷KU Leuven – University of Leuven, Master Student, Law, Leuven, Belgium;

⁸KU Leuven – University of Leuven, Master Student, Medicine, Leuven, Belgium;

⁹KU Leuven – University of Leuven, PhD Student, Clinical Pharmacology and Pharmacotherapy, Leuven, Belgium;

¹⁰KU Leuven – University of Leuven, Department of Pharmaceutical and Pharmacological Sciences, Leuven University Vaccinology Center, Leuven, Belgium;

*These authors contributed equally to the work;

^{\$}Email: corinne.vandermeulen@kuleuven.be

Abstract

The recent decline in vaccination rates across Europe has led to outbreaks of vaccine preventable diseases such as measles. Although there have always been persons opposed to vaccination, in recent years an increasing number of parents are losing confidence in or are being complacent about vaccinating their children. Given the accessibility of information on the internet, parents are actively and independently researching vaccines. They are exposed to negative claims about vaccines that appeal to their emotions and emotional stories tend to make parents doubt vaccinations. By contrast, most positive vaccine messages focus on providing information through scientific data which has proven to be ineffective for some hesitant parents.

Vaccine hesitancy can only be understood by looking at it from different perspectives and by exchanging knowledge between multiple fields of study. A transdisciplinary approach, in which individuals with different backgrounds search for solutions together, is necessary to be able to provide one or more solutions to the problem. Therefore, we spent eight months trying to solve part of this wicked

problem from a transdisciplinary perspective. Based on literature reviews of different topics within vaccine hesitancy, interviews with hesitant parents, interactions with various stakeholders within and outside academia, and analyses of popular views on social media concerning vaccines, we question the effectiveness of the current pro-vaccine approaches. We also suggest adopting 'storytelling' that incorporates scientific data to inform parents and we argue that narratives are intrinsically persuasive as they are easier to understand and could prove more effective than traditional scientific communication. We expect that this strategy will contribute to the increase in and maintenance of high vaccination coverage rates and stop the circulation and outbreak of vaccine preventable diseases.

Key words

Vaccine Hesitancy, Anti-vaxx, Vaccine Confidence, Vaccination rates, Vaccination coverage

Challenge Statement

A way to understand the circumstances that influence refusal of childhood vaccination

The recent decline in vaccination rates across Europe has led to outbreaks of vaccine preventable diseases such as measles. Although there have always been persons opposed to vaccination, in recent years an increasing number of parents are losing confidence in or are being complacent about vaccinating their children (Dube, *et al*, 2013, Yaqub, *et al*, 2014). Given the accessibility of information on the internet, parents are actively and independently researching vaccines. They are exposed to negative claims about vaccines that appeal to their emotions, since this is how the anti-vaxxer community tends to communicate. Emotional stories tend to make parents doubt vaccinations. By contrast, most positive vaccine messaging focuses on providing information through scientific data; this has proven to be ineffective for some hesitant parents (Larson *et al*, 2010).

As vaccine hesitancy is a wicked problem (Skarbuskis, 2008), it can only be understood by looking at it from different perspectives and by exchanging knowledge between multiple fields of study (Jahn *et al*, 2012). A transdisciplinary approach, in which individuals with different backgrounds search for solutions together, is

necessary to be able to provide one or more solutions to the problem. Therefore, we spent eight months trying to solve part of this wicked problem from a transdisciplinary perspective. Based on literature reviews of different topics within vaccine hesitancy, interviews with hesitant parents, interactions with various stakeholders within and outside academia, and analyses of popular views on social media concerning vaccines, we question the effectiveness of the current pro-vaccine approaches. As reported on the Falling Walls Lab and Facing The Future Symposium, we suggest adopting 'storytelling' that incorporates scientific data to inform parents (Dahlstrom, 2014). We argue that narratives are intrinsically persuasive as they are easier to understand and could prove more effective than traditional scientific communication. This strategy has already been shown to be effective in convincing women to get screened for breast cancer (Keuter, *et al*, 2010). Addressing parents in different ways, including 'storytelling', might result in more confidence and less complacency. We expect that this strategy will contribute to the increase in and maintenance of high vaccination coverage rates and stop the circulation and outbreak of vaccine preventable diseases.

Supplementary Materials

1. Original challenge
2. Falling Walls Lab Presentation
3. Facing the Future Symposium Presentation
4. Actor Constellation Game

References

1. Dahlstrom M. Using narratives and storytelling to communicate science with nonexpert audiences. *Proceedings of the National Academy of Sciences*. 2014;111(Supplement_4):13614–13620. doi:10.1073/pnas.1320645111.
2. Dubé E, Laberge C, Guay M, Bramadat P, Roy R, Bettinger J. Vaccine hesitancy. *Hum Vaccin Immunother*. 2013;9(8):1763–1773. doi:10.4161/hv.24657.
3. Jahn T, Bergmann M, Keil F. Transdisciplinarity: Between mainstreaming and marginalization. *Ecological Economics*. 2012;79:1–10. doi:10.1016/j.ecolecon.2012.04.017.
4. Kreuter M, Holmes K, Alcaraz K, Kalesan B, Rath S, Richert M, McQueen A, Caito N, Robinson L, Clark E. Comparing narrative and informational videos to increase mammography in low-income African

- American women. *Patient Educ Couns.* 2010;81:S6-S14. doi:10.1016/j.pec.2010.09.008.
5. Larson H, Cooper L, Eskola J, Katz S, Ratzan S. Addressing the vaccine confidence gap. *The Lancet.* 2011;378(9790):526–535. doi:10.1016/s0140-6736(11)60678-8.
 6. Skaburskis A. The Origin of “Wicked Problems”. *Planning Theory & Practice.* 2008;9(2):277–280. doi:10.1080/14649350802041654.
 7. Yaqub O, Castle-Clarke S, Sevdalis N, Chataway J. Attitudes to vaccination: A critical review. *Social Science & Medicine.* 2014;112:1–11. doi:10.1016/j.socscimed.2014.04.018.

Reading List

1. Amin A, Bednarczyk R, Ray C, Melchiori K, Graham J, Huntsinger J, Omer S. Association of moral values with vaccine hesitancy. *Nat Hum Behav.* 2017;1(12):873–880. doi:10.1038/s41562-017-0256-5.
2. Browne M, Thomson P, Rockloff M, Pennycook G. Going against the Herd: Psychological and Cultural Factors Underlying the ‘Vaccination Confidence Gap’. *PLoS ONE.* 2015;10(9):e0132562. doi:10.1371/journal.pone.0132562.
3. Butler R, MacDonald N. Diagnosing the determinants of vaccine hesitancy in specific subgroups: The Guide to Tailoring Immunization Programmes (TIP). *Vaccine.* 2015;33(34):4176–4179. doi:10.1016/j.vaccine.2015.04.038.
4. Corcoran B, Clarke A, Barrett T. Rapid response to HPV vaccination crisis in Ireland. *The Lancet.* 2018;391(10135):2103. doi:10.1016/s0140-6736(18)30854-7.
5. Dahlstrom M, Ho S. Ethical Considerations of Using Narrative to Communicate Science. *Sci Commun.* 2012;34(5):592–617. doi:10.1177/1075547012454597.
6. Dahlstrom M. Using narratives and storytelling to communicate science with nonexpert audiences. *Proceedings of the National Academy of Sciences.* 2014;111(Supplement_4):13614–13620. doi:10.1073/pnas.1320645111.
7. De keersmaecker J, Roets A. ‘Fake news’: Incorrect, but hard to correct. The role of cognitive ability on the impact of false information on social impressions. *Intelligence.* 2017;65:107–110. doi:10.1016/j.intell.2017.10.005.
8. Donzelli G, Palomba G, Federigi I, Aquino F, Cioni L, Verani M, Carducci A, Lopalco P. Misinformation on vaccination: A quantitative analysis of YouTube videos. *Hum Vaccin Immunother.* 2018;1–6. doi:10.1080/21645515.2018.1454572.
9. Dredze M, Broniatowski D, Smith M, Hilyard K. Understanding Vaccine Refusal. *Am J Prev Med.* 2016;50(4):550–552. doi:10.1016/j.amepre.2015.10.002.
10. Dubé E, Laberge C, Guay M, Bramadat P, Roy R, Bettinger J. Vaccine hesitancy. *Hum Vaccin Immunother.* 2013;9(8):1763–1773. doi:10.4161/hv.24657.
11. Dubé E, Vivion M, MacDonald N. Vaccine hesitancy, vaccine refusal and the anti-vaccine movement: influence, impact and implications. *Expert Rev Vaccines.* 2014;14(1):99–117. doi:10.1586/14760584.2015.964212.
12. Edwards K, Hackell J. Countering Vaccine Hesitancy. *Pediatrics.* 2016;138(3):e20162146-e20162146. doi:10.1542/peds.2016-2146.
13. Fadda M, Galimberti E, Fiordelli M, Romanò L, Zanetti A, Schulz P. Effectiveness of a smartphone app to increase parents’ knowledge and empowerment in the MMR vaccination decision: A randomized controlled trial. *Hum Vaccin Immunother.* 2017;13(11):2512–2521. doi:10.1080/21645515.2017.1360456.
14. Favin M, Steinglass R, Fields R, Banerjee K, Sawhney M. Why children are not vaccinated: a review of the grey literature. *Int Health.* 2012;4(4):229–238. doi:10.1016/j.inhe.2012.07.004.
15. Fokoun C. Strategies implemented to address vaccine hesitancy in France: a review article. *Hum Vaccin Immunother.* 2018;1–41. doi:10.1080/21645515.2018.1458807.
16. Gowda C, Dempsey A. The rise (and fall?) of parental vaccine hesitancy. *Hum Vaccin Immunother.* 2013;9(8):1755–1762. doi:10.4161/hv.25085.
17. Haverkate M, D’Ancona F, Giambi C, Johansen K, Lopalco P, Cozza V, Appelgren E, on behalf of the VENICE project group. Mandatory and recommended vaccination in the EU, Iceland and Norway: results of the VENICE 2010 survey on the ways of implementing national vaccination programmes. *Eurosurveillance.* 2012;17(22). doi:10.2807/ese.17.22.20183-en.
18. Hendrix K, Sturm L, Zimet G, Meslin E. Ethics and Childhood Vaccination Policy in the United States. *Am J Public Health.* 2016;106(2):273–278. doi:10.2105/ajph.2015.302952.
19. Hinyard L, Kreuter M. Using Narrative Communication as a Tool for Health Behavior Change: A Conceptual, Theoretical, and Empirical Overview. *Health Education & Behavior.* 2007;34(5):777–792. doi:10.1177/1090198106291963.
20. Kolodziejcki L. Harms of Hedging in Scientific Discourse: Andrew Wakefield and the Origins of the Autism Vaccine Controversy. *Technical Communication Quarterly.* 2014;23(3):165–183. doi:10.1080/10572252.2013.816487.

21. Kreuter M, Holmes K, Alcaraz K, Kalesan B, Rath S, Richert M, McQueen A, Caito N, Robinson L, Clark E. Comparing narrative and informational videos to increase mammography in low-income African American women. *Patient Educ Couns.* 2010;81: S6-S14. doi:10.1016/j.pec.2010.09.008.
22. Larson H, Cooper L, Eskola J, Katz S, Ratzan S. Addressing the vaccine confidence gap. *The Lancet.* 2011;378(9790):526–535. doi:10.1016/s0140-6736(11)60678-8.
23. Larson H, Jarrett C, Eckersberger E, Smith D, Paterson P. Understanding vaccine hesitancy around vaccines and vaccination from a global perspective: A systematic review of published literature, 2007–2012. *Vaccine.* 2014;32(19):2150–2159. doi:10.1016/j.vaccine.2014.01.081.
24. Larson H, Clarke R, Jarrett C, Eckersberger E, Levine Z, Schulz W, Paterson P. Measuring trust in vaccination: A systematic review. *Hum Vaccin Immunother.* 2018;1–11. doi:10.1080/21645515.2018.1459252.
25. Lawler E. Effectiveness of vaccination recommendations versus mandates: Evidence from the hepatitis A vaccine. *J Health Econ.* 2017;52:45–62. doi:10.1016/j.jhealeco.2017.01.002.
26. Nisbet M, Scheufele D. What's next for science communication? Promising directions and lingering distractions. *Am J Bot.* 2009;96(10):1767–1778. doi:10.3732/ajb.0900041.
27. Paterson P, Meurice F, Stanberry L, Glismann S, Rosenthal S, Larson H. Vaccine hesitancy and health-care providers. *Vaccine.* 2016;34(52):6700–6706. doi:10.1016/j.vaccine.2016.10.042.
28. Paulussen T, Hoekstra F, Lanting C, Buijs G, Hirasings R. Determinants of Dutch parents' decisions to vaccinate their child. *Vaccine.* 2006;24(5):644–651. doi:10.1016/j.vaccine.2005.08.053.
29. Peretti-Watel P, Ward J, Schulz W, Verger P, Larson H. Vaccine Hesitancy: Clarifying a Theoretical Framework for an Ambiguous Notion. *PLoS Curr.* 2015. doi:10.1371/currents.outbreaks.6844c80ff9f5b273f34c91f71b7fc289.
30. Périnet S, Kiely M, De Serres G, Gilbert N. Delayed measles vaccination of toddlers in Canada: Associated socio-demographic factors and parental knowledge, attitudes and beliefs. *Hum Vaccin Immunother.* 2018;14(4):868–874. doi:10.1080/21645515.2017.1412899.
31. Pohl C, Krütli P, Stauffacher M. Ten Reflective Steps for Rendering Research Societally Relevant. *GAIA - Ecological Perspectives for Science and Society.* 2017;26(1):43–51. doi:10.14512/gaia.26.1.10.
32. Sadaf A, Richards J, Glanz J, Salmon D, Omer S. A systematic review of interventions for reducing parental vaccine refusal and vaccine hesitancy. *Vaccine.* 2013;31(40):4293–4304. doi:10.1016/j.vaccine.2013.07.013.
33. Salmon D, Dudley M, Glanz J, Omer S. Vaccine hesitancy. *Vaccine.* 2015;33:D66-D71. doi:10.1016/j.vaccine.2015.09.035.
34. Schmid P, MacDonald N, Habersaat K, Butler R. Commentary to: How to respond to vocal vaccine deniers in public. *Vaccine.* 2018;36(2):196–198. doi:10.1016/j.vaccine.2016.09.065.
35. Yaqub O, Castle-Clarke S, Sevdalis N, Chataway J. Attitudes to vaccination: A critical review. *Social Science & Medicine.* 2014;112:1–11. doi:10.1016/j.socscimed.2014.04.018.

Relevant Websites

1. Shot By Shot. *Shot By Shot.* 2018. Available at: <http://www.shotbyshot.org/>. Accessed July 3, 2018.
2. CDC. *Centers for Disease Control and Prevention.* 2018. Available at: <https://www.cdc.gov/>. Accessed July 3, 2018.
3. WHO | World Health Organization. *Who.int.* 2018. Available at: <http://www.who.int/>. Accessed July 3, 2018.
4. Child's death from measles caught from unvaccinated brother reignites debate in Italy. *euronews.* 2018. Available at: <http://www.euronews.com/2017/06/23/childs-death-from-measles-caught-from-unvaccinated-brother-reignites-debate-in-italy>. Accessed July 3, 2018.
5. Why I wish my daughter had been vaccinated | Sophie Heawood. *the Guardian.* 2018. Available at: <https://www.theguardian.com/commentisfree/2013/apr/24/wish-my-daughter-vaccinated>. Accessed July 3, 2018.
6. A Good Story Is Always Far More Persuasive Than Facts and Figures. *Inccom.* 2018. Available at: <https://www.inc.com/james-sudakow/why-a-good-story-is-far-more-persuasive-than-facts.html>. Accessed July 3, 2018.
7. The Science of Storytelling: Why Telling a Story is the Most Powerful Way to Activate Our Brains. *Lifehackercom.* 2018. Available at: <https://lifehacker.com/5965703/the-science-of-storytelling-why-telling-a-story-is-the-most-powerful-way-to-activate-our-brains>. Accessed July 3, 2018.
8. Zivkovic B, Zivkovic B. Telling science stories...wait, what's a "story"? *Scientific American Blog Network.* 2018. Available at: <https://blogs.scientificamerican.com/a-blog-around-the-clock/httpblogsscscientificamericancoma-blog-around-the-clock-20110713telling-science-stories-wait-whats-a-story/>. Accessed July 3, 2018.

Supplement 1: ORIGINAL CHALLENGE

NAME: A WAY TO UNDERSTAND THE CIRCUMSTANCES THAT INFLUENCE REFUSAL OF CHILDHOOD VACCINATION.

Background of the challenge:

Apart from running water and hygiene, vaccines are the best preventive medical invention/intervention that have worldwide impacted significantly on morbidity and mortality 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 provide an individual with protection against disease, but a vaccinated person can, for most vaccines, be no longer infected and will thus stop transmission of the infectious pathogen. This phenomenon made eradication of smallpox possible as well as the elimination of many vaccine-preventable diseases (e.g. polio, diphtheria, measles, rubella, ...) in countries with a high vaccination coverage. By organizing vaccination programs, where >90–95% of the population is vaccinated, spreading of the disease 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 population immunity.

Despite the overwhelming scientific evidence of the positive effect of vaccination and of herd immunity, over the last decade vaccines have been the victims of their own success. The current generation of new parents is no longer familiar with the severity and complications of vaccine-preventable infectious diseases and parents are increasingly focused on (alleged) side effects of vaccines. This phenomenon, called vaccine hesitancy, has led to a lowering of confidence in the effects of vaccination and an increasing proportion of parents 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, it 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 about the alleged side effects of vaccines are spread more easily than solid scientific evidence. 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 postpone essential vaccination to a later, mostly undefined, age.

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 had been 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, new ways of tackling this issue would still 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.

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

1. People knowledgeable about social media
2. People who have dealt with crises regarding infectious diseases or vaccine crises
3. WHO Europe
4. Other academia developing tools to increase vaccination coverage
5. People who have suffered from vaccine-preventable diseases

Supplement 2: FALLING WALLS LAB PRESENTATION

Video:

1. Breaking the Wall of Vaccine Hesitancy | Falling Walls Lab Leuven. YouTube. 2018. Available at: <https://www.youtube.com/watch?v=cma2WwHSKiM>. Accessed July 3, 2018.
2. Another version is here.

FALLING
WALLS
LAB

Hours
KU LEUVEN
TRANSDISCIPLINARY
INSIGHTS

BREAKING THE WALL OF VACCINE HESITANCY

TARUN JOSE KATTUMANA
INDIA
KU LEUVEN

FALLING WALLS LAB ENTER LAB

TARUN JOSE KATTUMANA

BREAKING THE WALL OF VACCINE HESITANCY



Pro-Vaccine Messages need to use **Personal Stories**

Summary:

Our project was selected to participate in the KU Leuven chapter of the Falling Walls Lab, an international forum for researchers to present their ideas to both a wider public audience and a panel of specialist judges. We argued for a better understanding of vaccine hesitant parents who refused to vaccinate their children fearing the unverified side-effects vaccines might have. This was important given the return of vaccine preventable diseases as seen in the case of 35 deaths and a three-fold increase in measles cases across Europe.

Our presentation focused on the differences between pro-vaccine and anti-vaccine messaging. While pro-vaccine messages focused on facts and figures; anti-vaccine messages relied on narrative structures that had tremendous emotional appeal and talked to the fears and anxieties that parents have. This difference contributed to the ineffectiveness of pro-vaccine messaging. This in turn contributed towards reduced vaccine coverage in several European states. To counter this trend, we argued that pro-vaccine messages need to use 'storytelling' and personal narratives to convey facts effectively in a manner that spoke to the concerns of hesitant parents. We had had the opportunity to present a version of this presentation at the REGA Institute, KU Leuven.

Text:

Let me tell you a story. A story about William.¹ William was born in 2017, but also died that very same year of measles. He got infected by the neighbour's son whose parents were against vaccination. A tragedy like this could easily have been prevented by vaccination.

This is not an isolated incident. Last year we saw 35 deaths and a 3-fold increase in measles cases across Europe.

But why are these parents hesitant?

Parents care about the health of their children. This makes them vulnerable to anti-vaccine messages. These messages repeat myths that vaccines would cause side-effects like autism. While most of us would laugh this off as crazy conspiracy theory, we forget that people are no longer familiar with deadly diseases because vaccines prevent them from happening. Thus, vaccines have become a victim of their own success.

On the other hand, parents keep hearing about bad things vaccine do to children.
So a hesitant parent is faced with a very difficult choice.

1. Vaccinating for a disease that does not seem to exist anymore
2. Not vaccinating and preventing the autism side-effect.

Most pro-vaccine messages try to combat these fears with facts, graphs and numbers. But this does not seem to work. One of the primary reasons for this is the increasing distrust in the government, pharmaceutical companies and the language of science. Just as biblical evidence would not convince an atheist, scientific evidence will not convince a sceptic of science.

We need to change the way we communicate with hesitant parents.

Pro-vaccine messages need to rely less on brute facts and more on personal stories if we want to convince parents that they need to vaccinate.

Coming back to William. A story like this speaks about the concerns that parents have. It makes its point without overly relying on facts, graphs or numbers. It is a story that parents can identify with.

And this is my most crucial message to you.

Vaccines work best if a significant number of us are vaccinated. Otherwise, tragedies like William's, where diseases spread through people who are not vaccinated, is only more likely to happen.

Vaccines are a good and safe solution but they need to be implemented widely.

And we can only effectively implement them if we can take away the fears and anxieties that hesitant parents have.

So when you encounter a hesitant parent, do not just give them facts and figures. Do not just say science is right. Tell them a story because stories speak to the heart.

¹ The name has been changed

Supplement 3: FACING THE FUTURE SYMPOSIUM PRESENTATION

Video: [here](#)

Text:

Vaccines are considered to be one of the discoveries with the highest impact on public health. Currently, there are vaccines available against 26 different diseases. Every year they prevent approximately 2–3 million deaths. However, by increasing immunization coverage an additional 1.5 million deaths could be prevented. In addition, vaccines limit the spread of antibiotic resistance, which is an important healthcare concern worldwide nowadays.

But today, the rise of vaccine hesitancy is causing a rapid decrease in vaccine coverage, resulting in a higher risk of epidemics of vaccine preventable diseases, such as measles, polio, and whooping cough. Last year alone, we saw a 3-fold increase in measles cases across Europe.

To further illustrate the impact vaccine hesitancy can have, let me tell you a story about Alessandro.¹ Alessandro was a six-year-old Italian boy suffering from leukemia who died last year from measles complications. He caught measles from his older sibling, who was not vaccinated. Alessandro's death could have been avoided if everyone in his community had been vaccinated.

Imagine now, you are a parent and need to decide whether or not you would vaccinate your child. Which of these two messages would you find more convincing? A WHO poster or Alessandro's story?

Let us know by voting and we will have a look at the end of this presentation.

There is not just one reason why parents are hesitant to vaccinate their children.

In fact, vaccine hesitancy is such a serious problem that the reasons for it were categorised by the WHO into three groups:

1. Convenience: the decision to vaccinate is influenced by vaccine accessibility.
2. Complacency: this is when people think vaccination is no longer necessary.
3. Confidence: this is about the lack of trust in vaccines.

We focused on confidence and complacency in early childhood vaccinations, such as measles, mumps, rubella (also called MMR), mainly because confidence and complacency are important issues in Belgium.

We began with a literature review. There turned out to be a lot of different factors or reasons for vaccine hesitancy. For example, no longer being familiar with deadly vaccine-preventable diseases and distrust in government, Big Pharma and science. But this is only the tip of the iceberg. There are so many other reasons. Like concerns about vaccine safety and side effects, the use of animals in vaccine testing and production, and the ineffectiveness of pro-vaccine messaging.

We also conducted interviews with key stakeholders, including experts in social sciences, filmmaking, virology, public health, as well as a WHO Europe representative. We would like to thank all of them for their contributions.

After talking to these stakeholders we have identified social media as a powerful tool in propagating anti-vaccine messages. Search engines play a big role in this problem. They are easily accessible. However, the algorithms that deliver the search results standing behind them are unknown. What is known is that the search results are filtered on

¹ The name has been changed

popularity and previous search history, but are not based on the reliability of the content. For example, parents that look for 'vaccines' get on a rollercoaster of negative information, and cannot make a well informed decision.

Anti-vaccine communities are popular and widespread on the Internet. They are accessible and open to communication. They are dynamic and up to date, and able to catch one's attention. Therefore they are attractive to hesitant parents. And these anti-vaccine communities use emotional stories to convey their message.

We have compared pro-vaccine and anti-vaccine strategies using the most popular YouTube videos related to vaccination.

Analysis of different types of videos revealed that most of the anti-vaccine videos are presented in a format that can include 'storytelling', such as home-made videos, collages, interviews, public speeches and YouTube or TV shows. In contrast, pro-vaccine videos were presented in a wider range of different formats, most of which were not suitable for emotional stories.

Furthermore, we also conducted a couple of interviews with parents hesitant about vaccinations.

For example, a parent told us: *'I talked to doctors .. but I also spoke to a Somali woman, because I know that in their culture they often don't vaccinate due to religious viewpoints. What she told me was worth thinking about. She told me about her uncle who had 6 children. Unfortunately, he didn't have them anymore, they all died of measles. .. It shows how deadly measles can be and that vaccinating does work. ...'*

We asked her: *'What had the biggest impact on your decision, the personal story or what the doctors said?'*

And she replied: *'To be honest, the personal story. For me as a layman a personal story has more impact.'*

Interview analysis supported our hypothesis about 'storytelling' being more convincing than official reports.

In fact, personal stories have already been shown to be an effective strategy with respect to other health related issues, such as convincing women to get tested for breast cancer.

We have identified three promising ways to tell personal stories about vaccines:

1. Vaccines as part of the 'green' lifestyle
2. Protection for immunocompromised patients
3. Consequences of vaccine-preventable diseases

However, we have a very heterogeneous group of hesitant people, so it is crucial that a strategy of 'storytelling' is well adapted to a particular subgroup.

There is a spectrum of attitudes to vaccinations, and we want to focus on only hesitant people, since anti-vaccine people are very hard to convince, because they would stand up for their beliefs as if they were a religion.

Our future plans would include making videos of these personal stories that could be shared through social media. A pilot study with them would help us better understand which factors would be more efficient, for example, positive or negative emotional stories.

Supplement 4: ACTOR CONSTELLATION GAME

Description:

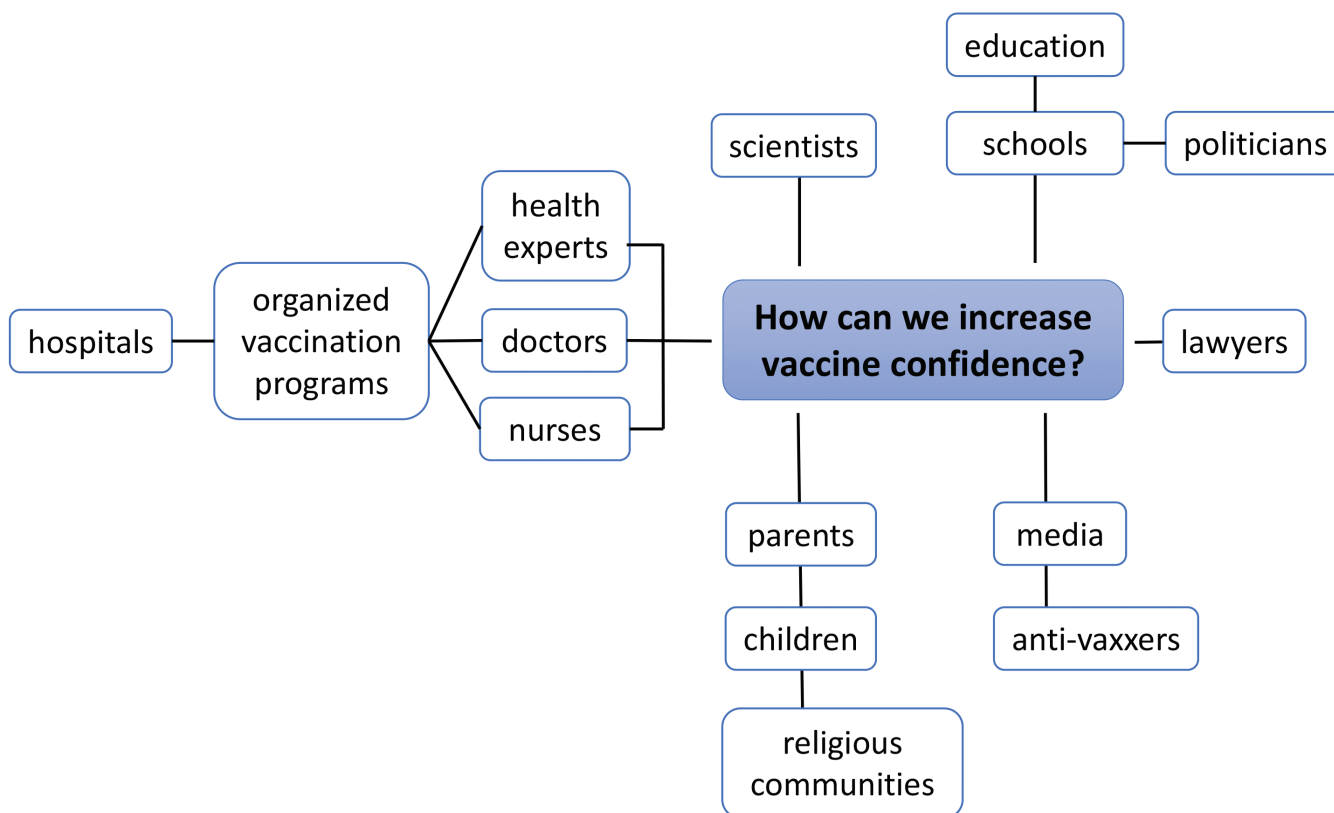
Actor constellation | Co-producing Knowledge. *Naturalsciencesch.* 2018. Available at: https://naturalsciences.ch/topics/co-producing_knowledge/methods/actor_constellation_final_. Accessed July 3, 2018.

Result:

1. 1st Actor Constellation Game is attached
2. 2nd Actor Constellation Game is attached

1st Actor of Constellation: Vaccine Hesitancy

Transdisciplinary Insights – KU Leuven



2nd Actor of Constellation: Vaccine Hesitancy

Transdisciplinary Insights – KU Leuven

