

Lost in translation

Why fundamental findings are not translated to medical contexts, and how to optimize the translational activity in the neuroscience field.

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Summary

Neurological disorders are the leading cause of disabilities and second leading cause of death worldwide. Important discoveries therefor have the potential to save or aid large patient populations. However, valorising this research in a way that leads to this societal impact is not without its obstacles. A lack of resources, a lack of awareness from researchers and institutions, and differences between fundamental and clinical researchers are often mentioned in the literature as bottlenecks limiting the translational activity.

For this study, semi structured interviews were held with researchers from varying backgrounds in either fundamental, translational or clinical neuroscience. Transcripts were coded using iterative coding strategies and analysed for common themes. Based on this analysis, it seems expertise regarding effective translational research is not widely available, collaborators are difficult to find, and resources are sometimes only available for those with interdisciplinary collaborators. There seems to be an interest among researchers in a professional body focussing on translation embedded within the research institute. This body would have a role in helping find collaborators, increasing crosstalk and connections between clinical and fundamental researchers, as well as serving as a source of expertise regarding best translational practises.

These organisations, often called intermediaries, are characterised through three main roles: the knowledge broker, the network manager, and the system transitioner. Based on these three roles and available literature, different intermediary organisations are discussed through a novel framework that builds upon existing models from different fields. Two case studies are used to validate the framework and further explore trade-offs and strategic choices made during the founding of the organisation or transitioning to a new strategy. Interviews with experts involved in these organisations were held and used to compare these two organisations based on the proposed framework. Based on their relationship to bridging and bonding social capital, autonomy, and knowledge aggregation, a first proposal is made regarding the best approach for this translational intermediary.

This intermediary tasked with optimizing the translational activity in the neuroscience field should be tasked with collecting and maintaining knowledge, be a centralised organisations with strong ties with different researchers in the network, and function autonomously from any existing institution.

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1 Introduction

1.1 From bench to bedside

As science becomes increasingly specialised, what is and is not general knowledge in a field of research becomes less clear. Knowledge that is widely shared across researchers in a particular niche may not travel far outside that limited set of researchers. For example, something that is well studied is the fact that the cerebellum, part of the central nervous system, is involved in a variety of non-motor tasks. This observation was first published by 1987 in reference to older literature (Roland, 1987) and has received a lot of attention in recent years (Figure 1). Despite this attention, the non-motor effects are barely mentioned when discussing clinical relevance of the cerebellum, the cerebellum is often left out in imaging studies, and receives limited attention in education (Wang, LeBel, & D'Mello, 2025).

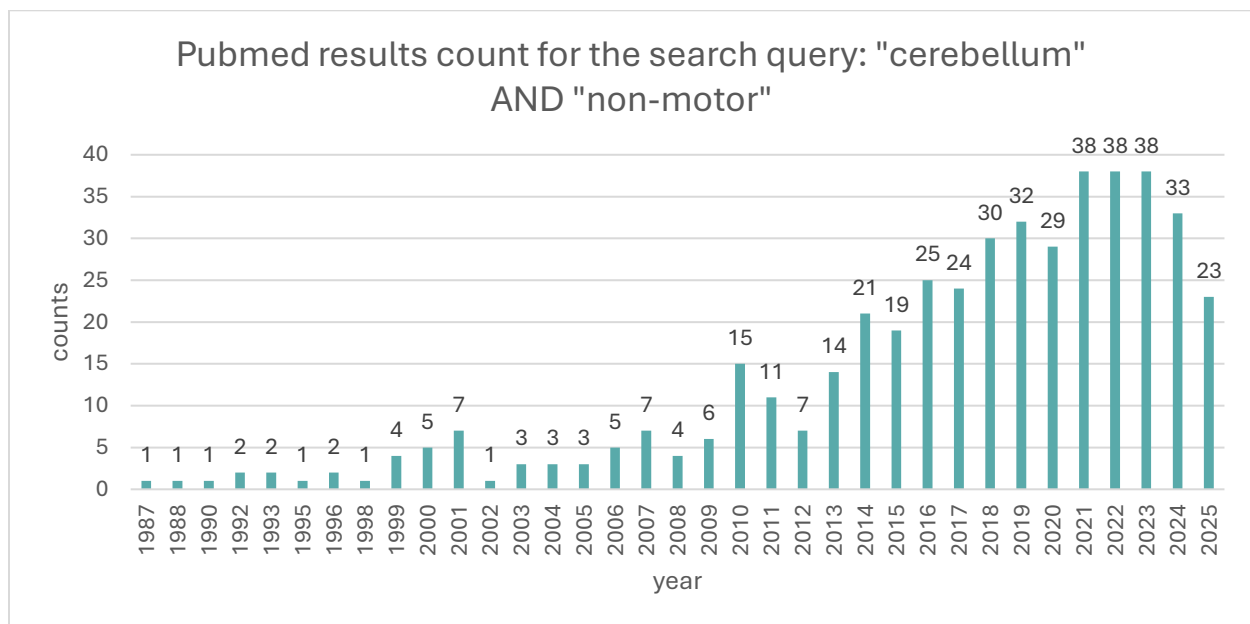


Figure 1 An overview for the results available on PubMed for the search query "cerebellum" AND "non-motor"

This disconnect between fundamental research findings and clinical knowledge is not unique to neuroscience. The process by which fundamental discoveries inform clinical practises is often referred to as going from bench to bedside (NIH). The barriers and difficulties in this translational process are well documented, but not often in the context of neuroscience (Fudge et al., 2016; Morris, Wooding, & Grant, 2011), despite the large societal impact neurological disorders have globally (Feigin et al., 2019). This report aims at elucidating the particular challenges for the translation of fundamental neuroscience findings into clinical research, followed by a suggestion on how to optimize the translational process.

1.2 Research questions and approach

The project can be described through the main research question and its sub questions.

RQ: How can translational activity be optimized through targeted interventions to overcome the unique and overlapping bottlenecks with the highest impact on fundamental-to-clinical research translation in neuroscience?

- Sub question 1: What are common bottlenecks found in literature regarding translational research?
- Sub question 2: Which of the discussed bottlenecks have the highest perceived impact on the translational activity in the neuroscience field?
- Sub question 3: What are unique bottlenecks in the field of neuroscience, not commonly found in the literature, experienced by fundamental, translational, and clinical researchers?

The first sub question was answered through a literature review presented in the next section of this report. The next two sub-questions were answered in parallel through interviews with researchers from fundamental, translational, or clinical backgrounds in the neuroscience field. The perceived impact of bottlenecks from the first sub question were examined through ranking. Unique bottlenecks to the neuroscience field were identified through the analysis of semi structured interviews. A more in-depth description of the methodology, including the approach to interviews, coding, and data analysis, can be found in the methodology section.

The research, like this report, was structured following the design-based research approach from the British Design Council (2005). The first phase, research, included the problem definition and literature search described in the literature review. This discovery portion of the research phase ended with the developing of the research questions and methodology. During the define portion of the research phase, the results from the interviews were analysed, themes were formulated, and a comprehensive problem definition was described. These results are presented in the results section and discussed in the discussion section. The problem definition is presented in the conclusion section, concluding both the research phase as well as the first chapter of this report (Figure 2).

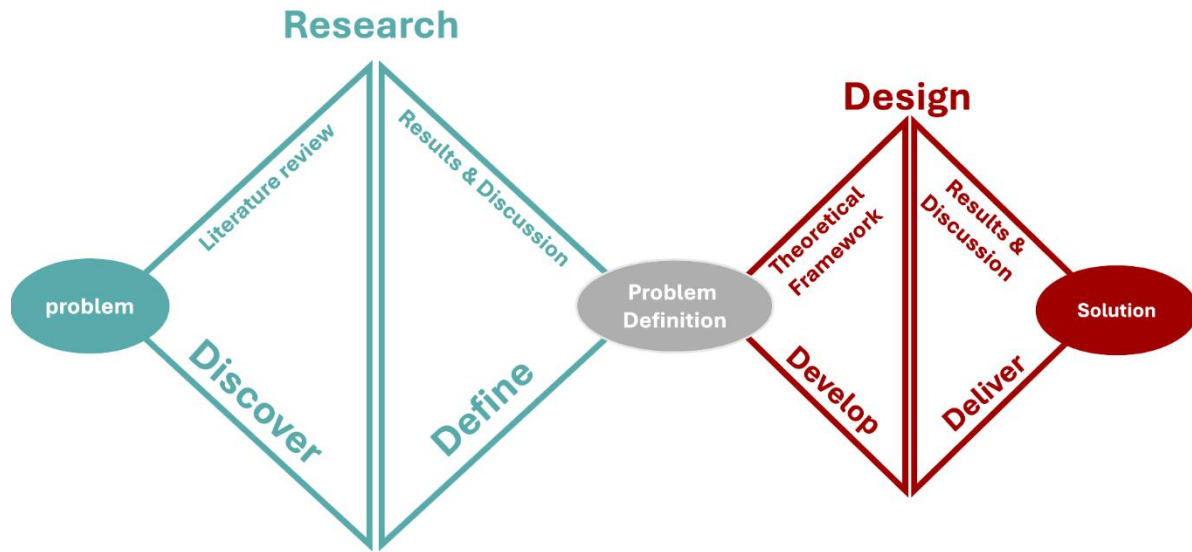


Figure 2 A visual representation of the double diamond model from the British design council (British Design Council, 2005), and how the sections of this report relate to different sub sections. The first portion of the research phase includes the literature review and design of the methodology. This phase ends in a problem definition, described in the conclusions. This problem definition is the start of a new literature review, described in its own theoretical framework, with the aim of developing a model used to design and deliver a proposal for a solution.

This new problem definition is the starting point of the design phase starting with the developing of a model based on the literature, described in a second literature review about intermediary organisations. The following methodology section describes the approach to validating this model and concludes the development portion. The results from this second, smaller, study are based two case studies and discussed in a second discussion section. The design phase ends with a conclusion on the necessary requirements for a translational intermediary, and suggestions for future work. Finally, the report ends with a reflection that discusses the larger research process, choices made at different stages and acknowledges potential biases and personal involvements.

Chapter 1 - Research

2 Literature review

2.1 Translation is an essential step for valorisation

Valorisation is considered an important part of the scientific process by both scientists and policy makers alike. While definitions differ between institutions, it can be broadly defined as the process by which scientific research is turned into societal impact (Drooge, 2016). Societal impact is a broad term that can mean a lot of different things, but when it comes to biology research, medical applications are an obvious example. While there is some discussion on how long the process of adapting research into medical practice generally takes (Morris et al., 2011), it is an uncontroversial opinion that it takes a long time. As a result, clinicians treating patients in one room of a university hospital may be unaware of information, discovered several years ago in a different room in that same building, that directly stands to benefit the patient's current treatment.

This study of the process by which scientific research results are adapted to medical practises is often referred to as translational science and studied across several fields (George et al., 2019; Oliveira, Hyppolito, Malheiros, Stewart, & Pannuti, 2021; Tracy, 2014). Morris et al. (2011) model translational science as a two-step process, based on its use in the literature. The first step, T1, regards the translation from fundamental research towards human and medical context, crucial for clinical research like the design of a medical trial based on research done in animals. The second step, T2, considers the research to practice process where clinical research informs future medical practise. Imagine the implementation of a new guideline for nurses based on evidence from a medical trial for example.

While this model and its descriptions are commonly used by translational researchers (George et al., 2019; Tracy, 2014), it is not universally adopted. The Department of Translational Neuroscience at the UMC Utrecht focusses on the translation of fundamental knowledge to pathogenesis and disease models (T1) (UMC), and other researchers refer to T2 as implementation science (Samanta & Landes, 2021). Additionally, some variations of the models exist such as the one from the PennState Clinical and Translational Science Institute, that distinguishes between human and clinical translation as its own T1 and T2, followed by translation to clinical practice as T3, and an additional step translating medical practice to populations as T4.

To avoid confusion between different terms and models we will simplify things for the purposes of this project. In this work we will refer to translation of all fundamental research to clinical research as *research translation*. Research translation is thus about translating cell, animal, or computer models to a human and medical context. The step that takes us

from a human and medical context to actual medical practise will be referred to as *clinical translation* (Figure 3).

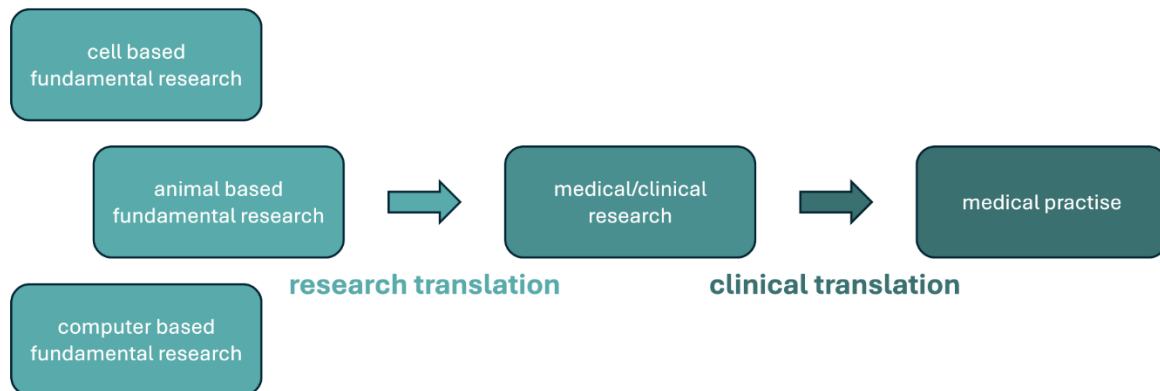


Figure 3 Translational science model based on literature (Morris et al., 2011) and adapted to the needs of this report.

2.2 Translational science barriers and themes

Researchers from a variety of fields have identified several barriers to both research and clinical translation. Common barriers regarding clinical translation are institutional, regarding the time, training and available money for clinical personnel to access and read scientific literature (Brown, Wickline, Ecoff, & Glaser, 2009; Duncombe, 2018; Oliveira et al., 2021; Spallek et al., 2010). Additional barriers have to do with unconvincing or contradictory literature, or a lack of perspective for clinical actions based on available evidence (Oliveira et al., 2021; Spallek et al., 2010). They explain that institutional barriers require institutions to be aware off, and appreciate, the value and benefits of translational science.

Fudge et al. (2016) describe five themes that are covered in the current body of literature discussing the barriers found in translational science.

1. Concepts of translational research
2. Research processes
3. Research versus clinical care
4. Interdisciplinary collaborations
5. Entrepreneurial science

While there is literature available discussing each of these themes, most of them take a policy centred perspective with a focus on entrepreneurial science and innovation (Fudge et al., 2016). According to Fudge et al. (2016), only a small number of papers, 2 out of 14, analysed in their systematic analysis take an approach focussing on team science and only within a limited scope. Additionally, Fudge et al. (2016) note that some researchers opted to discuss dilemma's instead of barriers. They explain that just because something slows the translational process down, does not mean it is a barrier to be overcome, as good, ethical,

and careful science takes time. Perhaps bottlenecks, suggesting a limiting factor without the implied need to be something to overcome, serves as a better description of what we are looking for.

2.3 Unique challenges in translational neuroscience

It seems self-evident that every medical domain comes with their own challenges. Dentistry, for example, has a unique position within the larger field of biomaterials and requires material science and biocompatibility testing (Tracy, 2014). It should take little convincing that the research translation from material science to human applications requires different knowledge and expertise than translating cancer research done on isolated cells to human environments. Similarly, the field of neuroscience has its own unique challenges and characteristics. Animal behaviour often needs to be translated into human behaviour, brains differ vastly across species, and taking the step from single neuron behaviour to neural networks, and a whole brain is incredibly complicated due to emergent properties (Azkona & Sanchez-Pernaute, 2022; Markram, 2013). Additionally, overly optimistic interpretation of statistical data in animal studies leads to disappointing results in human trials (Hogue, 2022).

Despite these unique challenges and several translational neuroscience departments, a paper discussing the unique challenges from the viewpoint of both clinical and fundamental scientists seems to be lacking from the literature, especially regarding research translation. The goal of this study will be to determine both the overlapping and unique challenges in translating discoveries within the field of neuroscience to human and medical contexts.

2.4 Translational science in a social network

So far, translational science has been discussed as a process that happens without discussing the community it takes place in. A popular model to describe communities and their interactions is known as social network theory. Social network theory models a community as a network of relations (Spier, 2017; Wasserman & Faust, 1994). In this model, the smallest unit of a community is the relation between two individuals, not the individual itself (Durrance, 2008). The edge connecting the nodes describes how resources, either material or not, may be transferred through the network (Wasserman & Faust, 1994). In research contexts this resource is often knowledge, as can be seen in its use to model the flow of knowledge and estimate the efficacy of scientific conferences (Liberman & Wolf, 1997), as well as in describing the cross-institutional sharing of scientific knowledge between industry and universities (Liebeskind, Oliver, Zucker, & Brewer, 1996).

Two important characteristics of these networks that drive the shape are transitivity and homophily (Spier, 2017). Spier (2017) explains that transitivity is the suggestion that if two

nodes, A and B, are both connected to C, they are likely connected to each other as well. If two scientists have collaborated with a third, it is more likely that they have also collaborated with each other or are at least familiar with each other's work. Homophily is the notion that nodes that are more similar are more likely connected than those that are very different. If two scientists study a similar topic, the chance is higher that they are familiar with each other. These concepts lead to the hypothesis that fundamental researchers would thus be more likely to be connected with other fundamental researchers, and less with clinicians. Of course this hypothesis goes both ways, with clinicians being more likely to be connected with other clinicians than with fundamental researchers as well.

Through the modelling of a community in a familiar network structure, with nodes and edges connecting them, properties of the network can be used to describe characteristics of the community. Take a concept like 'sparsity' for example, sparse regions where there are little connections between nodes would signal subsets of the network through which information is less efficiently shared among a group of individuals. Generally, you would expect clusters of dense sections of the network connected to each other through a sparser section called a bridge (Spier, 2017). In our context, we would expect fundamental researchers to inhabit a denser cluster, with a sparse bridge section connecting to the clinical researchers who are also more densely connected among themselves (Figure 4). We can speculate on who the "bridge researchers" are. Perhaps they are translational neuroscientists, the more interdisciplinary neuroscientists, or MDs participating in both fundamental neuroscience and clinical research. Identifying the bridge scientists may be an important aspect in the discussion on how to increase information transfer between clusters.

This concept of dense clusters and more open bridging regions is captured in a different sociology model based on the concept of social capital as defined by Bourdieu (1985). This definition of social capital regards the resources one can access by virtue of their social network. Social capital can either be bonding or bridging social capital, although this distinction is seldom made explicit and papers often, implicitly or not, focus on one of the two (Patulny & Svendsen, 2007). Bridging social capital, according to Putnam (2000), is outward focussed and arises from, what Granovetter (1973) calls, weak ties to people outside your close network. Bonding social capital is inwardly focussed and relates to your close inner circle. A network can be defined as either stimulating bridging or bonding social capital and Patulny and Svendsen (2007) argue that integrating this distinction is crucial in research. Based on our current model (Figure 4), the current network of fundamental and clinical researchers supports the aggregation of bonding social capital, in other words, the aggregation of knowledge found within networks of people within your own discipline. A network that stimulated the aggregation of bridging social capital would increase the knowledge flow between the clusters.

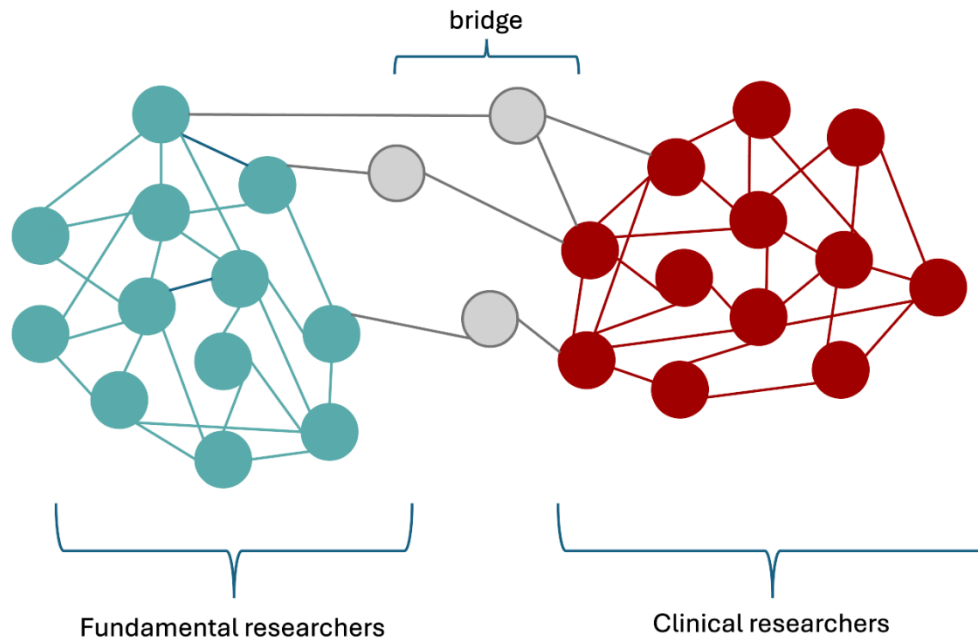


Figure 4 social network model for fundamental and clinical researchers including a bridge connecting the two. [based on the descriptions by (Spier, 2017; Wasserman & Faust, 1994)]

Using this model to describe research translation redefines the problem. Research translation now becomes explicitly about the sharing of resources, scientific knowledge, between clusters within the social network. The notion that this specialization and increasing compartmentalization of fundamental and clinical researchers is blocking the translational process has already been suggested almost 30 years ago and reiterated since (Goldstein & Brown, 1997; Kim, Welch, & Johnson, 2017). Based on the paper by Goldstein and Brown, the bridging region would be made up from the so called “physician scientists”, scientifically trained MD’s that combine patient oriented- with fundamental research. They identify a decline of MDs that have gravitated towards the fundamental sciences and away from patient-oriented research. They attribute this decline to the fast development of fundamental science. Since the 90s, biology has remained a fast-developing field with new technological breakthroughs happening every year. The suggestion that it is therefore difficult to keep up at the top of the fundamental science, while also being a top clinician, could still very well hold up.

Interdisciplinary collaboration has come up before (Fudge et al., 2016) and was also taken into account when considering translational science using social network theory (Kim et al., 2017). Kim et al. (2017) hypothesize that interdisciplinary collaboration results in more translational activity than collaboration between researchers within the same discipline does. While they don’t find support for this hypothesis, this would suggest that a network in which there are more connections between nodes belonging to a different cluster, would produce more translational work. Despite the reasonability of this hypothesis, Kim et al.

(2017) did not find interdisciplinary collaboration to be a significant predictor of new clinical research activity.

Translational homophily, however, a measure for how similar two people are in their affinity with translational science, did appear as a significant predictor of new clinical research (Kim et al., 2017). In the network view this would potentially suggest that collaborations between researchers in the bridge section of the network produces more translational activity.

2.5 Assumptions and themes to cover

As mentioned before, similar themes come up throughout papers on translational research, but some are covered more often than others. Additionally, papers cover a wide variety of medical/research fields as a context for this translation, but neuroscience has had relatively little attention. To close this gap in the literature, this project will focus on themes of collaboration, communication, and interdisciplinary work between fundamental and clinical researchers in the neuroscience field.

While translational science is often understood as an abstract process knowledge goes through as it goes from initial discovery to practical implementation, some have studied it as a process embedded in a social network through the lens of social network theory (Kim et al., 2017). Redefining research translation as the process through which fundamental knowledge is shared throughout the social network, and reaches clinical researchers, inspires to different ways of increasing this information flow. Questions like “who are the bridging researchers between clinical and fundamental researchers?” and “what factors allow for more interconnectivity between clinical and fundamental researchers?” naturally arise when looking at translational science from the perspective of social network theory.

Both models have their uses and may bring forth different or converging solutions. Through the consideration of both perspectives, they may be related or compared based on the results of this research.

3 Methodology

3.1 Project design

This project followed a design-based research approach taking the double diamond model as a guide (British Design Council, 2005). The first phase, the research diamond, took up the majority of the time and ended with the problem definition, in this case the characterisation of a subset of bottlenecks found in the research translation process. The second phase focussed on the design of a strategy to optimize the translational process based on this characterisation of bottlenecks.

3.2 Literature search

The discover portion of the research phase consisted mostly off an exploratory literature search. Given the broad variety of contexts, approaches, and perspectives in the available literature, a formal systemic review was deemed unfeasible within the time constraints of this project. Instead, iterative rounds of google scholar searches allowed for newly obtained knowledge to be used in later rounds of searching, exploring the available literature as knowledge on the topic developed. Interesting citations from reviews and papers were selected for further examination as well.

At first, general searches were done for papers mentioning “barriers”, “translational science” or “translational research” in the title or abstract. Papers that were about translational research being conducted in the field, and not research about translation from the meta perspective, were not considered. Additionally, commentaries or opinion pieces were also not included. Based on the most recent papers and a few reviews on the topic an understanding of the current state of the translational science field was built.

After the discovery that most research regards the implementation of clinical research and not the translation from fundamental understanding to clinical contexts, search terms included “T1” and were filtered based on whether the topic was part of the research or only mentioned in their theoretical framework. Because there seemed to be a lack of papers discussing translational research from a more communication and collaboration point of view (Fudge et al., 2016), search terms including terms like “collaboration” or “team science” were also used. Search terms that mentioned specific models like “social network theory” or “social capital” were tried to explore different perspectives from the common linear description of translational research, but to limit the scope of the review a focus was put on social network theory given its close relation to collaboration and connections between people.

3.3 Sampling and data collection

As mentioned previously, both the perspective of the fundamental as well as that of the clinical scientists had to be considered for a broad view of the challenges within the field of translational neuroscience. However, it ended up being more difficult to plan interviews with clinicians than expected, and the variation among fundamental researchers regarding their experience and focus on translation was broader than imagined. For logistical reasons our sample was limited to scientists that work at the Erasmus MC. Due to these limitations the final sample consists of mostly fundamental researchers within the Erasmus MC with varying experience regarding translational work. This report therefor considers the translational researcher as a somewhat separate group from the pure fundamental researchers.

As mentioned before, based on the nuanced views some researchers have regarding “dilemmas” in translational research (Fudge et al., 2016), this report considers bottlenecks rather than barriers. Sometimes it might not be bad that there is some time delay between discovery and clinical implementation, good science takes time after all. To allow for these nuanced discussions, semi structured interviews were used instead of more restricted surveys. This method allows for the use of models and frameworks to guide the conversation, while leaving room for unexpected topics and nuanced views to be part of the discussion as well. The goal is to find ways to make the research translation process more efficient and faster, but without being blind to the nuances some “barriers” might have.

The protocol was tested with two initial participants and revised to better target the research questions and literature, as well as include some quantitative questions. These quantitative results served both as a way to rank the severity of these bottlenecks as well as a way to score motivation and perceived importance regarding translation. The two initial interviews making use of the old protocol are not included in the results of this project.

3.4 Interview questions

The interview protocol, available in the appendix, was based on the literature review and consisted of five sections. The first section, the introductory questions, are meant to explore the participant’s personal perspective on translation and their research background. Using a combination of open and Likert style scoring questions the participant is asked about the type of research they do, how long they have been doing it, how important they believe translation is, and to what extent it plays a role in their own research. The answers to these questions serve two goals. First, they serve as a control, if the motivation is low in one group that might have a larger impact than the more social, collaborative, or systemic bottlenecks

found in the literature. A second goal of these questions is to understand the context someone works in and be able to explore how that may influence their perspective.

Next was a section based on the bottlenecks in the literature, including the lack of a variety of resources and awareness from institutions (Brown et al., 2009; Duncombe, 2018; Oliveira et al., 2021; Spallek et al., 2010), bottlenecks relating to the flow of information and finding of collaborative partners (Fudge et al., 2016; Kim et al., 2017), and related to the literature and evidence-based practises (Oliveira et al., 2021; Spallek et al., 2010). The bottlenecks included in the interview protocol ranking question are presented in the appendix. Before presenting any bottlenecks, participants are first asked to name three bottlenecks they are aware of in the general neuroscience field. This avoids biasing their perspective when offering those bottlenecks that are on top of their mind. Only after this open question are they presented with cards containing bottlenecks that were found in the literature. Participants were asked to rank these and elaborate on their top three. Regardless of the bottlenecks mentioned in the previous question, participants are presented with the same set of cards. Additionally, participants are asked how they could be aided to overcome these bottlenecks to provide inspiration for the design phase of the project

The next two sections of the interviews zoom in on collaboration and a social network theory perspective to elaborate on those themes less present in the available literature. Open questions are used to ask participants about how collaborations are set up, who they collaborate with and why, and challenges they experience regarding collaboration. After this discussion on collaboration, participants are presented with a social network model that offers two states of the neuroscience field including clinical- and fundamental researchers. One model has few bridging people limiting the connections between the clinical and fundamental cluster and the other has many bridges connecting the two (see protocol in appendix). Participants are asked which they believe is the more accurate model, what they believe the effect will be of increasing or decreasing these bridging connections, and about their potential role in a transition from one to the other.

The interview wraps up with two closed questions regarding their view on how translation should be done, and at which system levels: individual, collaborative, or systemic, they believe there is the most to gain. Before the end participants are asked if there was anything they would still like to mention.

3.5 Data management and ethical considerations

Because human subjects are part of the research, the TU Delft requires a data management plan, informed consent form, and a risk assessment and mitigation plan. These documents can be found in the appendix. Some important aspects of these considerations for data

interpretation are the absence of any research data that could be tracked back to an individual. All interview transcripts were anonymized and destroyed after completion of the project. All data presented in this thesis is aggregated, when quotes are used, only the type of research performed is linked to the quote. Additionally, explicit consent was given through the informed consent form (available in the appendix).

3.6 Data analysis

While the intention was to compare clinical- and fundamental researchers, it became apparent that a third group, the translational researcher, should be considered separately. Interview questions where participants are asked to rank or score bottlenecks or statements are analysed through quantitative methods, calculating means and variation among participant groups. No statistical analysis regarding significance is performed however, given the small number of participants per group and the focus on qualitative results.

Atlas.ti was used for iterative coding of the transcripts, with a round of broad inductive coding followed by line-by-line coding. An attempt was made to assign every line given by the participants a code to ensure the entire transcript was properly considered. This further ensured that previous biases did not skew the focus of the coding process. Because the goal of this project was to analyse and describe translation from perspectives rarely discussed in the available literature, including collaboration, social network theory, and in the context of neuroscience, codes were not formulated before analysis to allow for novel insights based on these perspectives. Inductive coding was used as a means to decrease bias, either informed from personal expectations or previous literature based in different contexts. However, when common themes or concepts from the literature were encountered, care was taken to be consistent in the naming of these codes.

The iterative strategy allowed to define codes as they start to show up more often and then go back to make sure mentions of these codes in already coded transcripts were also caught. Codes were specific and when relating to the same concepts were collected in broad categories including bottlenecks, drivers, or reasons for collaboration. Bottlenecks and drivers were further subdivided into groups tied to common themes that were found throughout the different interviews. A table with the complete coding tree exported from Atlas.ti can be found in the appendix.

For the design process, I focussed on bottlenecks that were relevant to the communication field. This focus is both because of its relation to my own expertise, as well as the fact that it fills a gap in the literature. Bottlenecks not part of the literature review, and thus not part of the ranking question, were assessed on importance based on the frequency of their

occurrence across different transcripts. Themes that occurred more frequently were considered more important to more people than themes that only occurred once.

4 Results

4.1 Participants

A total of six participants were included in the final analysis. Two of the participants focus exclusively on fundamental research, three have a heavy focus on translation within their fundamental research, and one is a clinical researcher currently collaborating with fundamental researchers (Table 1). All participants have finished their PhD and have varying years of experience within Neuroscience, ranging from 7 to 26 years. While every participant does research related to the neuroscience field, their research focus differed quite a lot, from fundamental question related to motor control and behaviour, to immunology and its relation to autism, or population neuroscience using imaging data to answer both fundamental and translational questions.

Table 1 Table with participants and their backgrounds

Participant	Background
Participant 3	Translational
Participant 4	Translational
Participant 5	Fundamental
Participant 6	Fundamental
Participant 7	Clinical
Participant 8	Translational

4.2 Ranking data

To give some context to the views expressed by the participants, they were asked how important they believed translation to be in general, and in their own work specifically. All participants agreed that translation is important to the neuroscience field, with them ranking the importance with a 4.6 out of five on average, and no one ranking it lower than a four (Figure 5). However, within their own work, the importance of translation scored lower, with a 3.6 out of five (Figure 5). To the question of what the potential benefits of a shift towards more connectivity between fundamental- and clinical researchers would be, participants unanimously answered that they believed such a shift would increase translational activity in the neuroscience field. This believe is in line with the social network perspective based on the work by Kim et al. (2017) described above. Additionally, all participants were motivated to contribute to such a shift (4.6 out of five) (Figure 5).

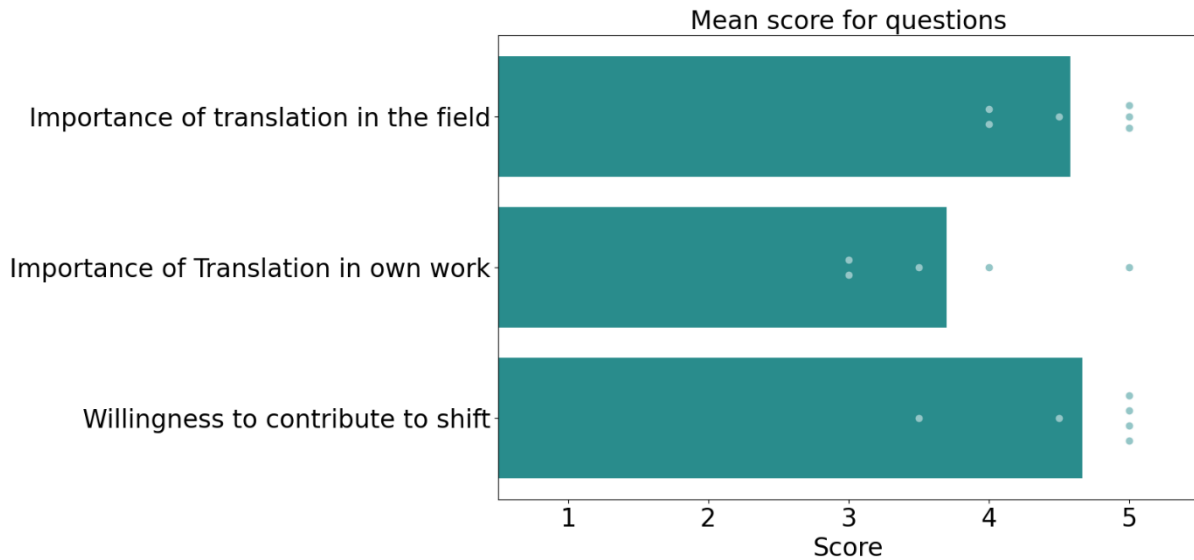


Figure 5 Distribution of answers to the ranking questions relating to the importance of translation in the field, in their own work, and the willingness participants had to contribute in a shift towards more connectivity between clinical and fundamental researchers. All ranking questions were scored on a scale from 1 to 5.

To address the second research question, participants were asked to rank the bottlenecks found in the literature from the ones with the most severe impact on translation to the one with the least impact on translation. The information transfer between fundamental and clinical researchers was ranked highest, followed by a lack of funding and awareness of researchers (Figure 6). It should be noted that the inherent challenges of translation, difficulty finding the right collaborators, and lack of institutional awareness did not score much lower. Bottlenecks relating to the literature discussed by Oliveira et al. (2021) and Spallek et al. (2010) do not rank highly in this sample, contrary to the inherent challenges from the neuroscience field discussed by Azkona and Sanchez-Pernaute (2022) and Markram (2013). It is worth noting that bottlenecks relating to collaboration and information transfer between researchers scored high, despite how little these topics were discussed in literature in the context of translational science (Fudge et al., 2016).

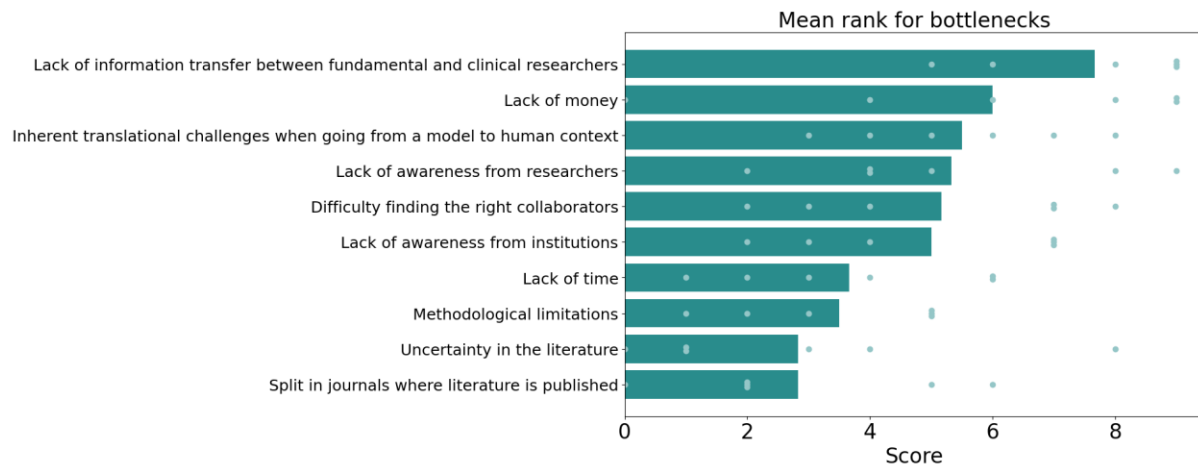


Figure 6 Mean ranking of bottleneck importance with individual ranks given by participants displayed as dots. Scores were calculated using the total number of bottlenecks (10) – rank, with the highest rank being one.

4.3 Qualitative findings

Iterative coding of the interview transcripts revealed reoccurring themes in the bottlenecks mentioned. Some themes were more common than others, yet regardless of the type of research performed by the participants, fundamental, translational, or clinical, themes occurred with similar frequencies (Figure 7).

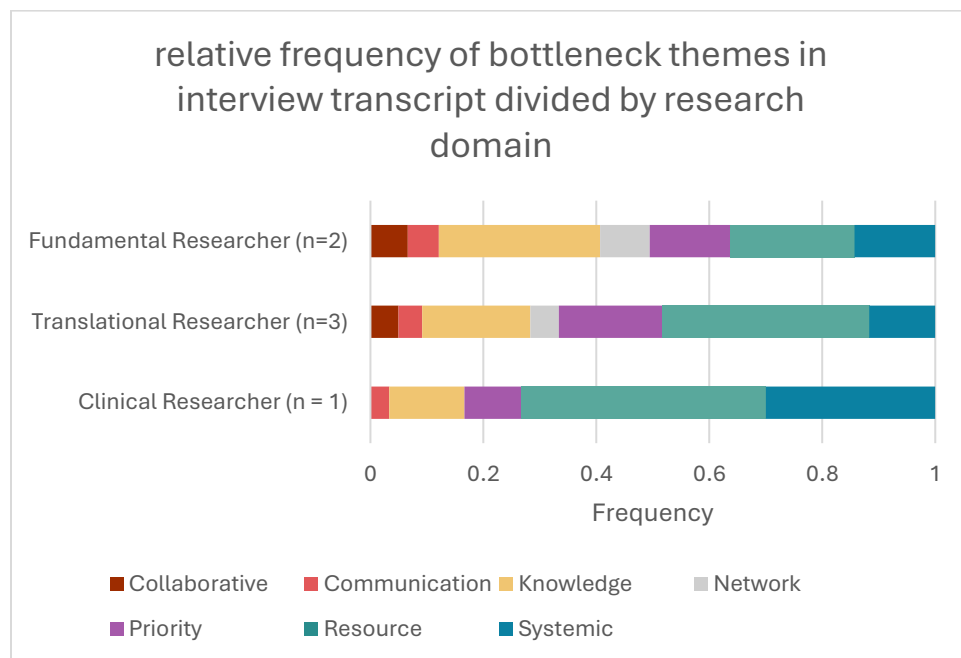


Figure 7 The relative frequency a particular bottleneck theme occurred in the transcripts relative to all times bottlenecks were mentioned, divided by research domain.

Participants explain that while a description of translational opportunities is often required in the proposal during grant applications, separate resources to act upon these opportunities are not awarded. As put by participant 8 while elaborating on why the lack of money is in their top three most significant bottlenecks: *“if I budget for [translational work] in one of my grants, then I have to sacrifice my actual scientific time for it and that shouldn't always be the case.”* As they explain, because fundamental researchers are mostly awarded grants based on their fundamental work, priority is put on this part of the research. This creates a situation where translation is often considered *“the cherry on top, but never the cake”*, according to participant 4 while describing the factors that limit translational collaborations.

Participants of all backgrounds recognise that clinicians are allotted limited time to do scientific research, enforcing a similar priority to the work that directly benefits their research focus. When asked what would allow clinicians to be a part of a shift towards more translational activity the clinical participant (participant 7) responded: *“Give me more time for research”*. This suggests that, like was observed in the 90s by Goldstein JI Fau - Brown and Brown (1997), clinical researchers still do not have the time to focus on fundamental research. The specific argument from Goldstein JI Fau - Brown and Brown (1997) regarding the fast development of the field as a cause was not put forward by any participant.

Collaboration is often a means to an end

“If you find something that you yourself cannot solve, then you decide, OK, I'm going to find someone else and that can evolve into a big collaboration.” Participant 3

Participants describe an inherent link between several bottlenecks and collaboration. A lack of a resource such as time, knowledge, data, or expertise is frequently mentioned by participants as a reason for collaboration. When asked when participants start looking for people to collaborate with, there are two specific timepoints mentioned. Either, at the start of a project's conception, or at the point where a group runs into a problem. Based on the participants descriptions, it seems these collaborations can indeed resolve a lack of time, expertise, or data, but more often take the form of cooperations in contrast to “true” collaboration. As described by Frey, Lohmeier, Lee, and Tollefson (2006), many models of collaboration suggest a range where in more cooperative projects, decisions are made independently and information is provided to each other, whereas collaborative projects rely on shared decision making and sharing of primary resources.

It seems that in some cases, a limited collaboration may greatly increase the translational potential of a project, for example when it comes to accessing patient data. Participants describe how collaboration partners are often one of the few ways you may be able to access

patient data, which can be crucial for effective translational research. According to participants, patient data is often difficult to find and access, stored in badly maintained repositories, and come with a large number of legislative barriers. As participant 3 put it when asked to elaborate on the lack of access to patient data: *“sometimes the patient data is there, but it's very difficult to access. I've been contacting different repositories of patient data, and I couldn't even get a reply to my e-mail. I don't even know if the repositories are still active”*. While patient data is not often mentioned in the discussion surrounding translational research found in the literature, it is not a unique problem to the field in Neuroscience and already a topic of discussion in the context of genetic studies (Amorim, Silva, Maia, & de Freitas, 2020; Bonomi, Huang, & Ohno-Machado; Lee).

Participants also mention that finding collaborators is a large time investment that has little guarantee to result in anything. They explain that, like with the patient repositories, potential collaborators might not respond or not be willing to invest the time. It is a *“coin toss”*, according to participant 4 when asked how they find researchers that are willing to collaborate, yet it does take considerable time to even reach out to the right people. Additionally, as several participants note, because clinical and fundamental researchers publish in different journals, use different terminology, and have their own networks, finding the right people to reach out to is already challenging in and of itself.

Participants do mention a few options to increase your chances of success. Firstly, making use of personal contacts always gives you an edge. Additionally, when asked on how to overcome these challenges, one participant stresses the importance of balancing your request to what you have to offer. While seemingly obvious, being explicit about the transaction you are offering when reaching out can really help. Participant 8 explains: *“You have to try to make the collaboration as appealing as you can to them, on different levels, and that depends on the group that you're talking to. So, if it's a time thing, make that appealing. If it's a financial thing, make that appealing. Generally, it's about fine tuning the requests that you have for your collaborators to match what you know they have available or find out what it is they would need to do the collaboration.”*

In the end, collaborations that are focused on solving a particular problem loop back to the same issue; people are focused on their own scientific work and have little resources to spend on what is considered “extra”. As participant 5 succinctly worded it when describing the three bottlenecks to translation they are aware of: *“Everybody is focusing on the food on their own plates. basically, collaboration is also a process where you have to share your food and try to get other people's food on your own plate. [...] Everybody says we want to collaborate, but during the collaboration, most people only pay attention to what's already on their plate.”*

Translation as the end

“Of course, in the end you're trying to find out what is wrong in humans and not in mice. I mean, we're not veterinarians, so it's quite important that you try to get something out of it”

Participant 7

Every participant agrees that translation is best done explicitly, with translation as the goal. This does not mean that there is no room for fundamental research, which is important in its own right, just that translation is less effective if it is considered extra and should thus always be explicitly considered, supporting a goal-oriented process view of translation like those found in classic models (Morris et al., 2011; Penn State Clinical and Translational Science Institute; Samanta & Landes, 2021; UMC). Additionally, every participant agreed that if we move towards a social network in which clinical and fundamental researchers are more strongly connected, as depicted in Figure 9, translational activity in the field will rise. They believe that such a shift would improve the quality, impact, and amount of translational research, aligning with the social network perspective from Kim et al. (2017).

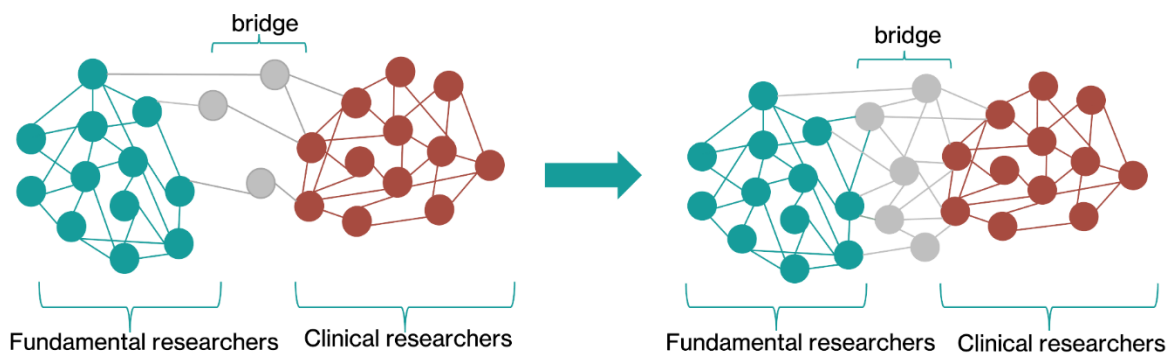


Figure 9 Diagram depicting a shift from a sparsely connected to a strongly connected network

Several suggestions were made by participants for who make up the bridging region. The most often suggested actor for this role were the clinical researchers (Figure 10), as was also suggested in the paper from Goldstein JI Fau - Brown and Brown (1997). In a minority of cases, interdisciplinary or translational researchers were mentioned by participants as natural candidates, echoing predictions made by Kim et al. (2017).

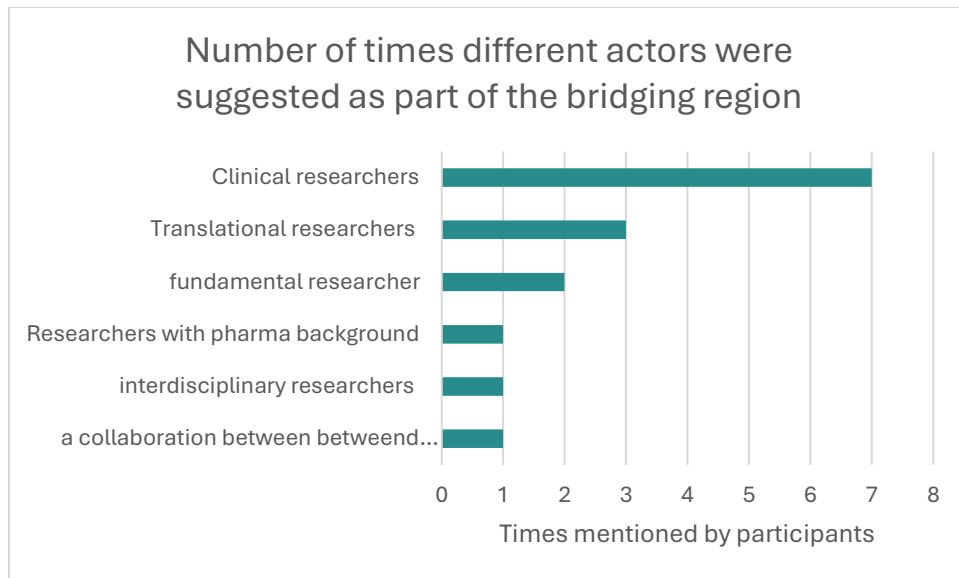


Figure 10 The number of times different actors were suggested to be part of the bridging region by participants

Several participants also mentioned the importance of having balance in the network and people with particular translational research expertise to mediate between fundamental and clinical researchers. When asked what the effects of increasing connections between clinical and fundamental researchers would be, participant 8 introduces this caveat: *“All of those folks have their role and are trying to maximize [their research goals]. [...] This [collaboration] breaks down a little bit when their role becomes unclear and everybody wants their own thing. It can't just be connections, but it has to be this harmonious throughput. Everybody has to have their role, understand and be content with what that role is. If the bridge becomes the driver of it all and brings it together, that's great.”* This may be a good explanation for why, in the paper by Kim et al. (2017), interdisciplinary collaborations do not predict higher translational activity, but translational homophily does. It could be argued that translational research requires a certain perspective and expertise to be done properly, offered by the people from this bridging region.

Big collaborative consortia already mirror these networks in the sense that different researchers from contrasting backgrounds work together on shared goals. While one participant (participant 4) made a point that these are still often split in subgoals separated across the participating labs, these types of collaborations do allow for more crosstalk and sharing of resources, following what Frey et al. (2006) call a coalition. These large-scale projects require time, money, and attention, however, and are thus a real investment according to participants familiar with these types of collaborations, yet they do provide novel opportunities for patient involvement and high-quality translational work according to other participants.

These consortia are a good example of institutionally provided platforms that stimulate translation. Participants mention these existing platforms as a potential solution, but projects that go even further are in the works as well. Participant 8 described an ongoing project when asked for potential solutions to overcome certain bottlenecks: *“We now have funding for pure Societal translation work, so talking to stakeholders, discussing things with stakeholders, actually having stakeholders designing experiments for us and embedding that translation right into the work. And it's shaping up to look like a hub. So not like any one study that's running and like having to think about translating those things in that one setting. But actually, like a hub where we have resources available that help us do this for any number of different studies that are going on. So, I think that's something. And there was dedicated money put into this, so that was a huge help, yeah.”*

Another example of such a platform suggested by participants were symposia that invite both clinical and fundamental researchers to share their current challenges, like the rare disease day already organised in the Erasmus MC. Lastly, multiple participants mentioned the idea of having “professional bridgers” or people that can aid in connecting you to people outside of your personal or professional circle.

5 Discussion

5.1 Sample and analysis

Despite the efforts of having a balanced sample containing both clinical and fundamental researchers, only one clinical researcher took part in this study. Where it was easy to find fundamental researchers willing to participate in this project, clinicians were unlikely to respond to emails, even when previously approached by colleagues regarding the project. Participants mentioned similar struggles getting in contact with clinical researchers and my attempts thus served as further evidence to this fact. The lack of clinical researchers does mean that my results are heavily biased towards a more fundamental perspective.

Another way in which the sample is biased regards the fact that the participants are all working at the same research institute. It is possible that the Erasmus MC has some unique characteristics that make the results less generalisable than presented. For one, some institutes, like the UMC in Utrecht, have a translational neuroscience department suggesting a more specialised expertise regarding translation. Other institutes have their own neuroscience innovation office, like in the UMC Amsterdam, who may offer expertise and aid in the translational process. It is difficult to predict how these differences across institutions affect the results presented in this report. However, given that a lot of the research context, like the funding agency policy, the legislation regarding patient data, and the journals in which publications are published are the same, a lot the results are expected to hold true across institutions.

Something that was not predicted was the high variety of translational affinity across fundamental researchers. This further supports the social network model based on the assumptions of homophily and clustered structures, as described by Spier (2017), as an accurate representation of the neuroscience field. This view would suggest that translational researchers form their own smaller cluster that also acts as a bridge between fundamental and clinical research, a sentiment supported by the participants. Furthermore, the suggestion from participants that translational research requires particular expertise explains the observation that interdisciplinary collaborations on their own did not predict increased translational outcomes, but translational affinity did (Kim et al., 2017).

As described in the methodology, care was taken to avoid biasing the interviewees as well as decreasing the potential for bias in the analysis. A large consideration here was to leave open the opportunity for novel insights that were not present in previous research focussing on different themes, a more exclusive linear view of translation, or a different field of medicine. Given the fact that both common and novel bottlenecks were brought up by participants, both before and after the ones from the literature were presented for ranking,

this seemed to have been a success. Additionally, novel themes and connections were made during the coding phase that were not previously predicted or found in the available literature.

5.2 Novel themes and perspectives

One of these novel themes was the difficulty accessing or finding patient data. While not discussed as a barrier to translation in the literature to my knowledge, it has been suggested that platforms that allow the reusing of electronic health records are an enabler for translational research in the biomedical field (Trifan & Oliveira, 2019). The social, legal, and ethical challenges that come with easy access of patient data is already a field of study and discussion (Brandizi et al., 2017), as well as the role of intermediary organisations and the use of novel technologies to take on these challenges (Puneeth & Parthasarathy, 2023; Saberi, Mcheick, & Adda, 2025; Zygmuntowski, 2025). Data governance and computer science techniques, and privacy are, however, beyond my expertise and scope of this report.

While collaboration was mentioned as a barrier in previous literature, it got relatively little attention (Fudge et al., 2016). Participants in this project suggested the need for collaboration as a means to acquire expertise, resources, access to data, and translational outcomes, but research into the benefits of collaboration for translational ends suggests not all of the expected benefits are realised in practice (Harris, Provan Kg Fau - Johnson, Johnson Kj Fau - Leischow, & Leischow, 2012). In their study, Harris et al. (2012) studied the benefits and drawbacks of inter-organisational collaborations in cancer research and concluded that researchers indeed experienced improved knowledge transfer as a result of collaborations, but not the increased acquisition of additional resources or the faster development of new tools and methods. The researchers suggest that more intense, long-term collaborations are needed to realise these outcomes. Highlighting that perhaps the approach to collaboration, as described by Frey et al. (2006), are an important factor to the outcomes realised.

An aspect that is, to my knowledge, not discussed in any of the previous literature regards the differences between research goals in fundamental and clinical research and the varying priorities. It is clear that reaching out to clinical researchers takes a lot of time, both from my own attempts as well as those from fundamental researchers. Based on speculation and experience from fundamental researchers, and limited feedback from a clinician, this is partially due to the limited time clinical researchers have to do research. Similarly, fundamental researchers don't get extra resources to perform "extra" translational work. This causes both parties to heavily prioritize research that benefits their research goals. A different party that can mediate, give expertise, and help find collaborative partners may be able to reduce some of the time and resources researchers are required to spend on setting up translational collaborations and enable translational activity throughout the field.

6 Conclusion

The literature review addressing the first sub question revealed a broad variety of bottlenecks. Some common ones mentioned relate to the availability of resources, differences or uncertainties in the literature, or institutional awareness. A different perspective taking the social network model as a base considers bottlenecks that have to do with the flow of information, the ease by which you find collaboration partners, and the presence of bridging people that connect different disciplines.

Common bottlenecks found in the literature regarding translation are also relevant in the neuroscience field. Especially bottlenecks related to information flow, resource availability, and collaboration play an important role and are perceived as impactful to the translational activity by participants. Some unique aspects were also part of the discussion with participants, including education of researchers, access to patient data, and the differences in priority. These aspects were not found in the literature review, but are relevant in the field of neuroscience, and perhaps other fields of medicine.

Furthermore, bottlenecks are intrinsically linked to each other, expertise and knowledge are both considered resources, collaborations are often a means to fill in resources that are lacking, and translational collaborations require particular expertise not always present in every interdisciplinary collaboration. It is clear that both bottlenecks originating from the more linear view of translational research, as well as those based on social network theory are relevant in the neuroscience context and not necessarily separable. Adapting the structure of the field through the way people are connected to each other influences bottlenecks relating to resources and expertise.

It seems clear that according to people in the field, a shift to a strongly connected network of fundamental and clinical researcher will result in an increase of translational activity. Increasing the bridging region thus seems like an effective strategy for optimizing this process. Increasing the size of this region could be achieved by increasing the education given to fundamental researchers regarding effective translational research, as well as give clinical researchers more time for scientific research. Yet, such a large systemic shift occurs slowly and takes time. However, opportunities to catalyse such a transition do exist. Supplementing the bridging region with professional actors that aid in the process of finding collaborators, increasing crosstalk between clinicians and fundamental researchers, and hold expertise on how to effectively do translational research would both catalyse this transition and increase translational activity on the short term.

Chapter 2 - Design

7 Design questions

Based on the results of chapter 1, the idea of an organisational body with a formal role regarding translation emerged. This “translational hub” would act as a centre of expertise for people with questions regarding translation, improve connections between the fundamental and clinical research fields, and act as a catalyst for translational activity. These three roles: knowledge brokering, network managing, and system transforming, can also be found in literature on organisations called “intermediaries” (Howells, 2006; Kivimaa, Boon, Hyysalo, & Klerkx, 2019; Provan & Kenis, 2008). In this next chapter I will explore these three concepts and how they impact strategic choices considering the role and structure of this translational hub.

There exists a large variety of these intermediary organisations within the Netherlands alone. In this next chapter of the report, a variety of organisations will be introduced, each with their own box describing the organisation, what they do, and how they operate. These intermediaries are characterized differently depending on the paper discussing them or context they operate in where researchers often focus on one of the three roles mentioned above. This naturally leads to the following design question:

DQ: Which roles and characteristics does an intermediary organisation require to have the greatest impact in the optimization of fundamental-to-clinical research translation?

To answer this question, the rest of the report will have the following structure. First, the variety of characteristics and roles intermediary organisations can have is explored in a literature review on intermediaries, concluding with a proposed model that captures all three roles and effectively describes a variety of intermediaries. Based on this developed model, a methodology was designed to both validate this model and explore the trade-offs of these different characteristics based on the experience of people active in a selection of different intermediary organisations. This concludes the development portion of the design phase and brings us to the delivery portion (Figure 11). The results of the interviews are presented, discussed, and integrated into a new iteration of the model. Finally, the delivery concludes with a proposal for some key characteristics for the translational hub and future work is discussed.

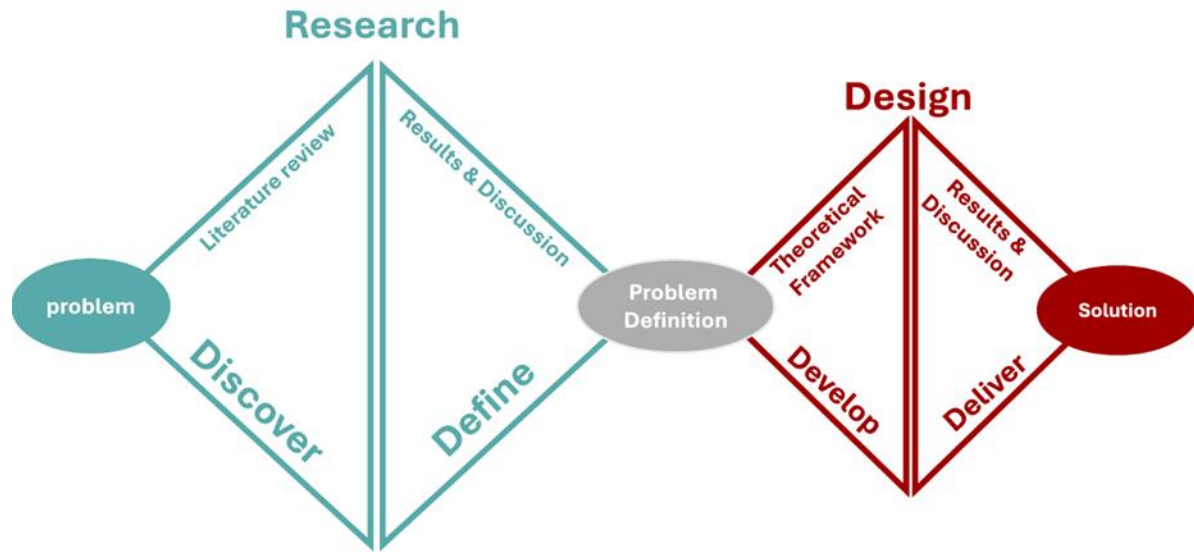


Figure 11 A visual representation of the double diamond model from the British design council (British Design Council, 2005), and how the sections of this report relate to each sub section. The first portion of the research phase includes the literature study and design of the methodology, described in the theoretical framework and methodology sections respectively. This phase ends in a problem definition, described in the conclusions. This problem definition is the start of a new literature search, described in its own theoretical framework, with the aim of developing a model used to design and deliver a proposal for a solution.

8 Theoretical framework

8.1 Literature review on intermediary organisations

8.1.1 Knowledge broker or guide

This results discussed in the research phase of this project seemed to follow in a tradition in making “novel” conclusions regarding the role of “bridgers”, that could already be found in literature from slightly different, but related fields (Howells, 2006). Howells (2006) notes that there is a surprising lack of cross referencing in literature about the role of, what he calls, intermediaries in the innovation process and suggests this is holding the research field back.

Intermediaries are meant to solve similar problems in their field. The role intermediaries have, according to, Howells (2006), is to be a collector, maintainer, adaptor, and distributor of knowledge. In essence you could argue that in writing his review, Howell is acting as an intermediary between disparate fields, bringing their knowledge together, adapting it into a single piece of writing, and distributing it again. Such an agent collecting, maintaining, adapting, and distributing knowledge was referred to as a knowledge broker by Hargadon (1998). A good example of such an organisation in the Netherlands is the Dienst Analyse en Onderzoek (DAO), an organisation embedded within the house of representatives who describe their work as “question-based structuring, maintaining, interpreting, presenting of, and counselling about, information.” (Tweede Kamer)

A different relationship to knowledge is that of a guide to knowledge instead of a holder of knowledge. It is not uncommon for companies or organisations to have helpdesks that aid you in finding information rather than explain or teach you something. Like a librarian that guides you to the right books but does not answer your specific questions. This distinction between a knowledge broker and such a “knowledge guide” or “knowledge navigator” is, to my knowledge, not found in any of the literature surrounding intermediaries. However, a similar distinction is made by Pielke (2007) in the context of policy and politics. In his book, Pielke describes four roles one can take on when giving policy advice: the pure scientist, the science arbiter, the issue advocate, and the honest broker. In his example, illustrating the key differences between each role, Pielke (2007) describes how each of these roles would

Dienst Analyse en Onderzoek (DAO)

The DAO is an organisation tasked with supporting the members of parlement with factual information during the law-making process. They are embedded within parlement, operate on a question-based system, and offer whatever background information members of parlement require to make well informed decisions on policy. They produce factsheets, answer questions, and organise events for members of parlement and their staff.

handle advising on picking a restaurant where to eat. The pure scientist offers a source on dietary science, the science arbiter answers any question factually, the issue advocate attempts to convince you of a particular choice, and the honest broker gives you a short description of every restaurant with the information you need to make a decision. These roles are ideals, however, and reality is often more nuanced (Pielke, 2007).

While Pielke (2007) categorizes these roles in a matrix based on political and scientific views, his point regarding engagement is a more interesting categorisation in this translational context. He describes that what differentiates the honest broker and issue advocate is that both actively engage with decision-making, whereas the pure scientist and science arbiter exclusively function as a source of knowledge. The other axis regards whether they seek to reduce decision options, in case of the issue advocate, or expand and clarify decisions, like the honest broker. While not made explicit, I would argue a similar distinction exists between the pure scientist and the science arbiter, where the pure scientist clarifies and expands choices by offering primary sources, and the science arbiter reduces choices through their answer on specific factual questions. The key difference being that in the case the science arbiter and pure scientist it is the “client” asking the questions deciding how to expand or narrow down the choices.

The DAO, according to Pielke (2007), would generally fit the role of the science arbiter with the key being their question-based structure and role in narrowing down choices. The librarian mentioned before would have the role of the pure scientist, pointing you to the right primary source, and a consultancy firm in the field of policy that of an honest broker, working out several scenarios for different options.

8.1.2 Maintaining or being a network

Where Howells (2006) describes the role of intermediaries primarily as knowledge brokers, he does mention that the traditional one-to-one relationships intermediaries used to hold is increasingly getting more complex and less one-to-one. In the review by Klerkx and Leeuwis (2009) three functions of the intermediary are considered: articulating demands, network formation, and innovation process management. The first relates to the knowledge broker’s role, generating and maintaining knowledge of the challenges in the field is part of being able

Het NEWS

Het NEWS is a national expertise centre tasked with improving the connection between science and society using better science communication. Het NEWS operates as an independent organisation that connects science communicators, science communication researchers, and policy makers. They consult people with question regarding science communication, connect people that may be able to help each other, and aim to improve the ways science and society interact.

to articulate demands. The second role, network formation, can be interpreted in our context as facilitating connections between fundamental and clinical researchers and increasing collaboration between the two.

This role in maintaining a network can be discussed from the perspective of network governance. Network governance exists on a continuum from very decentralized to very centralized and regards the structure through which a network is maintained (Provan & Kenis, 2008). Provan and Kenis (2008) describe three network governance approaches. In the first, every member of the network is an equal participant in the governance of said network. The second approach is embedding the governance responsibility within an existing organisation in the network, similarly to how the DAO is embedded within parlement. Lastly is an approach where an independent external organisation is responsible for network governance. Het NEWS, the Dutch national expertise centre for science and society, would be an example of the latter, whereas scicom NL, the association for people who do science communication in the Netherlands, more closely resembles the decentralized, equal participant approach.

Provan and Kenis (2008) suggest that there are four aspects that determine the ideal level of network governance centralisation: trust, number of participants, goal consensus, and need for network level competencies. In short, more centralisation is ideal when there is little trust across individuals in the network, there is a larger number of participants, there is little consensus on the goal, and a high need of network level competences. Based on the interviews from chapter 1, there is consensus on the goal and participants could be limited to those within an institution, suggesting a more equal participant model of network governance. On the other hand, if the goal is to realise a larger shift in the state of the network across institutions, potential participants increase and network level competences become important, suggesting a centralised network governance approach.

Within a very different context, that of political activism and union organisation, different approaches to network management are actually discussed as strategies for enacting systemic change. According to McAlevey (2016), unions have made a strategic shift away from organising towards mobilising and advocacy. The key difference between these three approaches is the inclusion of “normal people”. When advocating for a group, the group is not involved in the fight but represented by an institution, the union. Meanwhile, mobilisation

SciCom NL

SciCom NL is a network that is aimed at bringing science communicators together enabling the sharing of knowledge, expertise, and experience. They are an association made up of science communicators run by active members who organise events. Events include meetups, lunch lectures, and social events that allow participants to make new connections and exchange knowledge.

is about getting a large group of people at a protest or event, but often these are a select in-group and not the vast majority of the people involved in a particular system. Lastly, organising is a strategy where the involvement of the large majority is the explicit goal, especially those who still have little interest in becoming active for a cause. These three strategies, as described by (McAlevey, 2016), mirror the approaches to network governance discussed above. Advocacy is the external centralised approach, mobilizing the internal centralised, and organising is about decentralisation and equal participation. Organisations, like the Rotterdam student union STUUR, who have adopted the organisation strategy would thus be an example of the decentralised equal participant type of organisation.

8.1.3 An agent of systemic transition

The third aspect based on the results of the interviews is the idea that we need a system transition to truly optimize the translational activity in the neuroscience field. This matches the third role of the intermediary described in the review by Klerkx and Leeuwis (2009). In a more recent work, an organisation that focusses on these transitional processes is called a transition intermediary (Kivimaa et al., 2019). These transition intermediaries are characterised by the level on which they operate, either systemic, institutional, niche, process, or user.

For our purposes of translational neuroscience, two of these levels are potentially relevant. The first is the regime-based intermediary, which often results from institutional arrangements and carries a mandate to promote a particular transition. Secondly the systemic intermediary operates on all levels simultaneously to work towards a specific transitional goal that manifests on the systemic level. The point where these two types of intermediaries differ most is their origin and independence. Whereas systemic intermediaries are often established as an independent neutral party, the regime-based intermediary is usually embedded within an existing actor or created by an existing actor and considered to be a player in the system. Additionally, the systemic actor has more room to work on ambitious large systemic changes whereas the regime-based intermediary is somewhat constrained by the fact that it is embedded within an existing actor. This characterisation by Kivimaa et al. (2019) thus suggests a relationship between the network

STUUR

STUUR is the Rotterdam student union and aims at changing local systems in a way that benefits students. Before, using an advocacy and mobilizing approach, they mainly focussed on being a bridge between students and policymakers, bringing the issues students faced to those with power to change them. Now, STUUR is adapting an organising approach instead, acting as a structure within which members are educated about what they can do to enact change together. STUUR organises training sessions, social events, and protests to bring students together and build political power.

governance approach discussed before, and the reach and the types of systemic changes an intermediary may enact.

Two organizations in a similar context that illustrate this difference well is, once again, Het NEWS, and Parlement & Wetenschap (P&W). In this model, Het NEWS, as an independent agent created with the purpose of promoting a systemic transition, is a systemic intermediary. This organisation is not tied to any existing actors and has the freedom to promote large ambitious changes through interacting with different levels of the system. Contrary to Het NEWS, P&W is an organisation created by scientific organisations including the NWO, and the KNWI, and the Dutch government. P&W is financed by this covenant of scientific NGOs, was created to work within a particular scope, and is “only” tasked with improving the way science is incorporated into parliamentary processes (Parlement & Wetenschap, 2024). Where Het NEWS is tasked with promoting large system level transitions, P&W is focussed on optimizing particular structures within our political decision-making system.

An overview of all of the organisations mentioned above is displayed in Table 2.

Table 2 Table presenting the mentioned organisations and their respective centralisation, whether they are embedded within an existing institution, their primary role, the scope of change they try to enact, and their size in members or fte. Some attributes, like primary role and engagement in decision making, are assumed based on descriptions given by the organisations online. Whether this description holds true in practise is not considered at this time.

Organisation	Primary role	Engaged in decision making	Governance	Embedded	Scope of change	Size
DAO	Knowledge broker	No	Centralised	Yes	institution	Medium (50-200 fte)
Het NEWS	Equal spread	Yes	Centralised	No	System	Small (5-6 fte)
P&W	Network manager	No	Decentralised	No	institution	Small (1 fte)
SciCom NL	Network manager	No	Decentralised	No	field	Large (>1000 members)
STUUR	Changing systems	Yes	Decentralised	No	system	Small (~50 active members)

Parlement & Wetenschap (P&W)

P&W is an organisation tasked with improving the ways science is incorporated into the parliamentary process. They connect scientists to parlement based on the topics discussed and the expertise required acting as a liaison between parlement and science. P&W organises symposia, invites scientists to perform scientific assessments of proposed laws, and create lists of experts for relevant topics.

8.2 Proposal for a model integrating three roles

8.2.1 General characteristics of intermediaries

Based on the literature discussed so far, an intermediary organisation can be described as having three potential roles: knowledge broker, network manager, and system transitioner. Whether there is a trade-off between these roles is unclear, does a more system transition approach have a negative impact on whether you are effective at building and sharing connections? Can you both be effective at collecting and maintaining expertise and at pushing for systemic changes? While the literature often focusses on one of these three aspects when describing the role of an intermediary, it is clear that in practise these intermediary organisations usually play more than one of these roles (A. Verkade, 2023; Parlement & Wetenschap, 2024; systems transformation hub, 2025; Tweede Kamer). Therefore, I would like to suggest a model integrating these three roles into five characteristics (Figure 12):

- knowledge aggregation: the degree to which an intermediary collects, maintains, adapts, and distributes information
- Centralisation: the degree to which an intermediary has centralised governance
- Engagement: the degree to which an intermediary engages with the network and is an active participant in knowledge creation and network building
- Autonomy: the degree to which an intermediary operates autonomously from the network
- Reach: the degree to which an intermediary affects change at different levels of the system

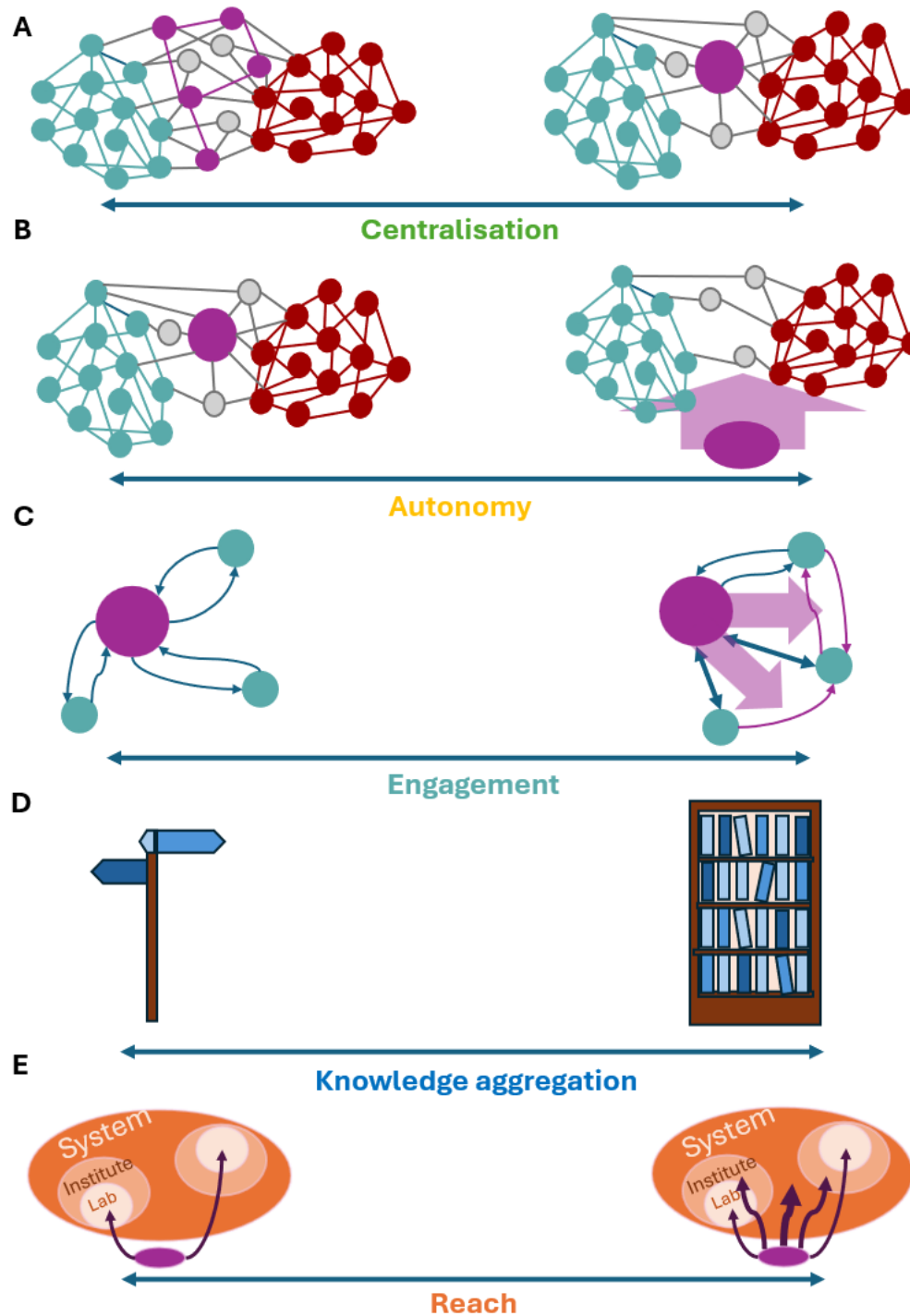


Figure 12 A schematic describing the proposed five characteristics of an intermediary organisation visually. A) Centralisation describes the governance of the intermediary organisation and whether this is distributed across the network or centralised within one separate node. B) Autonomy describes the extent to which the organisations are embedded within the network or influences the network from outside. C) Engagement measures the extent to which the intermediary organisation is an active participant in the network and takes an active role in decision making and knowledge creation. D) Knowledge aggregation describes whether the intermediary organisation points towards knowledge or holds and maintains knowledge themselves. E) Reach describes the degree to which different levels of the system can be accessed by the intermediary organisation

8.2.2 Relationships between characteristics

These five characteristics are not fully independent from each other. Autonomy and reach are characteristics based on the discussion of the paper by Kivimaa et al. (2019) regarding the trade-off between independence and the mandate to enact systemic change. Like independence and mandate, autonomy and reach have a relationship where the reach can only increase given enough autonomy (Figure 13). If your organization is strongly embedded within a particular department, low autonomy, your reach is unlikely to extend beyond the department, let alone other institutions. However, a fully autonomous organisation existing beyond the institute can still opt to only operate at the departmental level, organising training sessions or events for departments, interacting little with the system in which they exist.

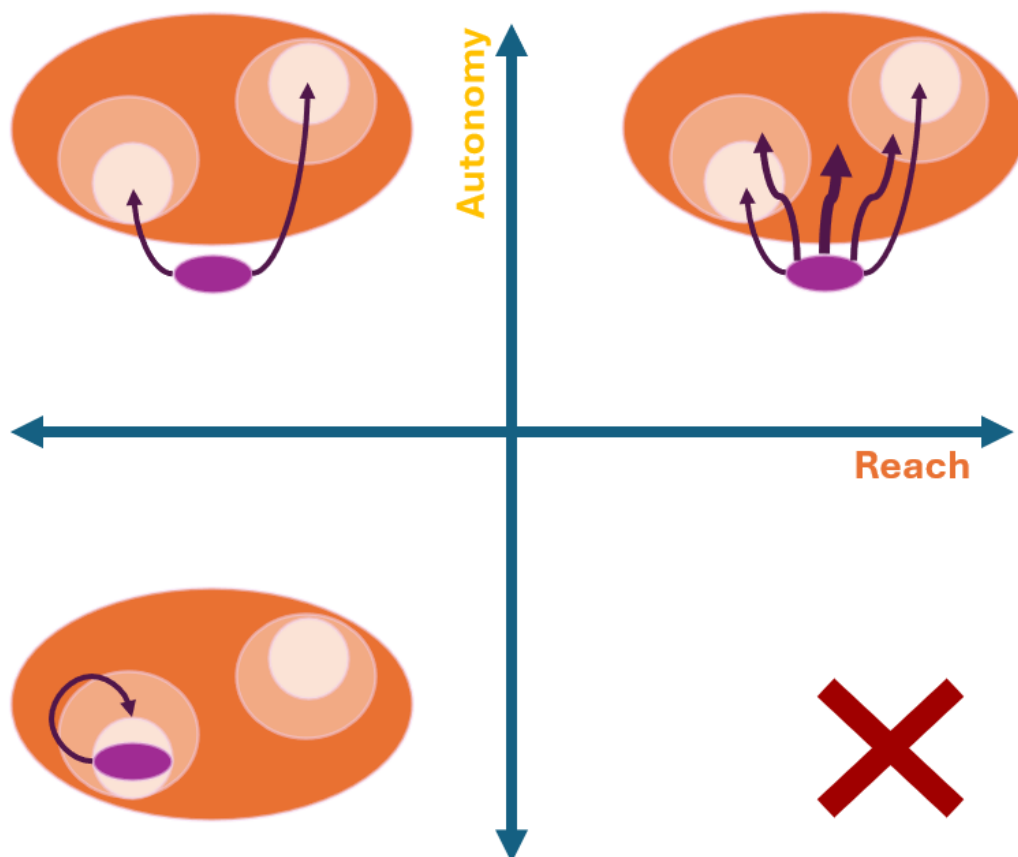


Figure 13 A visualisation of the relationship between autonomy and reach. While a highly autonomous organisation can either have high or low reach, an organisation with little autonomy is likely unable to have high reach.

While reach and autonomy are both strongly tied to the system transition role, autonomy also shows up in the discussion regarding network governance. In the paper by Provan and Kenis (2008) two approaches to a centralised network governance are described, either embedded in an existing actor in the network or within an external autonomous organisation. In this case it is the concept of autonomy that depends on another centralisation. Only a

centralised organisation can act autonomously from the network, as it should be self-evident that a distributed network could never operate autonomously.

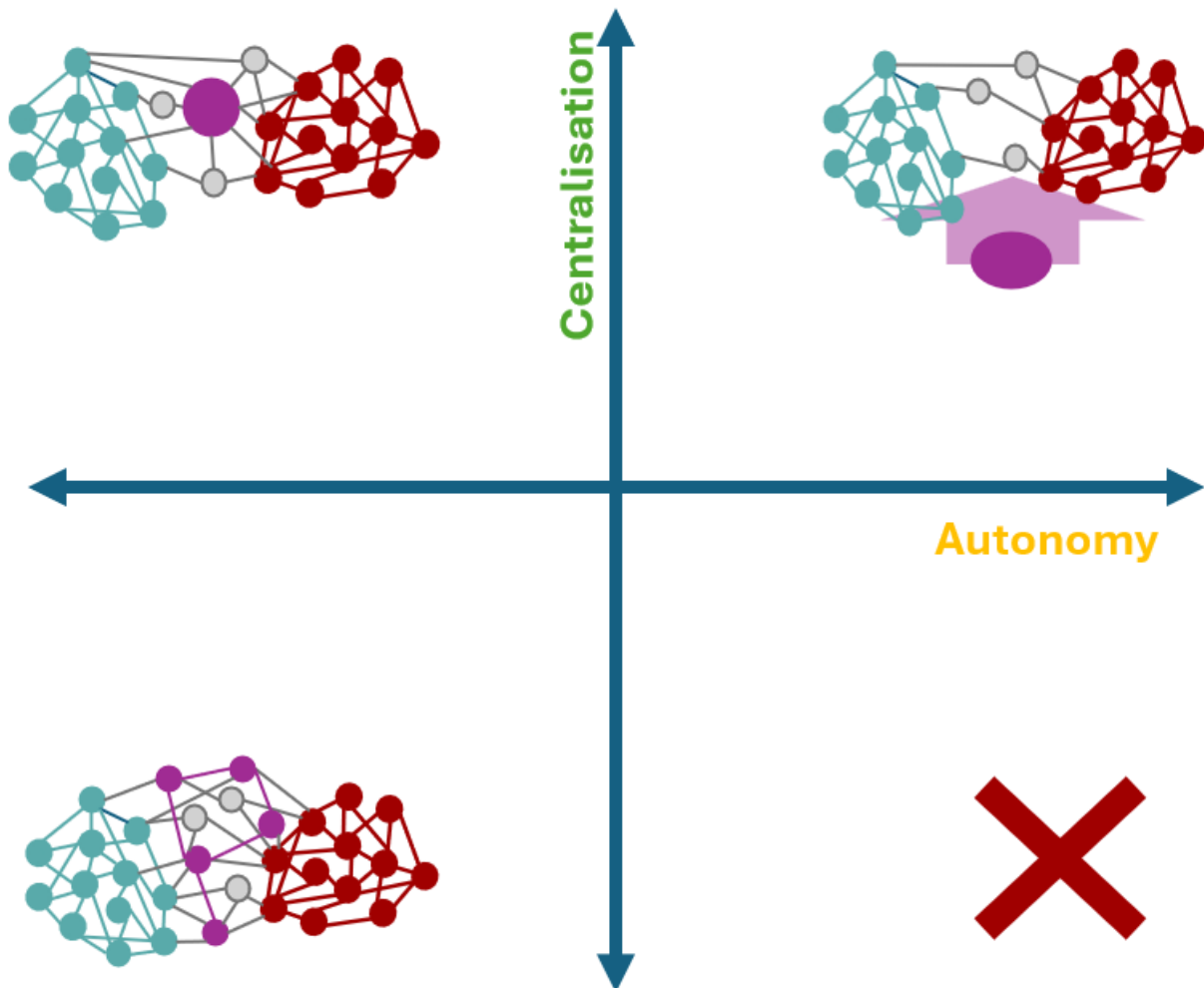


Figure 14 A visualisation of the relationship between autonomy and centralisation. While a centralised organisation can have varying degrees of autonomy, a decentralised network is unable to act autonomously from the network.

A third characteristic that pertains to this network role is engagement. Low engagement would suggest that you deal with people in the network on a one-to-one basis, like a classic consultancy firm (Howells, 2006). High engagement suggests that you are an active participant in the network, introducing people to each other and being a part of collaborative projects lending your expertise in the process of co-creating, which has become more common over time (Howells, 2006).

This last characteristic also brings us to the knowledge broker role. Being an active participant and sharing your expertise in a more collaborative role within the network requires that you have said expertise in house (Figure 15). The knowledge aggregation characteristic thus defines the extent to which an intermediary can have a high engagement.

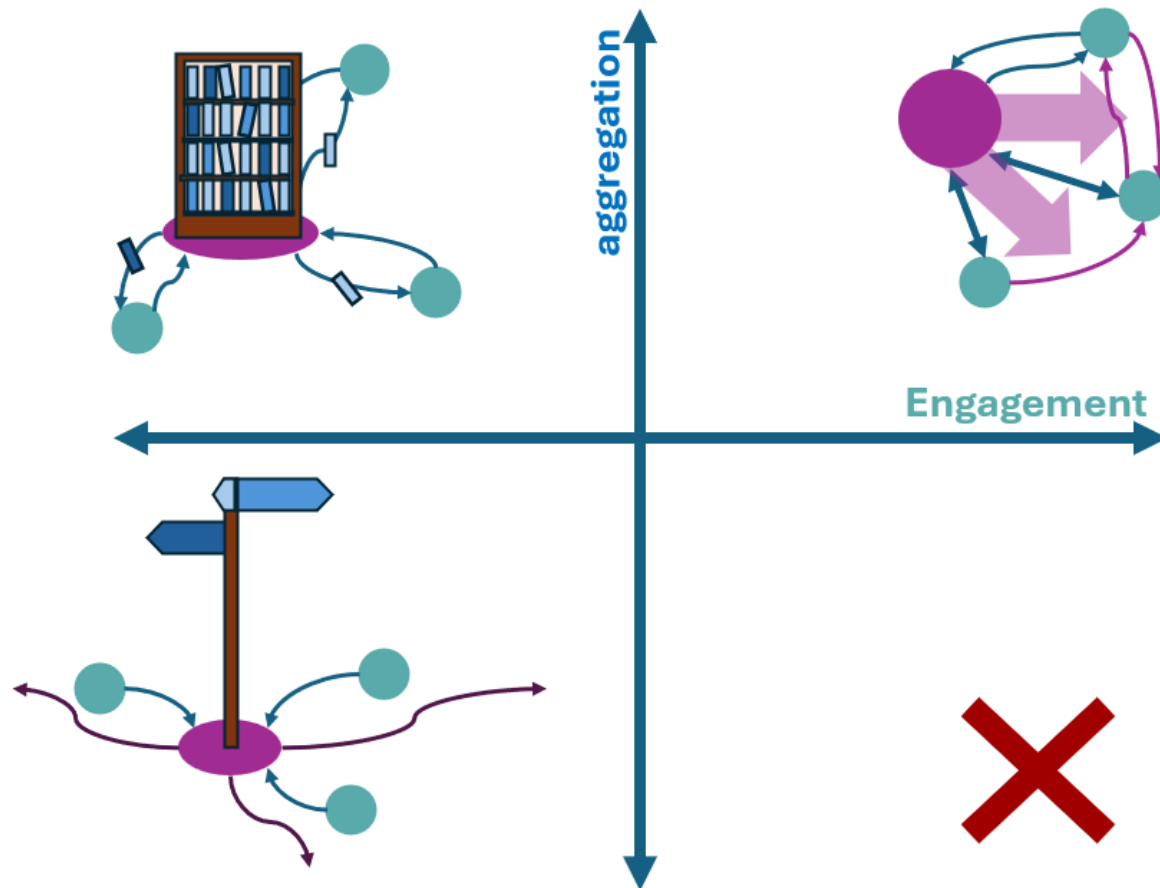


Figure 15 A visualisation of the relationship between engagement and knowledge aggregation. While an organisation that has high knowledge aggregation can have varying degrees of engagement, an organisation with little knowledge aggregation is likely unable to engage as an active participant in knowledge creation and decision making.

8.2.3 The model in practise

A large variety of hypothetical intermediaries can be described based on the model above. To provide some intuition to the model, three potential organisations are presented. These organisations are not based on any specific existing ones but are meant to represent types of organisations most people working in science would be familiar with. Scores are given based on personal familiarity with comparable organisations and not meant as a validated scientific results. This section serves as an example of how the model can be put into practise for some simulated organisations to increase intuitive understanding of these characteristics.

‘The Consultant’ is an organisation that resembles a classic consultancy firm, and would have high levels of knowledge aggregation, autonomy, and centralisation, but lower levels of engagement and reach (Figure 16). Classic consultant firms typically have one-to-one relationships with their clients and hold expertise on a particular subject. They are not

typically embedded within other organisations in the network and are their own, external organisation.

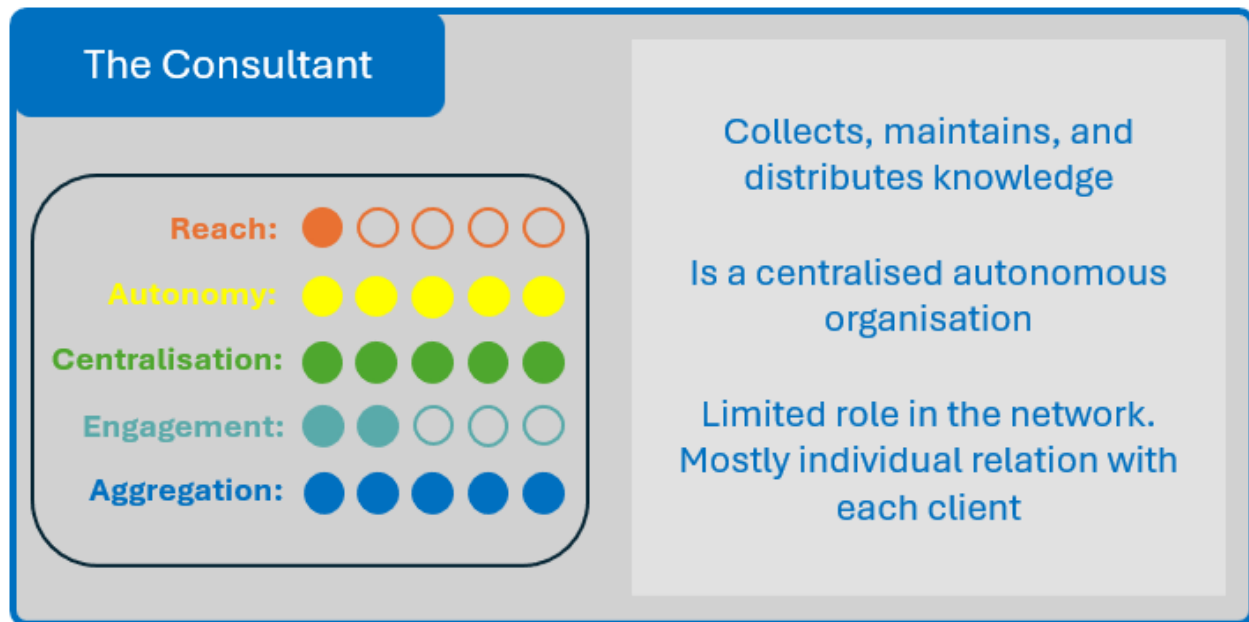


Figure 16 A description of a consultancy firm based on the proposed five characteristics

Another type of intermediary organisation would be based on the decentralised, equal participant type of network. This intermediary referred to here as 'The Network' could be described as having low centralisation, and thus low reach and autonomy, but high engagement. The knowledge aggregation could be either high or low depending on the type of network. They are characterized by their decentralized structure and are mostly meant as a way to connect people to each other.

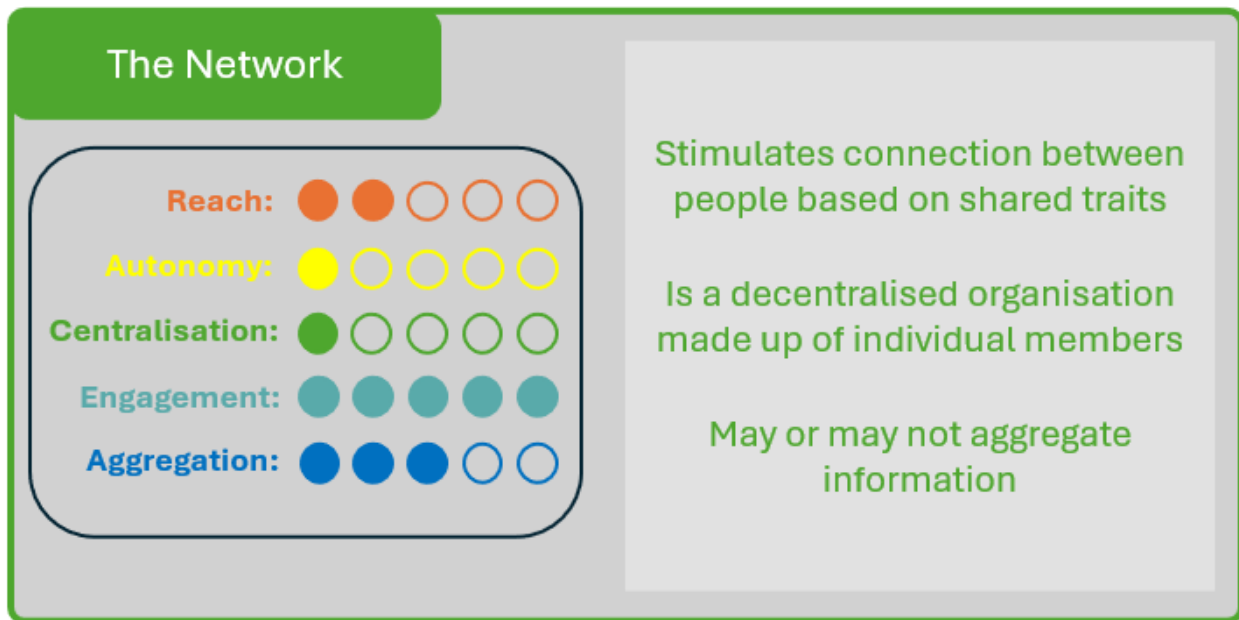


Figure 17 A description of an equal participant network based on the proposed five characteristics

Lastly an example focussed more on the system transition role would be ‘The Overseer’. An organisation with a high mandate to oversee a transition. Such an organization is characterised by high reach, autonomy, and centralisation, but low engagement. Once again, the knowledge aggregation is a free variable that does not define such an organisation very strongly as they may lean more or less on outside expertise depending on the topic.

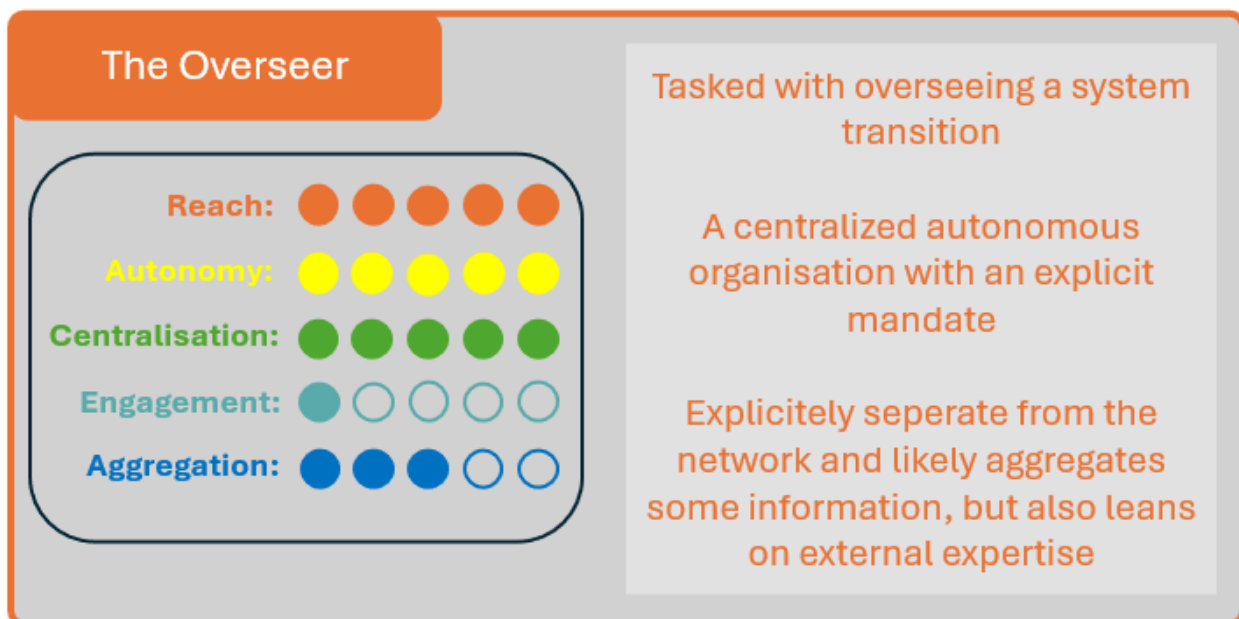


Figure 18 A description on "the overseer" as an intermediary based on the proposed five characteristics

9 Methodology

9.1 Literature review

The literature search was based around the concept of intermediary organisations. Searching for scientific literature on knowledge brokers and intermediaries naturally led to the review by Howells (2006). This review functioned as a starting point from where papers that elaborated on different roles of intermediary organisations were found. Papers that cited Howells (2006) or were cited by him served as useful literature to build up knowledge regarding this field of research. Furthermore, intermediaries exist in many contexts, but for the case of translation, those discussed in the context of innovation and system transitions were assumed to be the most relevant. For this report, however, the three reviews that propose a model (Howells, 2006; Kivimaa et al., 2019; Provan & Kenis, 2008) functioned as the foundation on which the new model was built. This literature was supplemented by familiar literature that offered complementary views or alternative perspectives on concepts discussed in the literature surrounding intermediaries. Additionally, available reports and publicly available resources from intermediaries in the Netherlands were used to contextualize concepts from the literature.

Information on a variety of organisations that played similar roles as the hypothetical translational hub in other fields was collected. Most organisations mentioned in the report were those that were already familiar to me, while others were found when actively searching for “intermediary organisations” online. The ones that were discussed were picked based on how well their own description of themselves matched concepts in the literature. Het NEWS was a particular organisation of interest given the similarity between the way the organisation was described in their founding report, (A. Verkade, 2023), and the way participants described the potential role of an intermediary in the translational research field.

9.2 Interviews

To further develop a first proposal for an intermediary tasked with improving translational activity, experts with experience regarding similar organisations were contacted. Once again, semi structured interviews were held with these experts. However, because the goal of these interviews was not to find common themes in the experience of multiple people from a similar background, but to explicitly compare different contexts to each other, each interview was tailored to the individual. Each interview was broken up in two parts. In the first, the focus was put on particular aspects of their organisation and how specific strategic decisions were made and why. The three roles of intermediary organisations were

addressed, as well as particular characteristics of the organisation in question such as activities it does and does not perform.

In the second part of the interview, questions relate to the five characteristics proposed in the model. The interviews are meant to both create a deeper understanding on how the context of their problem shaped the structure and role of their organisation, as well as validate the proposed model as a good description for a variety of intermediary organisations. The organisations discussed primarily operate in Dutch and available reports were written in Dutch as well, therefore, Contrary to the interviews in the research phase, these interviews were held in Dutch as well to avoid wasting time translating concepts during the interviews. Quotes used in the results were translated to English by me to maintain the consistency within this report.

9.3 Data analysis

Transcripts were coded using new codes and an altered strategy. As the goal was to foster an understanding of the strategic choices and different roles intermediaries can have, a more deductive approach was taken. An emphasis on coding strategic decisions, roles of the organisation, activities it performs, and strategic trade-offs that were considered. Because each organisation is represented by a single participant, two interview reports are presented as well, which can be found in the appendix.

10 Results

To gather a deeper understanding of how different intermediary organisations are structured and make strategic decisions, people with ties to different intermediary organisations were interviewed. Prof. Ionica Smeets: quartermaster, founder, and head of the board of Het NEWS, and Jasper Schut: previous chair of STUUR and responsible for a strategic shift from a focus on advocacy to a focus on organising, were interviewed. This section contains two parts as established in the methodology. First, the relationship of these two organisations to the concepts found in the literature are explored. Next, the participants view on the characteristics as described in the proposed model are presented. A more extensive interview report for both organisations is presented in the appendix.

10.1 Perspectives on the intermediary roles

10.1.1 Knowledge broker

Both Het NEWS and STUUR have a role as knowledge brokers according to Smeets and Schut. Both representatives of these organisations state that they hold knowledge on their respective domains, educate or inform people, and collect and maintain knowledge, following the role of an intermediary as described by (Howells, 2006). Both STUUR and Het NEWS recognize this knowledge broker role, but there is one critical difference in their approaches. Het NEWS explicitly states in their founding report that they do enrich the trainings offered, but are not a training bureau (A. Verkade, 2023). When asked what the difference is, Smeets elaborates *“It has to do with the competition in the field, for example, in Germany there is a national centre for science communication who only does training workshops, because in Germany there was no such thing for science communication. In the Netherlands that is very different. [...] There are quite a lot of places that could give such a training well.”* Smeets explains that while they might design a workshop or training, Het NEWS will not be giving those sessions but instead allow someone else to adopt it instead.

What is Het NEWS?

Het Nationaal Expertise Centrum Wetenschap en samenleving (Het NEWS) is a Dutch organisation that offers expertise regarding science communication. They act as a sort of consultancy bureau for questions and advise on how to share your scientific work with society at large. Their goal, as it is stated on their website, is to increase connectivity between science and society through improved scientific communication. In their founding report, they lay out three strategic lines: expertise, connection, and system (A. Verkade, 2023). These three lines echo almost exactly the three roles of intermediaries discussed above: knowledge brokering, network managing, and system transitioning.

This is in contrast to STUUR where Schut explains how STUUR employs this knowledge broker role: *“We are one of the unions that is pioneering this new theory of change within the student unions and even the Dutch left. [...] So I personally gave a lot of workshops.”* As Schut explains, because there is still relatively little information and experience on organising in the Netherlands, and few places where someone can learn about it, STUUR takes a more active role when it comes to training people and organisations.

10.1.2 Network manager

The network managing role is perhaps the most important part of the strategy for both STUUR and Het NEWS. The mission statement of Het NEWS focusses explicitly on connection: *“The centre improves the connection between science and society through better science communication”* (A. Verkade, 2023), and Schut, when asked about the degree to which STUUR has a network managing role, calls it their *“Their entire function, the whole raison d’être”*. In the case of Het NEWS this role is heavily intertwined with the knowledge broker role. When asked about the degree to which these different roles can be separated Smeets explains *“A natural part of collecting expertise and connecting people is sharing and spreading expertise and using the connections to receive knowledge.”* Meanwhile, in STUUR’s case, it is more tied to the role of the system transitioner. Schut explains that the managing of the network is the strategy by which they aim to change the system, following McAlevey (2016) theory of change. When asked how this role changed when adopting this new strategy, he explained: *“First, the binding of members was a way to survive, I think a way to collect enough money to fund the advocacy. [...] Now it is the whole point, it maybe always was, but the tools and the goals are so heavily intertwined there is no way around it.”*

What is STUUR?

STUUR is the local student union in Rotterdam and, according to its previous chair, one of the front runners in adapting to an organising approach in the Netherlands. While the goal, changing local systems such that it benefits students more, has not changed, the philosophy on how this change occurs has. On their website, STUUR describes what they do as informing, organising, and protesting, with a focus on organising as defined by McAlevey (2016). Jasper Schut, previous chair of STUUR, wrote his master thesis on the shift to an organising strategy within unions and was responsible for introducing this approach in STUUR and other student unions. This change in strategy has changed the way STUUR positions itself towards the network of students and people in power, as well as adopt a new theory of change to enact systemic transitions.

10.1.3 System transitioner

Both organisations build their strategy around a theory of change, a model that is meant to aid in defining how a set of activities will be achieving a particular outcome, in this case a system transition (Belcher B, 2020). For Het NEWS, the goal of this theory of change is not better science communication, but better connectivity between science and society. Smeets explains the difference: *“Why do you do it? Equal chances for people, and reciprocal trust between science and society. It is good to make that clear, because our goal is not necessarily ‘better science communication’. If the connection between science and society is completely fine, well that is what ultimately matters.”* According to Schut, STUUR is involved in two systemic transitions. First, at the local level this new strategy is meant to build power and push for changes at universities and the municipality of Rotterdam that benefits students. At the national level, STUUR pushes for the adoption of this organising model in other (student) unions and activist organisations.

10.2 Perspectives on the model

10.2.1 Knowledge aggregation and engagement

Smeets and Schut recognize the characteristic of aggregating knowledge within their respective organization. Schut does confirm that the type of knowledge that is aggregated has changed with their strategic shift when asked: *“So [STUUR] was indeed also about collecting information from students [...] which is subsequently translated to people in power. [...] Now it is a place to collect and spread knowledge on this new theory of change. To give people who want to enact change the tools to actually do so, giving them knowledge and structures.”* Het NEWS, being explicitly an expertise centre, tries to help answer questions about science communication by actively engaging with those that have questions (A. Verkade, 2023), a method which, according to Smeets, works well in practise.

Different aspects of the engagement characteristic returned in the interview transcripts. The active engagement of people with questions was an important consideration during the founding of Het NEWS, as Smeets explained when asked about the reasons for this approach. She explained that many people asked for a database that allowed them to just look up the experts they needed, but that this is actually a bad idea. Not only does it take a lot of resources to build and maintain such a database, but actually interacting with people allows you to gain further insights into the true questions and engage with the wider network. She elaborated *“People often come in with a single simple question, but throughout the conversation they discover that they actually have a much more complicated one. What we also see happening now is that someone comes with a question and the representative from NEWS says ‘oh, but I just spoke to someone, and you should really get to know each other.’”*

However, Het NEWS will not join in project proposals and does not participate in knowledge creation in this way. Smeets did mention that she considered these two aspects of engagement to be different things.

Similarly, STUUR actively tries to connect to people who aren't yet part of the union. Schut explained that it is an explicit part of their strategy as described by (McAlevey, 2016). However, this does demand a lot of capacity, when asked on the degree to which STUUR actively engages with people this way, he responded *"At the moment [STUUR] is mostly being approached by people. [...] We are trying to organise it in such a way that these people can then reach out to others, because capacity is always an issue."* Increasing STUUR's engagement with the wider network is thus a process that depends on the available capacity resulting from active members.

10.2.2 Centralisation and autonomy

When presented with the depictions of different relationships to the network (Figure 19), both participants clearly recognize the different levels of centralisation. Het NEWS, according to Smeets, matched depiction B the best. Smeets noted that this depiction reminded her of a recent design they made in which Het NEWS is a puzzle piece connecting the policy makers, science communicator researchers, and those who do the science communication. Schut explained that STUUR used to be more like B, but is now structured as depicted in A. In fact he stated that *"The union and the workers, and in this case the students, are one and the same. [...] When [students] come together, we call it a union, but it is not an external organisation."* This point of not being an external organisation is important in how STUUR operates, as Schut explained, STUUR used to have a mediating role acting as a bridge between students and people in power, and that now *"STUUR has no bridging function in that sense."*

Where both organisations differ greatly in their centralisation, they have a similar view on autonomy. Both parties regard their autonomy as very important, yet did not consider it to mean being separate from the network. They described it more in terms of being independent from institutions. When asked to elaborate on the importance of autonomy, Smeets explained *"even if you would have the same organisation structure, mission, and everything, but you are embedded within the university of Leiden, even if you are called a national institute, you are not taken seriously as an organisation when telling the university of Utrecht 'hey guys, you should do this differently.'"* Similarly, Schut explained when asked about their autonomy, *"We are fully autonomous from institutes, but not from the students."*

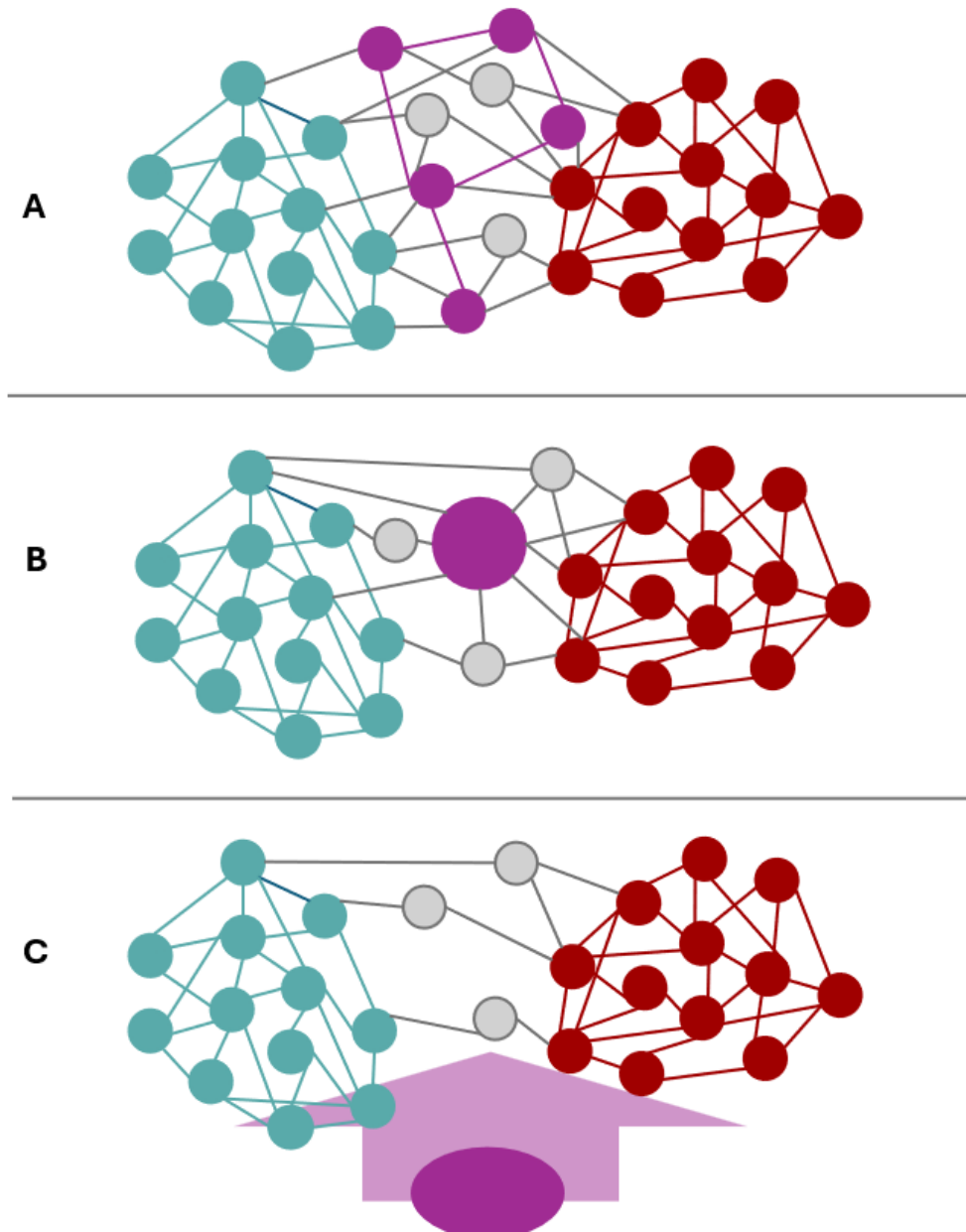


Figure 19 a depiction of different relationships to the network based on the network governance model of (Provan & Kenis, 2008).. In A, the organisation is characterised by their decentralised nature. B is characterised by being a centralised organisation but still embedded within the broader network. C is characterised by both being centralised and separate from the greater network.

10.2.3 Reach

Reach, defined as the degree to which an organisation influences different levels of the system, did not come up naturally, and when prompted raised the most questions. Smeets suggested that it is rather a matter of capacity, and not so much a defining characteristic given how relative it is to the context. She explained: “It very much depends on the scale. [...] for example, we decided to not reach out to a lot of actors. [...]. Meanwhile, the Brits think we

are crazy for including colleges and musea, they only do universities.” Similarly STUUR recognized they do influence different levels of the system, but from very different roles. When asked which levels they concretely influence Schut describes that *“at the local level we actually think we can enact change and achieve something that improves [students their] life. [...] On the meso scale you see that we are starting to achieve things in the university, through the setting up of larger structures, and also by pushing against the world to change smaller things. I also think we indirectly influence things at the macro scale, through us being an organisation that tries to do things differently we influence others on the progressive left.”* So while STUUR indirectly influences different levels, their focus is limited to what is within their more immediate reach.

11 Discussion

11.1 Similarities and differences

The cases presented have some interesting similarities and differences in their approach to being an intermediary organisation. Their missions are framed along three similar lines: expertise, connection, and system in the case of Het NEWS, or inform, organise, and protest in the case of STUUR. Both mirror the three roles of intermediaries presented based on the literature: being a knowledge broker, a network manager, and system transitioner. Yet, the way these roles interact is different between the two.

In their role as a knowledge broker, Het NEWS and STUUR organise events, educate and inform people, and collect and maintain knowledge. However, where Het NEWS explicitly states that they are not a trainingbureau, STUUR does give workshops on organising to other organisations and students. This difference makes sense in the light of something mentioned by Smeets regarding the importance of being aware of what already exists in the field. In the field of science communication, there are already trainingbureaus in the Netherlands that have the ability to give these types of training, while according to Schut, expertise regarding organising is not widely available within the country. Given the fact that there is a lot of translational expertise out there, but where to find it is not obvious, and building databases is not recommended, our hypothetical translational hub would also have a heavy focus on knowledge aggregation, though maybe not so much on knowledge creation.

Both organisations also have a significant focus on connecting people and building new connections between them, however here we find a big difference in their approach. Where Het NEWS connects people with differing expertise building new connections between producers of science communication, researchers of science communication, and policy makers, STUUR connects people from a similar background: students, based on shared

interests: the problems they experience. Het NEWS explicitly has a bridging function and STUUR admits that they no longer try to fill this role in their new strategy. An overview of the roles Het NEWS and STUUR do and don't fulfill, as well as where they overlap, is presented in Figure 20.

Both organisations stressed the importance of their autonomy. The fact that they operate independently from any institution is what allows them to push for systemic change. Both Het NEWS and STUUR recognized that they can't be taken seriously if they are embedded within an existing actor and valued their freedom to remain critical. While they did view themselves as autonomous, they did not consider this to mean that they were separate from the network. Autonomy from their perspective was truly about the degree to which you are embedded or dependent on a different actor in the system.

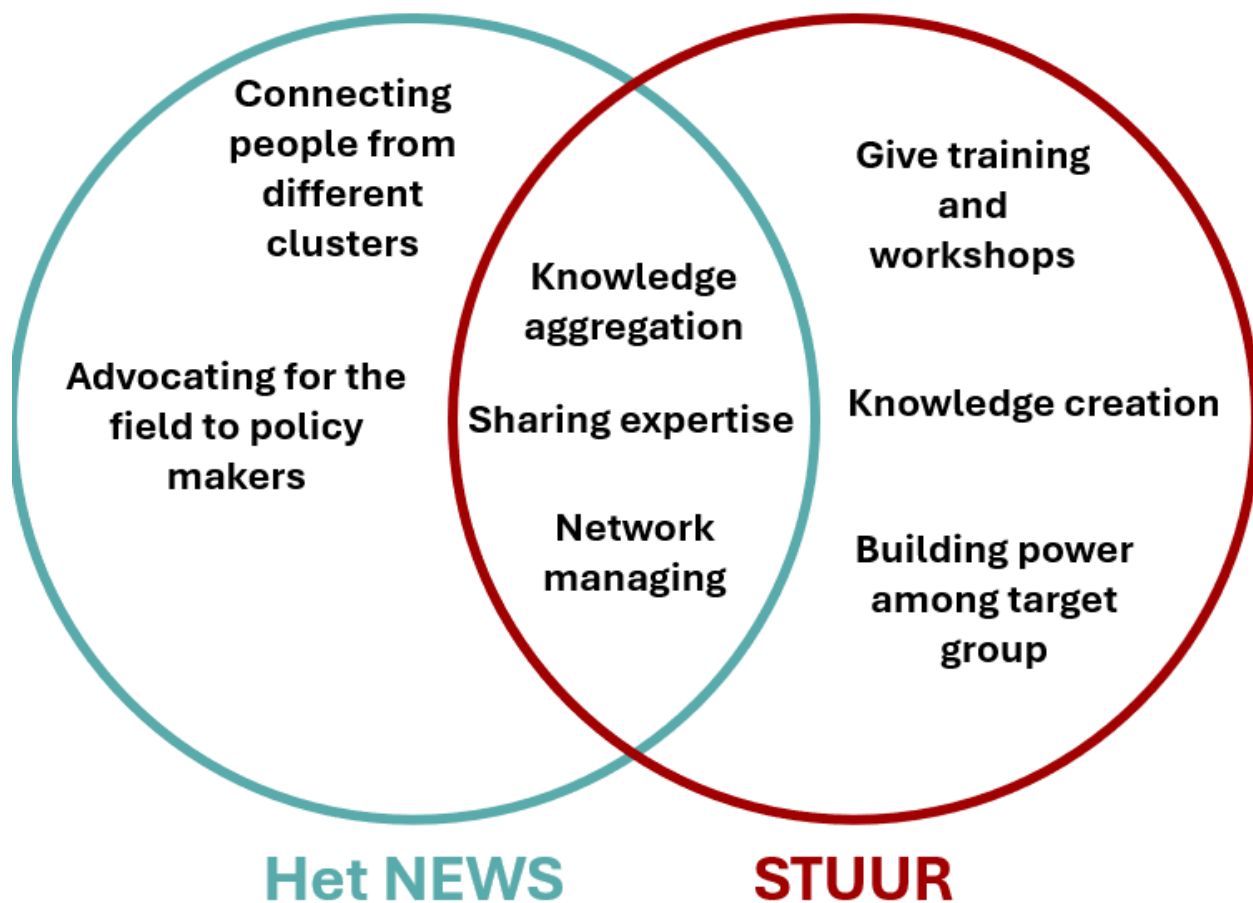


Figure 20 an overview of similarities and differences in the roles STUUR and Het NEWS do and don't fulfil

11.2 Bonding and bridging intermediaries

You could argue that these two different organisations focus on contrasting types of social capital. Het NEWS attempts to increase the bridging social capital for people in the network,

which increases external assets, information diffusion, and broadens identities (Putnam, 2000). STUUR, in contrast, increases the bonding social capital for people in the network, mobilizing solidarity and solidifying reciprocal bonds (Putnam, 2000). This contrast explains their differing organisational structures, where Het NEWS describes itself as a puzzle piece that fits in between different groups, STUUR describes itself as nothing but the network of students. Where Het NEWS is centralised, connecting to the different clusters in the network, STUUR is decentralised and distributed throughout the network, but limited to one cluster.

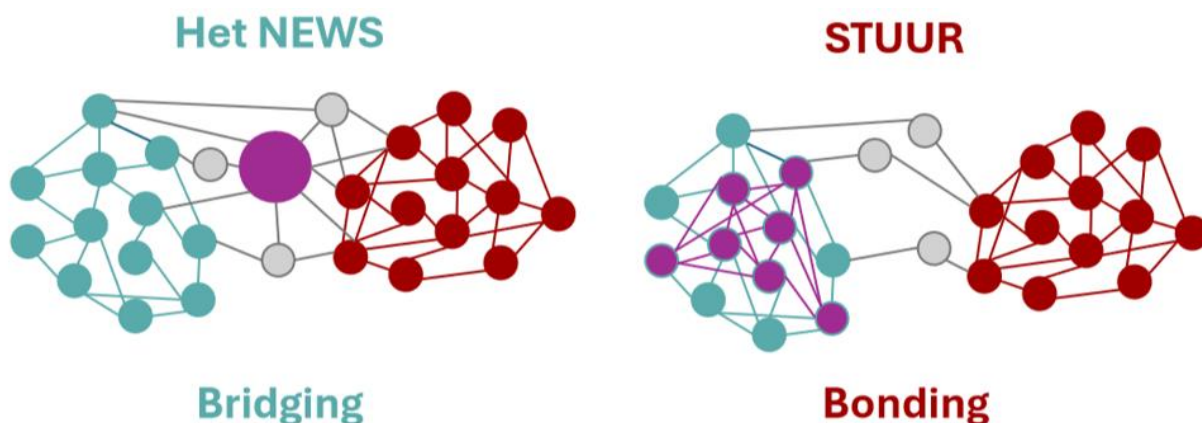


Figure 21 A stylistic depiction on how Het NEWS and STUUR differ in their approach to the network and how this relates to bonding or bridging social capital

This gives us a framework that we can use to discuss the hypothetical translational hub suggested at the end of the research phase of this report. Based on the interviews, the problems in translational research arise from a lack of information flow, a need for external resources, and difficulties in finding the right collaborators. These problems all suggest the need for an increase of bridging social capital and thus, based on my analysis of Het NEWS and STUUR, a more centralised organisation.

Long, Hibbert, and Braithwaite (2016), show in their evaluation of a translational research network in the UK, the Translational Cancer Research Network, that this approach works effectively at fostering new collaborations and changes in clinical practise. While they do refer to this organisation as a network, it is characterised by active central actors and brokers, has dedicated staff, and does seem to position itself as an external organisation's people go to for help. It organises events, distributes funding, and aids in finding collaborators. This organisation may serve as a good source of inspiration for a potential translational hub in the Netherlands.

11.3 Engagement, reach and dependencies

Het NEWS makes a 2-fold consideration to opt for personal contact when answering questions relating to their expertise instead of maintaining databases with this information. For one, maintaining a database is a time-consuming task, but more importantly it allows for dialogue which has been proven effective (A. Verkade, 2023; Land-Zandstra, 2023). Having these personal connections can be helpful in the future. Something that would hold true in the context of a translational hub and building a network to connect different types of researchers. However, both STUUR and Het NEWS mention that this type of pro-active engagement does take a lot of capacity and is something that you build up over time.

While Engagement was initially proposed as a characteristic of an organisation that encompassed participating in knowledge creation, pro-active reaching out to people in the network, and the building of connections between different people, considering all these aspects together makes it difficult to use as a metric. Both Schut and Smeets said that some aspects of this metric were very relevant to their case, whereas others less so. The question might rather be what you engage in and what not. What is required in your context and what is already done by others? What capacity do you have and what has priority? The answers to these questions may change over time, suggesting that the level of engagement is not really a fundamental characteristic of an intermediary organisation. However, it is still true that the more of an active participant you want to be, the more knowledge and expertise of the field you require. If you have the capacity to actively approach someone for a project, you still require some knowledge and expertise to even know who to approach. This suggests that the relationship between knowledge aggregation and engagement holds up, even if the level of engagement is no longer a fundamental characteristic.

Like engagement, the reach an organisation has is heavily dependent on the capacity of the organisation and the context it exists in. Reach is in practise more of a choice about who you engage with given the capacity of the organisation. Making choices on what you do and where you do it depend on what is already there and who is doing what. The relationship between autonomy and reach still holds up. Regardless of your capacity, your ability to influence actors across institutions is severely limited when you are embedded within a particular institution.

However, the relationship between autonomy and centralisation needs to be re-examined. STUUR considered themselves to be very autonomous, yet also very decentralised. At first this feels contradictory, if your organisation is nothing more than the members in the network, how can you be autonomous from it? This paradox is resolved by the redefinition of autonomy based on the participant's input. Autonomy should be focussed on whether you are embedded or dependent on a particular actor in the network, and not about

independence from the network itself. If we only consider autonomy from those who are not part of the intermediary, centralisation and autonomy are no longer related. You can be a both a decentralized network embedded or dependent on one particular institution, or separate and independent from any particular institution. Where STUUR provides a good example of the latter one, a study association may provide the counter example. Like STUUR, a study association is comprised of its members but is usually (partially) financed by the institution it resides in.

11.4 Validity design and first iteration

So far, the model has only been tested using two examples of intermediaries. While quite different from each other, STUUR and Het NEWS do not capture the total breadth of possibilities in the intermediary landscape. It is thus undoubtedly the case that further conversations and comparisons reveal more nuances and aspects that would influence the model. This model is idealised in the sense that it does not take practical considerations into account. Size, capacity, and funding are not considered limiting the focus on what is required in your field and not what is possible with your means. I believe limiting the scope and setting priorities should come after defining the best-case scenario where you are able to do everything you deem helpful. To set priorities you should first define everything you would like to do and who you would like to influence to allow for all of these to be considered when limiting your scope. While it is still an early version, the proposed design does effectively offer a framework to discuss characteristics of very different intermediaries. This makes it, at the very least, a useful tool even if it is not a fully valid representation of all intermediaries yet.

Despite the limited input on the design so far, there are some useful changes to be made based on the discussion above. For one, engagement and reach seem less fundamental than initially suggested. Additionally, none of the remaining fundamental characteristics: knowledge aggregation, centralisation, and autonomy, actually depend on each other. Meanwhile, the two less fundamental characteristics: reach and engagement, do depend on these fundamental aspects. These considerations naturally lead to a more hierarchical structure with three fundamental aspects that match each of the three roles: knowledge broker, network manager, and system transitioner, and two aspects that build on combinations of these three roles that are more dynamic but limited depending on the three fundamental characteristics. Additionally, reach and engagement heavily depend on the capacity you have, which is itself not directly tied to those fundamental characteristics. The scope, in terms of reach and engagement, are thus limited by the foundational characteristics and define the required capacity. The same is true in the other direction, the capacity defines the possible scope and thus the required foundation (Figure 22).

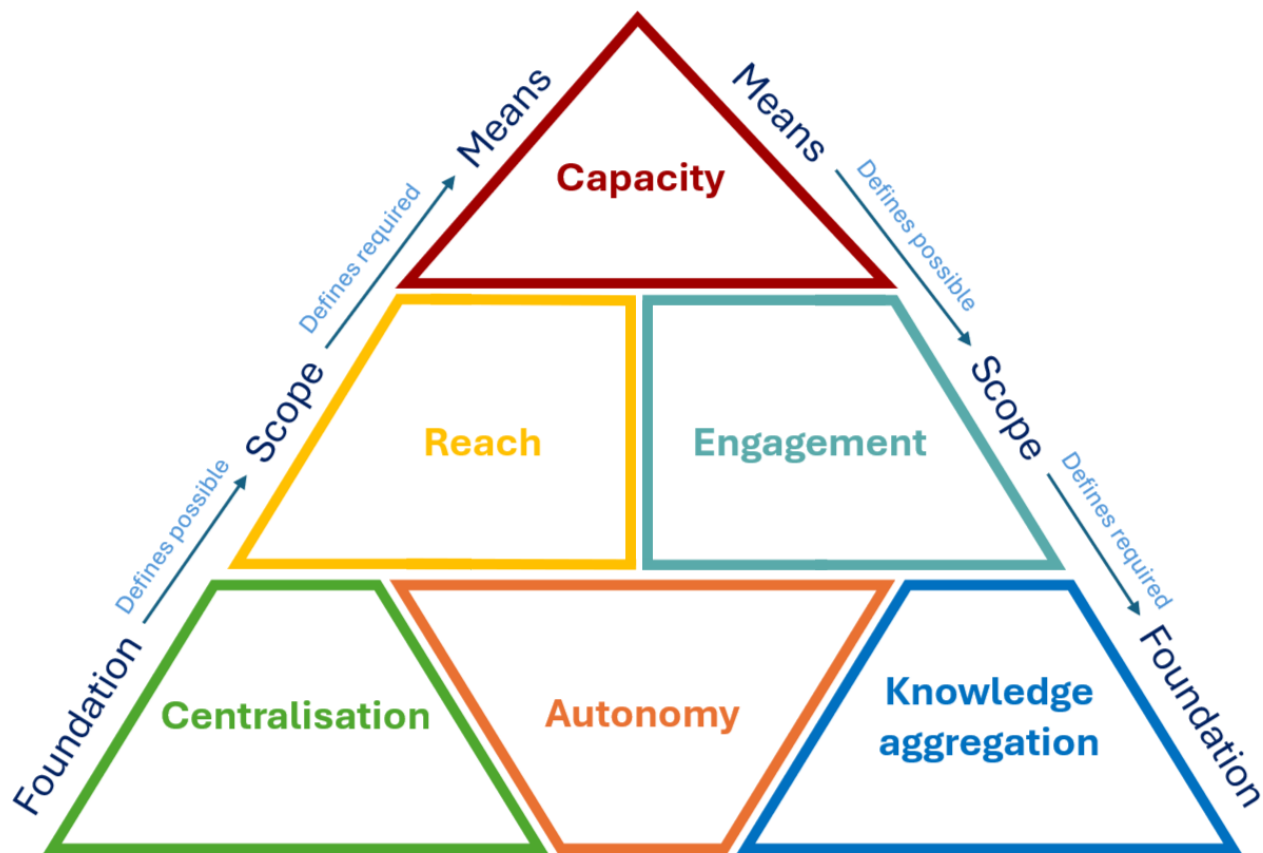


Figure 22 Visual representation on how the previous five characteristics actually build on each other. Centralisation, autonomy and knowledge aggregation are fundamental and determine the limits for reach and engagement

Of course, this new iteration still requires further validation and should be seen as a hypothesis for a follow-up research project. It raises some interesting questions on how the centralisation and autonomy influences reach and engagement respectively. Are organisations better structured top down, starting with the capacity which defines the scope in terms of reach and engagement shaping the requirements of the foundational characteristics? Is it better to start with the foundation based on what is lacking in the field, allowing those to naturally limit your potential scope and required capacity? It would probably be best to have an iterative process where practical considerations defining the capacity are introduced once you go up the pyramid, redefining your scope and foundational requirements as you go back down. These questions leave a lot of room for interesting future work.

11.5 An expertise centre for translational research

Based on this slightly adapted understanding of the intermediary characteristics we can propose some considerations for our translational intermediary.

Firstly, the level of centralisation is heavily dependend on whether the actors in the network require more bonding or bridging social capital and defines the way the network manager role is realised. Networks where accumulation of influence and knowledge within a particular group of people is needed require bonding social capital and a decentralised structure. In the case of translational research, however, knowledge from different groups is required suggesting a need for bridging social capital and a centralised organisation that can enable connections across fundamental- and clinical researchers.

Secondly, an intermediary their autonomy from other actors in the network heavily influences whether they can enact systemic change. This autonomy determines the mandate you have to operate at different levels, as well as your ability to push different instutions to change their ways. Given the need for a neutral party that can mediate between fundamental and clinical researchers, and the fact that an increase of translational activity would benefit multiple organisations, an intermediary facillitating the increase of translational activity should have high levels of autonomy.

Finally, whether an intermediary aggregates knowledge and builds expertise influences the way it engages with other actors in the network. An organization that mostly redirects towards those with expertise requires less knowledge themselves. On the other hand, if your goal is to be an active participant in the creation of knowledge there is a need for expertise within your organization. Given that translation requires particular expertise that is not always present in just any interdisciplinary collaboration, it would seem obvious that this intermediary should be a centre of expertise as well.

This set up would allow the intermediary organisation to engage actively with the network and reach different institutions at different levels. They operate independently, increasing their mandate to propose changes to systems in different institutions. They can mediate between researchers from different backgrounds and offer expertise on effective translational research. They will be able to build up a network through the consulting of people that come to them with questions, connecting those that could benefit from working together. Such an organization would be perfectly suited to optimize the translational process and aid in overcoming the most impactful bottlenecks found in the neuroscience field.

However, this set up would also require a lot of capacity. One could reduce the required capacity by reducing the engagement in knowledge creation, requiring less expertise, or reducing the reach and targetting fewer actors. The capacity thus shapes the possibilities regarding reach and engagement as well.

11.6 Capacity and scope

The consideration on capacity brings us to some practical considerations. While the scope of this project was limited to the Erasmus MC and the field of neuroscience, the challenge of translating fundamental research into clinical applications is found in several fields of medicine (Brown et al., 2009; Fudge et al., 2016; Oliveira et al., 2021; Spallek et al., 2010; Tracy, 2014). This suggests that it might be advisable to expand the scope of the translational intermediary to work in between fundamental and clinical researchers across domains. However, this does potentially increase the different expertise required when wanting to actively engage with the researchers in the network. Tools and methods used in different domains can be quite different and the steps to go from fundamental result to clinical context may differ.

An increase in capacity requires an increase in funding. As a high level of autonomy is proposed, this funding cannot come from the research institutions themselves. In the end, a lack of translation is a societal issue. It is tax money being spend that does not efficiently improve the wellbeing of those spending it. Given these considerations, it would not be strange to fund an organisation tasked with increasing the efficiency of this translational process through government funding, similar to how Het NEWS was funded. This way, the organisation is autonomous from actors in the network, holds responsibility for this shift towards improved translational activity, and can be held accountable through traditional governmental structures.

Given the current political climate, receiving funding to set up a broad organisation with a large scope is unlikely. However, starting small and growing as effectivity is proven is quite possible. The field of neuroscience would be a great starting point for such an organisation. As mentioned before, neurological disorders have a very large impact on society (GBD 2016 Neurology Collaborators, 2016), and as discussed in the research portion of this report the lack of translational activity can be well explained by bottlenecks that relate to the roles of intermediary organisations. Within a limited scope, such an organisation could act effectively with limited capacity. It would need a board to run things and a few employees with a background in neuroscience, the medical field, and translational research. Het NEWSs currently works with 6 fte and has an arguably larger scope given the plethora of organisations that deal with science communication. A similarly sized organisation should be able to effectively improve translational activity in the neuroscience field across the country.

12 Conclusion

The process by which fundamental findings are translated into clinical research and practise runs into several bottlenecks. Some of the most significant bottlenecks: a lack of expertise, difficulties in finding collaborators, and differing priorities among potential collaborators, could be alleviated through an organisation that holds expertise regarding translational research, stimulates connections across the broader network, and mediates among researchers of different backgrounds. Such organisations, also known as intermediaries, can take a few forms. While they can be recognised through their roles as knowledge brokers, network managers, and system transitioners, they can also be viewed through their relationship to centralisation, autonomy, and knowledge aggregation.

Given that the needs for the translational neuroscience field can be characterised as a lack of bridging social capital, a need for systemic transitions across intitutions, and the lack of specific expertise, an intermediary organisation that is more centralised, is not embedded within an existing institution, and holds and maintains expertise is proposed as an effective party to fill this need (Figure 23). This structure allows the organisation to actively engage with researchers in the network and reach them in and across different institutions. The capacity required for this intermediary organisation will likely need to be governmentally funded, increasing the mandate and independence from other institutions in the network. This government funded organisation would thus be an expertise centre for translational neuroscience, have strong connections throughout the field, and operate autonomously from any specific institutions.

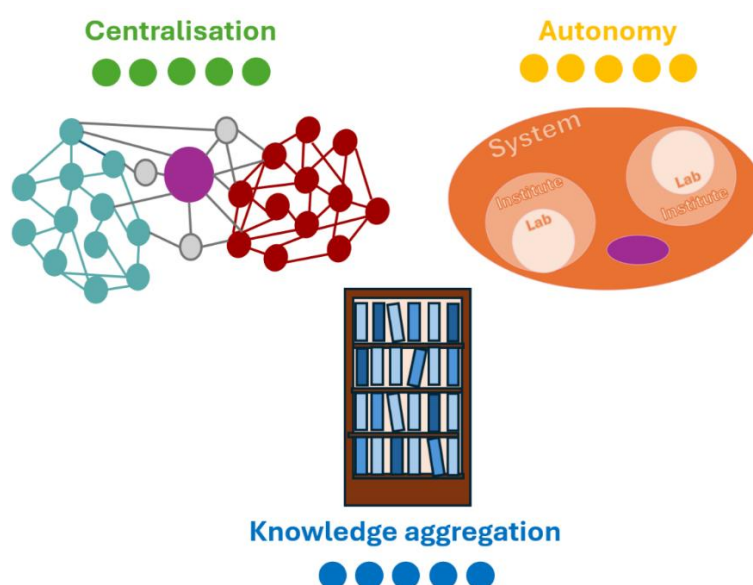


Figure 23 A schematic depicting the relationship of the proposed intermediary to the network, system, and knowledge based on the fundamental characteristics of centralisation, autonomy, and knowledge aggregation.

13 Future work

This proposal should not be considered as the starting point for setting up an organisation tasked with increasing the translational activity in the neuroscience field. Rather, it is meant to offer a framework for the way certain considerations inform the way an organisation is structured and decisions are made. The starting point should instead be the development of a Theory of Change. Both STUUR and Het NEWS have built their current strategy, organisational structures, and approaches on a solid foundation encompassed by their respective theories of change. A theory of change is a participative process however (Belcher B, 2020), one that should include many clinical and fundamental researchers, and other stakeholders such as patient organisations, and policy makers within the medical and research fields.

Building a Theory of Change is thus a process far beyond the scope of this report, but I would like to offer a first consideration. Increasing translational activity is not an end in itself, it is a method with which to achieve more intrinsic goals. Different stakeholders may focus on slightly different ones, however, like patient wellbeing, quality of research, effectiveness of treatment, or societal benefits. Coming to an agreement which of these are the most fundamental should be the starting point and act as a way to navigate future choices. When discussing what this organisation should look like based on this fundamental starting point, the framework offered above might aid when making these considerations. Other organisations may offer more insights into what works and what does not, which additional roles may exist, and which activities should and should not be a part of this organisation. Talking with international organisations that have a similar function, examining the differences between them, and similarities to organisations we have here was an effective strategy according to Prof. Smeets, and is thus highly recommended.

If similar conclusions are made as the ones presented in this report, the suggested structure, capacity, and source of funding likely hold up. This would mean that we need a push from the research field to convince parliament to invest in such an organisation. A potential benefit from the interdisciplinary nature of this problem is that there are two potential ministries that could adopt this project: the ministry of health, 'Volksgezondheid, Welzijn en Sport' (VWS), or that of education and science, 'Onderwijs, Cultuur en Wetenschap' (OCW). Whether adopted by VWS, OCW, or a combination of the two, it is my belief that this organisation would have an ideal position to effectively increase the translational activity in neuroscience, and perhaps other fields of medicine as well.

14 Reflection

14.1 Literature review

This analysis resulted in novel insights in large part because of the focus on themes such as collaboration and communication between fields, which was lacking in most literature according to Fudge et al. (2016). Using the social network model as a lens through which to analyse the translational activity in the neuroscience field gave rise to new opportunities and perspectives. Even so, many conclusions and insights could also already be found in existing literature. An interesting aspect of a project that touches upon topics that are researched in several fields is that you sometimes don't have the language to describe what you are looking for until after you finished the research analysis. It is possible though that a more thorough literature review and consideration of alternative models would have led me to encounter the idea of intermediaries and their roles already before starting the first interview. Whether I would have recognised the intermediary as a potential solution, had I not first spoken to the researchers, and whether it would have shaped my interview protocol, is impossible to say.

14.2 Interviews

Something else that became apparent throughout the research and design process is that, despite initial considerations, finding participants was even more difficult than expected. A lot of time was spent on trying to get particular participants to plan an interview. The approach was to limit the amount of participant invitations to those for which was believed they would be easy to get in contact with. Researchers that collaborated with colleagues, had a pre-established connection with me or my master programs, or seemed interested in the topic were specifically targeted. The goal was to focus my resources and attention on a few people rather than having to find and keep track of a large number of potential participants. This strategy did not pay off, despite the fact that many people showed interest, agreed to participate, and sometimes even plan an interview, before cancelling after all. In the future, a different strategy will be considered for similar projects.

Reducing researcher bias in a qualitative study is a challenge, especially considering all the interviews were conducted, transcribed, coded, and analysed by a single researcher. Initial trial interviews did show that there was a tendency to offer interpretations to participant's responses rather than having them spell it out. Attempts were made to consciously minimize this tendency in following interviews. I do not believe, however, that this tendency has biased my final results. I only code text that has been transcribed from participants their responses, and never from any interpretations I may have offered. Of course, I do offer some interpretation when I present quotes in this report and put them in a larger context, as is a common practise in qualitative research.

14.3 Design phase

During the design phase, I attempted to characterise a broad selection of intermediary organisations in a handful characteristics. “All models are wrong, but some are useful” is how the famous saying goes, and while I think every metric I suggested: knowledge aggregation, centralisation, autonomy, engagement, and reach, capture a true aspect of these organisations, sometimes maybe multiple true aspects, they are not equally useful at every stage. While I think there is merit in a model that captures all three main intermediary roles and describes how they shape the organisation, the version presented before needs further iterations. The scope of this report did not allow for a longer iterative process with different intermediaries and insights from experts in the field of intermediaries and innovation. Therefore, when discussing the hypothetical translational hub, a focus was put on defining aspects that are less variable over time, seem more fundamental, and pertain to the structure of the organisation the most: centralisation and autonomy, which was already quite well captured by (Provan & Kenis, 2008), as well as knowledge aggregation.

The design phase included fewer participants than was desired due to heavy time constraints. While I reached out to several organisations and people, the only positive responses I received were from people I either had a personal connection with or that knew my supervisor well. STUUR in particular is an organisation I know well and co-founded over five years ago. However, as also becomes clear in the interview with the previous chair, STUUR has changed a lot since then. I am still, to a lesser extent, involved in the organisation and am following these changes with great interest, but I was not responsible for pushing for, nor putting into practise any of the strategic changes discussed. While my personal relationship with STUUR was the reason I recognised its interesting position as an intermediary who had changed their approach to the network manager role, it did not influence my research approach or the interview protocol. My personal knowledge of strategic decisions made before or after the previous chair his term are not a part of the results.

In this report I have offered a comprehensive overview of the bottlenecks found in the translation of fundamental neuroscientific findings into clinical research. I have presented the context in which this process takes place and offered the key bottlenecks that limit translational activity. After offering a potential solution, an intermediary organisation, I have given an overview on what this organisation could look like and proposed some key characteristics. While I do recognise that any attempt to actualise such an organisation needs to take a few steps back when designing a theory of change, I do believe that this work may offer helpful insights when considering different aspects of this organisation.

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15 Appendix

15.1 Interview protocol research phase

Introduction

Interviewees are walked through the informed consent form which includes an introduction to the topic. Once they have signed the form, giving consent to record the interview, the recording is started, and the interview begins.

Definition translational research: “Research that aids in the translation of fundamental research findings into clinical research (and eventually implementation)”

Interview questions

Open/intro questions (personal relation with translation)

- How long have you been in the field of neuroscience / medical research
- In a short sentence, how would you describe the particular type of neuroscience/medical research you do?
- What would you say is the goal of your research?
- On a scale from 1 to 5, how important do you think translation is in the neuroscience field, and in your work specifically?
- Could you elaborate?
- On a scale from 1 to 5, how much do you consider translational outcomes during a research project?
- At what point do you take these considerations, if at all?
- What (doesn't) motivates you to take these considerations?

Bottlenecks

- Could you name three (or more) bottlenecks you are aware of that limit the translational activity in the general neuroscience field?
- How would you rank the severity of these bottlenecks? [include prepared cards and their own suggested ones]
- Could you elaborate on the top three?
- What are the specific bottlenecks that apply most to your research?
- Do you have any examples of you overcoming some of these bottlenecks?
- In which ways could you be aided in overcoming these bottlenecks?
- Could you categorize these bottlenecks on whether they occur on the individual, collaborative or systemic level?

collaboration

- When do you start making contact with potential collaborators?
- What are the driving factors for choosing who you collaborate with?
- Is translation ever a specific reason for collaboration?
- What are factors that limit your possibilities when setting up collaborations?
- Can you give examples of cases in which you overcame these factors?

Social network

- Of the Two visualizations of the neuroscience research community, which one do you think is the most accurate?
- Who do you think makes up the bridging region in the middle and how do you find them?
- Have you ever had a role in forming such a bridge? If yes, in what way?
- What do you think are consequences of increasing or decreasing interactions between the two clusters?
- On a scale from 1 to 5, how much effort would you be willing, and be able, to put in yourself to contribute to this shift?
- What would motivate you to put in more or less effort?
- Who could facilitate such a shift, and in what ways?

Wrap up questions

- Which of the following statements best describes your view:
 - Translational science is best done explicitly with translation as a goal
 - Translation is best left as a side effect that naturally comes out of science and scientific collaboration
- We have gone over different levels of the system, individual scientists, research collaborations, and the wider community. If you want to increase translational activity, where do you think there is the most to gain?
- Is there anything you would like to add to the discussion that we have not yet discussed?

Bottlenecks used for cards:

Collaboration and network based:

- Lack of information transfer between fundamental and clinical researchers
- Difficulty finding the right collaborators

Awareness of translation among actors based:

- Lack of awareness from researchers
- Lack of awareness from institutions

Resource based:

- Lack of time
- Lack of money

Systems of science based:

- Methodological limitations
- Inherent translational challenges when going from a model to a human context
- Uncertainty in the literature
- Split in journals where literature is published

15.2 data management plan

PLAN OVERVIEW

A Data Management Plan created using DMPonline

Title: Lost in translation, the barriers to translating fundamental- into clinical research

Creator: Nathaniel Germain

Affiliation: Delft University of Technology

Template: TU Delft Data Management Plan template (2021)

ID: 162920

Last modified: 11-11-2024

LOST IN TRANSLATION, THE BARRIERS TO TRANSLATING FUNDAMENTAL INTO CLINICAL RESEARCH

0. Administrative questions

1. Name of data management support staff consulted during the preparation of this plan.

My faculty data steward, Esther Plomp, has reviewed this DMP

2. Date of consultation with support staff.

2024-11-09

I. Data description and collection or re-use of existing data

3. Provide a general description of the type of data you will be working with, including any re-used data:

Type of data	File format(s)	How will data be collected (for re-used data: source and terms of use)?	Purpose of processing	Storage location	Who will have access to the data
Qualitative interview data	Word	Processing of interview transcripts	To analyse the barriers found in research translation	TU Delft linked One drive	Me and my supervisor
Anonymised Interview audio and transcripts	word and temporary mp3	Audio recordings of interviews and semi automatic transcription using Microsoft office tools. Recordings will be deleted once transcripts are made	These form the raw data used for analysis	TU Delft linked One drive	Me and my supervisor
Type of researcher interviews	csv file	Part of the selection process	One of the points of interest of the study is difference in experiences between clinical and fundamental researchers.	TU Delft linked One drive	Me and my supervisor

4. How much data storage will you require during the project lifetime?

- < 250 GB

II. Documentation and data quality

5. What documentation will accompany data?

- Methodology of data collection

III. Storage and backup during research process

6. Where will the data (and code, if applicable) be stored and backed-up during the project lifetime?

- OneDrive

IV. Legal and ethical requirements, codes of conduct

7. Does your research involve human subjects or 3rd party datasets collected from human participants?

- Yes

8A. Will you work with personal data? (information about an identified or identifiable natural person)

If you are not sure which option to select, first ask your [Faculty Data Steward](#) for advice. You can also check with the [privacy website](#). If you would like to contact the privacy team [REDACTED], please bring your DMP.

- Yes

8B. Will you work with any other types of confidential or classified data or code as listed below? (tick all that apply) If you are not sure which

option to select, ask your [Faculty Data Steward](#) for advice.

- No, I will not work with any confidential or classified data/code

9. How will ownership of the data and intellectual property rights to the data be managed?

For projects involving commercially-sensitive research or research involving third parties, seek advice of your [Faculty Contract Manager](#) when answering this question. If this is not the case, you can use the example below.

The datasets underlying the published papers will be publicly released following the TU Delft Research Data Framework Policy. During the active phase of research, the project leader from TU Delft will oversee the access rights to data (and other outputs), as well as any requests for access from external parties. They will be released publicly no later than at the time of publication of corresponding research papers.

10. Which personal data will you process? Tick all that apply

- Data collected in Informed Consent form (names and email addresses) Other
- types of personal data - please explain below

Type of research the interviewee performs (clinical or fundamental). This will be used in answering the research questions.

Audio recordings of the interviews. These will be deleted once transcribed. Once the thesis is done, transcripts will also be deleted.

The signed informed consent forms will be stored by my supervisor (Caroline Wehrmann), but are not further processed for the study.

11. Please list the categories of data subjects

Clinical researchers (between 5 and 8 in total)

Fundamental researchers (between 5 and 8 in total)

These researchers will be predominantly from the Erasmus Medical Center.

12. Will you be sharing personal data with individuals/organisations outside of the EEA (European Economic Area)?

- No

15. What is the legal ground for personal data processing?

- Informed consent

16. Please describe the informed consent procedure you will follow:

All study participants will be asked for their written consent for taking part in the study and for data processing before the start of the interview.

17. Where will you store the signed consent forms?

- Same storage solutions as explained in question 6

18. Does the processing of the personal data result in a high risk to the data subjects?

If the processing of the personal data results in a high risk to the data subjects, it is required to perform [a Data Protection Impact Assessment \(DPIA\)](#). In order to determine if there is a high risk for the data subjects, please check if any of the options below that are applicable to the processing of the personal data during your research (check all that apply).

If two or more of the options listed below apply, you will have to [complete the DPI](#). [A](#). Please get in touch with the privacy team: [REDACTED] to receive support with DPIA.

If only one of the options listed below applies, your project might need a DPIA. Please get in touch with the privacy team: [REDACTED] to get advice as to whether DPIA is necessary.

If you have any additional comments, please add them in the box below.

- None of the above applies

22. What will happen with personal research data after the end of the research project?

- Anonymised or aggregated data will be shared with others

25. Will your study participants be asked for their consent for data sharing?

- Yes, in consent form - please explain below what you will do with data from participants who did not consent to data sharing

If a participant does not consent to the sharing of aggregated data they will be thanked for their time, but not further interviewed and thus will not take part in the research.

V. Data sharing and long-term preservation

27. Apart from personal data mentioned in question 22, will any other data be publicly shared?

- All other non-personal data (and code) underlying published articles / reports / theses

29. How will you share research data (and code), including the one mentioned in question 22?

- My data will be shared in a different way - please explain below

The aggregated data will be part of the thesis that will be uploaded to the thesis repository.

30. How much of your data will be shared in a research data repository?

- < 100 GB

31. When will the data (or code) be shared?

- At the end of the research project

32. Under what licence will be the data/code released?

- CC BY

VI. Data management responsibilities and resources

33. Is TU Delft the lead institution for this project? ● Yes, the only institution involved

34. If you leave TU Delft (or are unavailable), who is going to be responsible for the data resulting from this project? my supervisor Caroline Wehrmann [REDACTED]

35. What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

The thesis will be uploaded to the thesis repository.

8

15.3 informed consent form

Informed consent – information

Dated: 11/11/2024

The following interview is part of my (Nathaniel germain) Thesis project. The topic will be the barriers to the translation of neuroscience from fundamental to clinical research. The interview will be conducted by me, a TU Delft master student, and take approximately 30 minutes.

Questions will regard participant's professional experience with the process by which fundamental research is translated to clinical research. The studies aim is to understand the barriers found in this process and use this understanding to design a potential way to facilitate more efficient translation.

To assure proper data collection, the audio will be recorded. These recordings will be stored on a secured storage environment of the TU Delft, are exclusively used for transcription, and will be destroyed once transcribed. Recordings and transcriptions will only be accessed by me and my primary supervisor (Caroline Wehrmann). Transcriptions will also be destroyed once the project is concluded. The only personal information included in the transcription is the type of research performed (fundamental or clinical). The final thesis will only include aggregated data. In the event that personal data that could be traced back to the participant is shared within the interview, this will be removed from the transcription. When requested, participants can see the transcripts from their own interview and ask for rectifications or erasure of particular segments. If the participant gives explicit consent, quotes may be used in the final thesis.

The aggregated results published in my final thesis will be uploaded in the TU Delft repository. When signed, this form will be stored in a database from the TU Delft.

Participation is voluntary and withdrawal is possible at any time. You are also free to not answer particular questions.

For questions, remarks, and requests of transcripts you may email me at [REDACTED]

Questions for my supervisor can be directed to [REDACTED]

Please tick the appropriate boxes

Yes No

- | | | |
|--|--------------------------|--------------------------|
| 1. I have read and understood the study information dated [11/11/2024], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction. | ☐ | ☐ |
| 2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions, and I can withdraw from the study at any time, without having to give a reason. | ☐ | ☐ |
| 3. I understand that any audio recordings and transcriptions will not be made available to anyone but Nathaniel Germain and their supervisor Caroline Wehrmann. | ☐ | ☐ |
| 4. I understand that the audio recordings are destroyed once the interview has been transcribed, and that the transcriptions are destroyed once the project is concluded. | ☐ | ☐ |
| 5. understand that I can request access to the notes or transcripts from my interview and ask for the rectification or erasure of particular segments. | ☐ | ☐ |
| 6. I consent to being recording with Audio. | ☐ | ☐ |
| 7. I consent to my responses, views or other input to be quoted anonymously in research outputs. | ☐ | ☐ |
| 8. I consent to the type of research I perform (fundamental or clinical) to be linked to my responses. | ☐ | ☐ |

Signatures

_____	_____	_____
Name of participant	Signature	date

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

_____	_____	_____
Researcher name	Signature	date

15.4 risk assessment and mitigation plan

Delft University of Technology

**HUMAN RESEARCH ETHICS
CHECKLIST FOR HUMAN RESEARCH
(Version January 2022)**

IMPORTANT NOTES ON PREPARING THIS CHECKLIST

1. An HREC application should be submitted for every research study that involves human participants (as Research Subjects) carried out by TU Delft researchers
2. Your HREC application should be submitted and approved **before** potential participants are approached to take part in your study
3. All submissions from Master's Students for their research thesis need approval from the relevant Responsible Researcher
4. The Responsible Researcher must indicate their approval of the completeness and quality of the submission by signing and dating this form OR by providing approval to the corresponding researcher via email (included as a PDF with the full HREC submission)
5. There are various aspects of human research compliance which fall outside of the remit of the HREC, but which must be in place to obtain HREC approval. These often require input from internal or external experts such as [Faculty Data Stewards](#), [Faculty HSE advisors](#), the [TU Delft Privacy Team](#) or external [Medical research partners](#).
6. You can find detailed guidance on completing your HREC application [here](#)
7. Please note that incomplete submissions (whether in terms of documentation or the information provided therein) will be returned for completion **prior to any assessment**
8. If you have any feedback on any aspect of the HREC approval tools and/or process you can leave your comments [here](#)

Applicant Information

PROJECT TITLE:	Lost in translation, the barriers to translating fundamental- into clinical research
Research period: <i>Over what period of time will this specific part of the research take place</i>	01/12/2024-01/03/2024
Faculty:	TNW
Department:	SEC
Type of the research project: <i>(Bachelor's, Master's, DreamTeam, PhD, PostDoc, Senior Researcher, Organisational etc.)</i>	Master's
Funder of research: <i>(EU, NWO, TUD, other – in which case please elaborate)</i>	--
Name of Corresponding Researcher: <i>(If different from the Responsible Researcher)</i>	Nathaniel Germain
E-mail Corresponding Researcher: <i>(If different from the Responsible Researcher)</i>	[REDACTED]
Position of Corresponding Researcher: <i>(Masters, DreamTeam, PhD, PostDoc, Assistant/ Associate/ Full Professor)</i>	Masters
Name of Responsible Researcher: <i>Note: all student work must have a named Responsible Researcher to approve, sign and submit this application</i>	Caroline Wehrmann
E-mail of Responsible Researcher: <i>Please ensure that an institutional email address (no Gmail, Yahoo, etc.) is used for all project documentation/ communications including Informed Consent materials</i>	[REDACTED]
Position of Responsible Researcher : <i>(PhD, PostDoc, Associate/ Assistant/ Full Professor)</i>	Assistant professor

Research Overview

NOTE: You can find more guidance on completing this checklist [here](#)

a) Please summarise your research very briefly (100-200 words)

What are you looking into, who is involved, how many participants there will be, how they will be recruited and what are they expected to do?

Add your text here – (please avoid jargon and abbreviations)

The goal of the research is to find out which barriers are limiting the translation of fundamental research into clinical research. A maximum of 16 researchers will be interviewed. Recruitment will happen through email and personal networks based in academia.

b) If your application is an additional project related to an existing approved HREC submission, please provide a brief explanation including the existing relevant HREC submission number/s.

c) If your application is a simple extension of, or amendment to, an existing approved HREC submission, you can simply submit an [HREC Amendment Form](#) as a submission through LabServant.

Risk Assessment and Mitigation Plan

NOTE: You can find more guidance on completing this checklist [here](#)

Please complete the following table in full for all points to which your answer is “yes”. Bear in mind that the vast majority of projects involving human participants as Research Subjects also involve the collection of **Personally Identifiable Information (PII)** and/or **Personally Identifiable Research Data (PIRD)** which may pose potential risks to participants as detailed in Section G: Data Processing and Privacy below.

To ensure alignment between your risk assessment, data management and what you agree with your Research Subjects you can use the last two columns in the table below to refer to specific points in your Data Management Plan (DMP) and Informed Consent Form (ICF) – **but this is not compulsory**.

It’s worth noting that **you’re much more likely to need to resubmit your application if you neglect to identify potential risks**, than if you identify a potential risk and demonstrate how you will mitigate it. If necessary, the HREC will always work with you and colleagues in the Privacy Team and Data Management Services to see how, if at all possible, your research can be conducted.

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
A: Partners and collaboration						
1. Will the research be carried out in collaboration with additional organisational partners such as: One or more collaborating research and/or commercial organisations Either a research, or a work experience internship provider ¹ <i>¹ If yes, please include the graduation agreement in this application</i>		X				
2. Is this research dependent on a Data Transfer or Processing Agreement with a collaborating partner or third party supplier? <i>If yes please provide a copy of the signed DTA/DPA</i>		X				
3. Has this research been approved by another (external) research ethics committee (e.g.: HREC and/or MREC/METC)? <i>If yes, please provide a copy of the approval (if possible) and summarise any key points in your Risk Management section below</i>		X				
B: Location						
4. Will the research take place in a country or countries, other than the Netherlands, within the EU?		X				
5. Will the research take place in a country or countries outside the EU?		X				
6. Will the research take place in a place/region or of higher risk – including known dangerous locations (in any country) or locations with non-democratic regimes?		X				
C: Participants						
7. Will the study involve participants who may be vulnerable and possibly (legally) unable to give informed consent? (e.g., children below the legal age for giving consent, people with learning difficulties, people living in care or nursing homes,).		X				
8. Will the study involve participants who may be vulnerable under specific circumstances and in specific contexts, such as victims and witnesses of violence, including domestic violence; sex workers; members of minority groups, refugees, irregular migrants or dissidents?		X				
9. Are the participants, outside the context of the research, in a dependent or subordinate position to the investigator (such as own children, own students or employees of either TU Delft and/or a collaborating partner organisation)? <i>It is essential that you safeguard against possible adverse consequences of this situation (such as allowing a student's failure to participate to your satisfaction to affect your evaluation of their coursework).</i>		X				

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
10. Is there a high possibility of re-identification for your participants? (e.g., do they have a very specialist job of which there are only a small number in a given country, are they members of a small community, or employees from a partner company collaborating in the research? Or are they one of only a handful of (expert) participants in the study?	X		The researchers will be mainly from the departement of neuroscience at the Erasmus MC or perform clinical research at the same institute. This is a relative small group and thus from interview transcripts people might be able to be identified	Only aggregated data will be shared with anyone else but my direct supervisor. All transcripts will be destroyed once the research is done.	X	
D: Recruiting Participants						
11. Will your participants be recruited through your own, professional, channels such as conference attendance lists, or through specific network/s such as self-help groups	X		While I will be using my personal network and those of the people I will recruit, I do not foresee any risks as a result	-		
12. Will the participants be recruited or accessed in the longer term by a (legal or customary) gatekeeper? (e.g., an adult professional working with children; a community leader or family member who has this customary role – within or outside the EU; the data producer of a long-term cohort study)		X				
13. Will you be recruiting your participants through a crowd-sourcing service and/or involve a third party data-gathering service, such as a survey platform?		X				
14. Will you be offering any financial, or other, remuneration to participants, and might this induce or bias participation?		X				
E: Subject Matter <i>Research related to medical questions/health may require special attention. See also the website of the CCMQ before contacting the HREC.</i>						
15. Will your research involve any of the following: Medical research and/or clinical trials Invasive sampling and/or medical imaging Medical and <i>In Vitro Diagnostic Medical Devices</i> Research		X				
16. Will drugs, placebos, or other substances (e.g., drinks, foods, food or drink constituents, dietary supplements) be administered to the study participants? <i>If yes see here to determine whether medical ethical approval is required</i>		X				
17. Will blood or tissue samples be obtained from participants? <i>If yes see here to determine whether medical ethical approval is required</i>		X				
18. Does the study risk causing psychological stress or anxiety beyond that normally encountered by the participants in their life outside research?		X				

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
19. Will the study involve discussion of personal sensitive data which could put participants at increased legal, financial, reputational, security or other risk? (e.g., financial data, location data, data relating to children or other vulnerable groups) <i>Definitions of sensitive personal data, and special cases are provided on the TUD Privacy Team website.</i>		X				
20. Will the study involve disclosing commercially or professionally sensitive, or confidential information? (e.g., relating to decision-making processes or business strategies which might, for example, be of interest to competitors)		X				
21. Has your study been identified by the TU Delft Privacy Team as requiring a Data Processing Impact Assessment (DPIA)? <i>If yes please attach the advice/ approval from the Privacy Team to this application</i>		X				
22. Does your research investigate causes or areas of conflict? <i>If yes please confirm that your fieldwork has been discussed with the appropriate safety/security advisors and approved by your Department/Faculty.</i>		X				
23. Does your research involve observing illegal activities or data processed or provided by authorities responsible for preventing, investigating, detecting or prosecuting criminal offences <i>If so please confirm that your work has been discussed with the appropriate legal advisors and approved by your Department/Faculty.</i>		X				
F: Research Methods						
24. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g., covert observation of people in non-public places).		X				
25. Will the study involve actively deceiving the participants? (For example, will participants be deliberately falsely informed, will information be withheld from them or will they be misled in such a way that they are likely to object or show unease when debriefed about the study).		X				
26. Is pain or more than mild discomfort likely to result from the study? And/or could your research activity cause an accident involving (non-) participants?		X				
27. Will the experiment involve the use of devices that are not ‘CE’ certified? <i>Only, if ‘yes’: continue with the following questions:</i>		X				
Was the device built in-house?						
Was it inspected by a safety expert at TU Delft?						

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
<i>If yes, please provide a signed device report</i>						
If it was not built in-house and not CE-certified, was it inspected by some other, qualified authority in safety and approved? <i>If yes, please provide records of the inspection</i>						
28. Will your research involve face-to-face encounters with your participants and if so how will you assess and address Covid considerations?	X		There are no covid regulations within the institute where the interviews will be taking place	-		
29. Will your research involve either : a) “big data”, combined datasets, new data-gathering or new data-merging techniques which might lead to re-identification of your participants and/or b) artificial intelligence or algorithm training where, for example biased datasets could lead to biased outcomes?		X				
G: Data Processing and Privacy						
30. Will the research involve collecting, processing and/or storing any directly identifiable PII (Personally Identifiable Information) including name or email address that will be used for administrative purposes only? (eg: obtaining Informed Consent or disbursing remuneration)	X		A name is required for the informed consent form, therefor there is a risk this data might be connected to research data	To mitigate this risk the informed consent forms will not be connected in any way to the transcripts nor be publically available. The list of participants should only be known to me and my supervisor		
31. Will the research involve collecting, processing and/or storing any directly or indirectly identifiable PIRD (Personally Identifiable Research Data) including videos, pictures, IP address, gender, age etc and what other Personal Research Data (including personal or professional views) will you be collecting?	X		Personal and professional views will be part of the research data	All data is aggregated and only aggregated and anonymized data will be part of the thesis. Transcripts will be destroyed once the research is done.		
32. Will this research involve collecting data from the internet, social media and/or publicly available datasets which have been originally contributed by human participants		X				
33. Will your research findings be published in one or more forms in the public domain, as e.g., Masters thesis, journal publication, conference presentation or wider public dissemination?	X		The master thesis might become part of the TU Delft repository	Any data in the thesis itself will be aggregated and anonymous		
34. Will your research data be archived for re-use and/or teaching in an open, private or semi-open archive?		X				

H: More on Informed Consent and Data Management

NOTE: You can find guidance and templates for preparing your Informed Consent materials) [here](#)

Your research involves human participants as Research Subjects if you are recruiting them or actively involving or influencing, manipulating or directing them in any way in your research activities. This means you must seek informed consent and agree/ implement appropriate safeguards regardless of whether you are collecting any PIRD.

Where you are also collecting PIRD, and using Informed Consent as the legal basis for your research, you need to also make sure that your IC materials are clear on any related risks and the mitigating measures you will take – including through responsible data management.

Got a comment on this checklist or the HREC process? You can leave your comments [here](#)

Signature/s

Please note that by signing this checklist list as the sole, or Responsible, researcher you are providing approval of the completeness and quality of the submission, as well as confirming alignment between GDPR, Data Management and Informed Consent requirements.

Name of Corresponding Researcher (if different from the Responsible Researcher) (print)
Nathaniel Germain

Signature of Corresponding Researcher: 

Date: 04-12-2024

Name of Responsible Researcher (print)

Caroline Wehrmann

Signature (or upload consent by mail) Responsible Researcher:



Date: 26-11-2024

Completing your HREC application

Please use the following list to check that you have provided all relevant documentation

Required:

- **Always:** This completed HREC checklist
- **Always:** A data management plan (reviewed, where necessary, by a data-steward)
- **Usually:** A complete Informed Consent form (including Participant Information) and/or Opening Statement (for online consent)

Please also attach any of the following, if relevant to your research:

Document or approval	Contact/s
Full Research Ethics Application	After the assessment of your initial application HREC will let you know if and when you need to submit additional information
Signed, valid Device Report	Your Faculty HSE advisor
Ethics approval from an external Medical Committee	TU Delft Policy Advisor, Medical (Devices) Research
Ethics approval from an external Research Ethics Committee	Please append, if possible, with your submission
Approved Data Transfer or Data Processing Agreement	Your Faculty Data Steward and/or TU Delft Privacy Team
Approved Graduation Agreement	Your Master's thesis supervisor
Data Processing Impact Assessment (DPIA)	TU Delft Privacy Team
Other specific requirement	Please reference/explain in your checklist and append with your submission

15.5 Coding tree Research phase

Table 3 Coding tree exported from Atlas ti based on broad categories. Some categories are underdivided into subgroups.

Code		Code Groups
○ Actors		
	○ a collaboration between fundamental and clinical researchers	
	○ Clinical researchers	
	○ evaluation panels	
	○ fundamental researcher	
	○ government	
	○ interdisciplinary researchers	
	○ Journals	
	○ pharmaceutical companies	
	○ Research institutions	
	○ Researchers with pharma background	
	○ Translational researchers	
○ assumptions		
	○ clinicians have more funding	
	○ fundamental researchers are more willing to collaborate with clinicians	
	○ Fundamental researchers don't care about translation	
	○ more translational people have it easy finding collaborators	
○ Biographic Info		
	○ Fundamental research	
	○ theoretical background	
	○ Time in the field	
	○ Translational research	
○ bottlenecks		
	○ Access to funding	Resource related bottlenecks
	○ bad maintained information	Knowledge related bottlenecks
	○ bridging people can be rare	Network related bottlenecks
	○ collaborations can be seen as extra	priority related bottlenecks collaborative bottlenecks
	○ Contradictions in literature	Knowledge related bottlenecks
	○ Different interest depending on discipline	priority related bottlenecks

	○ Different language depending on discipline	communication related bottlenecks
	○ different priorities	priority related bottlenecks
	○ Difficulty finding right collaborators	Network related bottlenecks collaborative bottlenecks
	○ domino effect when solving bottlenecks	Systemic bottlenecks
	○ education of researchers	Knowledge related bottlenecks
	○ Inherent difficulty of translational work	Systemic bottlenecks
	○ inheriting projects from supervisors	Systemic bottlenecks
	○ lack of awareness from institutions	Systemic bottlenecks
	○ lack of awareness from researchers	Systemic bottlenecks
	○ Lack of expertise	Resource related bottlenecks Knowledge related bottlenecks
	○ Lack of information transfer	Knowledge related bottlenecks communication related bottlenecks
	○ Lack of larger biomedical hubs in Europe	Systemic bottlenecks
	○ Lack of patient data	Resource related bottlenecks Knowledge related bottlenecks
	○ lack of reality awareness	Knowledge related bottlenecks
	○ Lack of time	Resource related bottlenecks
	○ Legislative barriers	Systemic bottlenecks
	○ multi vs interdisciplinary work	Network related bottlenecks collaborative bottlenecks
	○ neuroscience is a broad field	Knowledge related bottlenecks
	○ Neuroscience is young and needs more fundamental knowledge	Knowledge related bottlenecks
	○ no easy solution	Systemic bottlenecks
	○ no response to contact attempts	priority related bottlenecks communication related bottlenecks
	○ overselling your work for funding	Systemic bottlenecks
	○ Patient's perspective not taken into account	communication related bottlenecks

	○ project focussed benefit consideration	priority related bottlenecks
	○ research competitors	collaborative bottlenecks
	○ research not yet suitable for translation	Knowledge related bottlenecks
	○ science/clinical work priority	priority related bottlenecks
	○ some changes take time to take effect	Systemic bottlenecks
	○ some topics are easier to translate than others	Knowledge related bottlenecks
	○ split in journals	Network related bottlenecks
	○ The Netherlands is a small country	Systemic bottlenecks
	○ time = money	Resource related bottlenecks
	○ Translation is considered extra	Resource related bottlenecks priority related bottlenecks
	○ translation not considered at start	priority related bottlenecks
	○ travel costs	Resource related bottlenecks
	○ Uncertainty in the literature	Knowledge related bottlenecks
	○ unsure on how to contribute	Knowledge related bottlenecks
○ Drivers		
	○ being on the same page with collaborators	Collaboration related drivers
	○ bigger push where it is difficult	Resource related drivers
	○ Easy access collaborators	Collaboration related drivers
	○ Easy access of patient data	Resource related drivers
	○ effective use of resources	Resource related drivers
	○ esteem attracts talent	Systemic drivers
	○ Funding requirement	Resource related drivers
	○ Getting people with the right expertise in the department	knowledge related drivers
	○ Going outside your bubble	Collaboration related drivers
	○ higher chance of success	priority related drivers
	○ Increasing contacts between fundamental and clinical researchers	Collaboration related drivers
	○ institutionally provided platforms to interact	Systemic drivers
	○ large hubs breed translation	Systemic drivers
	○ Making use of personal contacts	Collaboration related drivers

	○ more time for science	Resource related drivers
	○ multidisciplinary projects	Collaboration related drivers
	○ new methods and technology	knowledge related drivers
	○ patient involvement	Systemic drivers
	○ people are motivated	priority related drivers
	○ Personal contacts with clinicians	Collaboration related drivers
	○ Political approaches	Systemic drivers
	○ Promoting collaboration	Collaboration related drivers
	○ reaching out to people	Collaboration related drivers
	○ realistic expectations	knowledge related drivers
	○ Research driven clinicians	priority related drivers
	○ shared responsibility	priority related drivers
	○ shift in priorities funding agencies	priority related drivers
	○ willingness to take risks	priority related drivers
○ goals		
	○ Fundamental understanding	
	○ Making impact	
	○ Translational goal	
○ Limiting factors for collaboration		
	○ balance ask with opportunities provided	
	○ difficult to reach right collaborators	
	○ reaching out is a time risk	
○ Motivation source		
	○ Curiosity	motivation intrinsic to research
	○ funding	motivation extrinsic to research
	○ helping patients	motivation extrinsic to research
	○ increase in quality of research	motivation intrinsic to research
	○ path of least resistance	motivation extrinsic to research
	○ personal experience	motivation extrinsic to research
	○ Profit motivation	motivation extrinsic to research
	○ sometimes translation occurs naturally	motivation intrinsic to research
	○ tangible impact	motivation extrinsic to research
○ Patient data		
	○ Badly maintained repositories	
	○ difficulty finding patient data	
	○ difficulty getting in contact with patients	

	☐ No access to patient data	
	☐ No need for personal patient info	
☐ places to meet new collaborators		
	☐ conferences	
	☐ talks	
☐ potential effects increasing connectivity		
	☐ Consequences of decreasing connections	
	☐ increase impact of research	
☐ more crosstalk between fundamental and clinical research		
	☐ more translational activity	
	☐ quality increase	
☐ successes at collaborative level can inform systemic changes		
☐ potential solutions		
	☐ Need for simple explanations	
	☐ overview of general patient information	
	☐ professional bridgers	
	☐ Public patient database for researchers	
☐ reasons for collaboration		
	☐ clinicians have access to data and knowledge	
	☐ Expertise requirement	
	☐ Funding requirement	
	☐ Lack of resource	
	☐ translational expertise	
☐ Research targets		
	☐ Animal models	
	☐ Effect of drugs	
	☐ Human subjects	
	☐ patient-based research	
	☐ Priorities regarding diseases to research	
☐ Results of bottlenecks		
	☐ Limiting scope	
	☐ No success overcoming bottlenecks so far	
☐ Social network model		
	☐ balancing of network	
	☐ bridging region	

	○ bridging region as mediators across fields	
	○ Fully saturated networks are less efficient	
	○ No disadvantage of highly connected clusters	
	○ small world networks	
○ System levels		
	○ Problems at collaborative level	
	○ Problems at systemic level	
	○ Problems at the individual level	
○ Timing for finding collaborators		
	○ During grant writing	
	○ During the project	
○ Timing for translational input		
	○ During grant writing	
	○ During the project	

15.6 Coding tree Design phase

Code	
○ Advice	
	○ explore similar institute internationally
	○ look outside your own context as well
	○ talk to a lot of people
	○ What not to do
○ alternative models	
○ Barriers and trade-offs	
	○ centralisation and power to change
	○ Competing with own field
	○ conflicting roles
	○ distribution of people is distribution of knowledge
	○ knowledge is constantly lost
	○ little available knowledge
	○ maintaining mission in a decentralised network
	○ mobilising targets the most active people
○ Biographic info	
	○ organisation characteristics outside scope
	○ Origin of organisation
	○ Role in organisation
	○ Time of involvement
○ good things about the model	
	○ autonomy is clear
	○ centralisation is clear
	○ positive reception
	○ recognition
○ model criticism	
	○ autonomy as independence of institution or network?
	○ does not capture a political position, but that might be all right
	○ leave outreach
○ Organisation activities	
	○ counselling talks
	○ Event organising
	○ influencing those in power
○ Other organisations	
	○ network organisation
	○ Previous failed attempt
○ Polestar goals	

	○ Equal chances for people
	○ reciprocal trust
○ Relationships between roles	
	○ building connections through knowledge
	○ Different people focus on different roles
	○ Equal importance of roles
	○ expertise-based considerations regarding network role
	○ Receiving knowledge through connections
	○ sharing knowledge through connections
	○ Steering systemic change based on expertise
	○ Steering systemic change through connections
○ Roles of organisation	
	○ advocacy
	○ agitating
	○ connecting
	○ coordinating
	○ distributing of resources
	○ educating/informing
	○ increasing power
	○ Intertwined roles
	○ knowledge aggregation
	○ mobilising
	○ pioneering of strategy
	○ producing
	○ systemic change
	○ training people
○ social capital	
	○ bonding
	○ bonding vs bridging
	○ bridging
○ stories	
	○ success story
○ Strategic considerations	
	○ an antagonistic relationship between groups
	○ Autonomy
	○ avoiding connecting them to the same few people
	○ awareness of what is already being done
	○ Balancing criticism on the system with collaboration

	○ capacity management
	○ Centralisation
	○ connecting as a goal vs a tool
	○ Fixing what is broken vs optimizing what is good
	○ Limiting your scope
	○ mandate
	○ Most advanced, yet acceptable
	○ Needs are context specific
	○ Priorities are time dependent
	○ Prioritisation of particular roles
	○ reach
	○ resource division across roles
	○ Safeguarding impartiality
	○ Standing between groups
	○ the network is the organisation
	○ the power to change
	○ theory of change
○ tactics	
	○ Actively approaching people
	○ being approached
	○ Engaging the network
	○ find people where they are at
	○ inviting specific people

15.7 Case 1: The outside expert (Het NEWS)

15.7.1 What is Het NEWS?

The Nationaal Expertise Centrum Wetenschap en samenleving (NEWS) is a Dutch organisation that offers expertise regarding science communication. They act as a sort of consultancy bureau for questions and advise on how to share your scientific work with society at large. Their goal, as it is stated on their website, is to increase connectivity between science and society through improved scientific communication. In their founding report, they lay out three strategic lines: expertise, connection, and system (A. Verkade, 2023). These three lines echo almost exactly the three roles of intermediaries discussed above: knowledge brokering, network managing, and system transitioning. To increase insight in the strategic considerations made during the founding of this organisation, Prof. Ionica Smeets, quartermaster, founder, and head of the board of Het NEWS was interviewed. The insights and descriptions presented below are based on this interview, the founding report (A. Verkade, 2023), and some relevant literature.

15.7.2 Roles and approach

“Those [three roles] can’t be seen separately, [...] they of course strongly belong together”

Het NEWS actually wasn't the first attempt to create an organisation that focussed on improving science communication. “Stichting WeTen” was a different organisation tasked with doing science communication, distributing financial resources for projects doing science communication, and connecting the field. These three roles were in conflict, as Smeets describes: *“[that threefold role] is of course very inconvenient if you need to bring everyone together. ‘You get money, and you don’t’, and then you also organise your own activities with which you compete [with others in the field]?”*. That is why, according to Smeets, they concluded that they should become an expertise centre instead. Instead of conflicting, the three roles of Het NEWS are crucially intertwined, supporting each other. She explains: *“A natural part of collecting expertise and connecting people is sharing and spreading the expertise and using the connections yourself to receive knowledge out of other areas. [...] The system transitioning is of course carried by the needs of the field, which you get through your connections and expertise.”* Using expertise to articulate demands was also recognized by (Howells, 2006) as a function of the intermediary in the context of consultancy firms.

This overlap in their expertise and networking role led to an important decision regarding the way people with questions are approached. While many people requested a database to make it easy to find someone with particular expertise, something also suggested by

participants in the research phase of this project, Prof. Smeets actually stresses that this is a bad idea. The reasoning is twofold, firstly it takes a lot of work to build, maintain, and update such a database, but, more importantly, it takes away the opportunity to connect with the field. Through active engagement with the people asking questions you build relationships, are able to figure out what is going on in the field and connect people if they might be able to help each other.

While intertwined, these three roles have varying priority depending on the context, which is both time and environment dependent. Smeets notes that right now, during the first few years of Het NEWS, the connecting with people is the most important, but in a later stadium a different role may take priority. She also notes the importance of your true goals vs your methods and approaches. While these three strategic lines are important, they are in service of the true goals. Science communication is the tool and the three strategic lines the ways to use that tool to achieve your goals, or as Smeets puts it: *“Why do you do it? Equal chances for people, and reciprocal trust between science and society. It is good to make that clear, because our goal is not necessarily better science communication. If the connection between science and society is completely fine, well that is what ultimately matters.”* This nuance is expressed in the Theory of Change of Het NEWS (A. Verkade, 2023), a model that describes how a set of activities is meant to achieve a particular outcome during a process (Belcher B, 2020).

15.7.3 Strategy and tensions

“I strongly believe that improving things that are going bad a little, might make more sense than making things that are going all right excellent.”

Several strategic considerations were important during the founding of Het NEWS. Firstly, the tension between people who are already quite far in the system transition and those lagging behind a little. In this case these are the people performing advanced participative research and the university boards. They resolved this tension using the MAYA principle, coined by Raymond Loewy (Kulik, 2003), which suggests looking for the most advanced, yet acceptable solution. Or in the word of Smeets: *“a mission that is acceptable for people already far ahead in the field, so that they can say ‘this is going in the right direction.’, but not so advanced that university boards think ‘ok do we actually want to do this?’.”* She also adds: *“I strongly believe that improving things that are going bad a little, might make more sense than making things that are going all right excellent.”*

A second important consideration concerns the competition with other organisations and the context in which you operate. As was mentioned in the discussion surrounding stichting WeTen, it becomes awkward when you are competing with the people in the field you are

supposed to work with. This is why Het NEWS has opted not to, for example, give their own training on science communication, but instead helps develop training packages and let other organisations that already give similar trainings use them. Smeets explains that it is important to be aware what is already available in your country and which organisations exist to avoid competing with those you work with and not waste limited capacity on something that already exists.

15.7.4 Position to the network

“Are you a fraternity, a mall, or Paw patrol to the rescue”

Lastly, and very importantly according to Smeets, was the independence of the organisation. Being autonomous from any already existing institution comes with a variety of benefits: it allows you to expand your scope, and it allows you to stand between different parties. She explains that she wants to be “a critical friend”, though for some more critical and other more a friend and that *“even if you would have the same organisation structure, mission, and everything, but you are embedded within the university of Leiden, even if you are called a national institute you are not taken seriously as an organisation when telling the university of Utrecht ‘hey guys, you should do this differently.’”*

When asked which of the three models depicting relations to the network fit Het NEWS the best, Smeets chooses B. She explains that being more distributed reduces the power you have to get things done. She notes an interesting nuance as well, independence from an institution is not the same as independence from the network. The autonomy of Het NEWS is crucial, yet they are deeply embedded in the network through their connections with partners. They have described themselves as a puzzle piece that connects policy makers, science communication researchers, and science communicators. The way they considered their relationship to the network was according to a *slightly* different model put forward by someone they talked to in the founding process. This person put forward three options: *“Are you a fraternity, a mall, or paw patrol to the rescue!”* In other words, are you an elite group that you want to be a part of, an open space everyone can come in and out, or are you a team that comes running when someone needs help. Smeets and Verkade were quickly convinced by the third option.

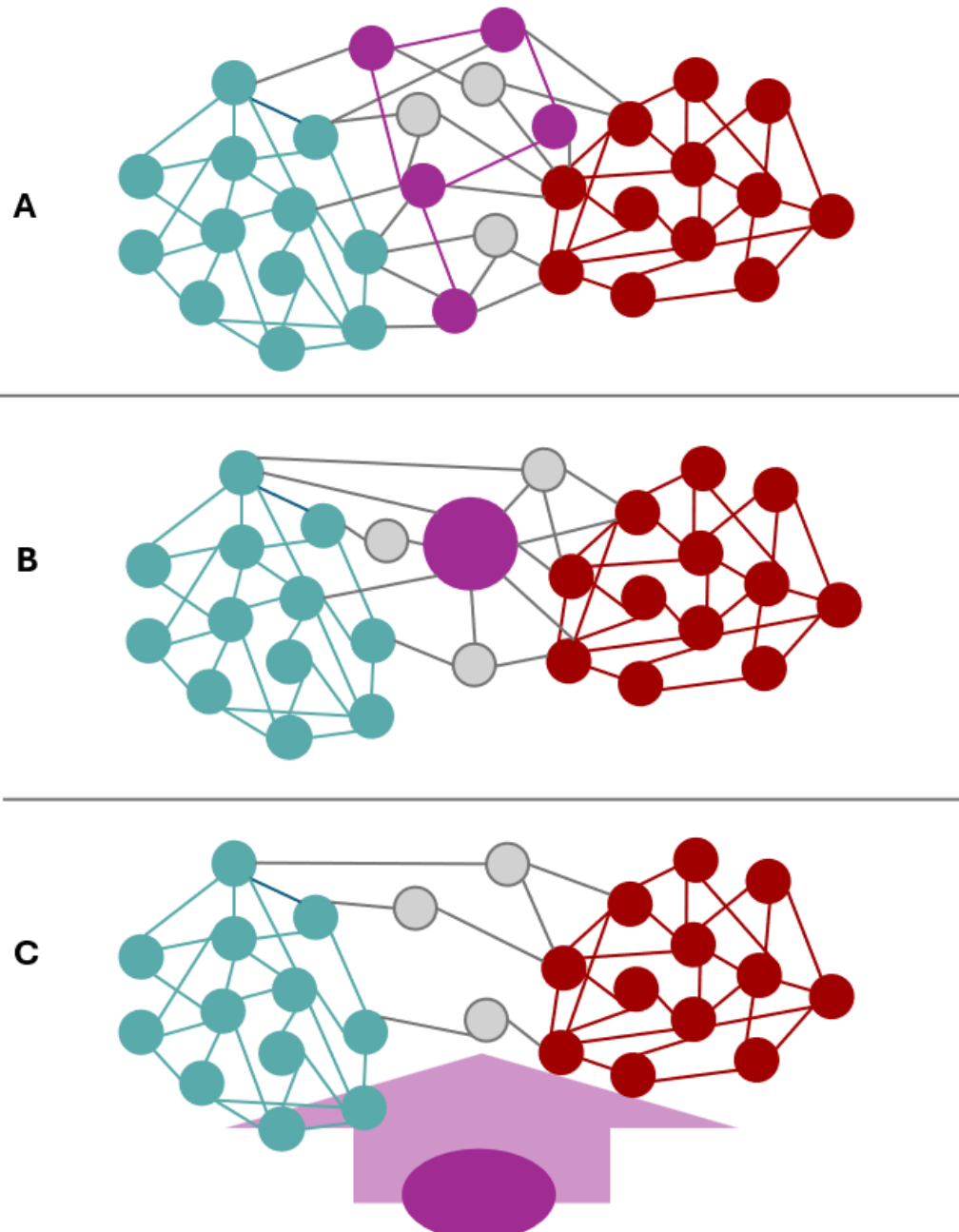


Figure 24 a depiction of different relationships to the network based on the network governance model of (Provan & Kenis, 2008).. In A, the organisation is characterised by their decentralised nature. B is characterised by being a centralised organisation but still embedded within the broader network. C is characterised by both being centralised but separate from the greater network.

15.8 Case 2: The organisation is the network (STUUR)

15.8.1 What is STUUR?

STUUR is the local student union in Rotterdam and, according to its previous chair, one of the front runners in adapting to an organising approach in the Netherlands. In the theoretical framework the difference between mobilizing, advocating, and organising approaches described by McAlevey (2016) was compared to the network management approaches inspired by the governance models of Provan and Kenis (2008). Jasper Schut, previous chair of STUUR, wrote his thesis on this shift to an organising strategy within unions and was responsible for introducing this approach in STUUR and other student unions. This change in strategy has changed the way STUUR positions itself towards the network of students and people in power, as well as adopt a new theory of change to enact systemic transitions. While the goal, changing local systems such that it benefits students more, has not changed, the philosophy on how this change occurs has. The below insights and descriptions regarding STUUR and this strategy shift are based on an interview with the previous chair, Jasper Schut and relevant literature.

15.8.2 Roles and approaches

“The tools and the goals are so heavily intertwined there is no way around it”

STUUR describes its mission on the website based on three strategic lines: inform, organise, and protest. Informing happens both on a small scale and a larger one. Both individuals as well as other organisations are taught how this strategy works and what their role is. Schut explains *“We are one of the unions that is pioneering this new theory of change within the student unions and even the Dutch left. [...] So I personally gave a lot of workshops.”* This has resulted in STUUR being a hub of knowledge that it shares and distributes across different organisations within the country, but also actively creates new knowledge given the little that has been built up in the field. According to Schut, there is very little available knowledge on how to put the new theory of change into practise within the particular context of the Netherlands.

The network management role is, as the previous chair says: *“Their entire function, the whole raison d’être”*. The building of communities, getting people together, and connecting them to each other for collective action is the cornerstone of their new Theory of Change. Schut also explains that this role always existed to some degree, but now it is explicit and raised from an instrumental tool to an explicit goal. *“First, the binding of members was a way to survive, I think a way to earn enough money to fund the advocacy. [...] Now it is the*

whole point, it maybe always was, but the tools and goals are so heavily intertwined now that there is no way around it”

STUUR has a role in systemic change at both the local and national levels, but in a different sense. Locally, educating and organising students is meant to allow them to enforce changes within their institutions. Nationally, STUUR tries to push similar organisations to adopt this organising approach, changing the strategies of unions and other organisations throughout the country. At both levels, the knowledge broker and network manager role are there to support the systemic changes STUUR tries to accomplish.

15.8.3 Strategy and tensions

“We are trying to organise it in such a way that these people can then reach out to others, because capacity is always an issue.”

Like Het NEWS, the autonomy of STUUR is important to the way it functions. Schut does explain a nuance to this concept of autonomy: “*We are fully autonomous from any institutes, but not from the students.*” Reaching out to people that are not already on your side is an explicit part of the organising strategy (McAlevy, 2016). There is some tension there, how do you maintain a particular point of view as an organisation when some people in the network look at things differently. Schut describes the tension as follows: “*Are we autonomous? Yes, because we maintain [our point of view], even while we claim to organise all students. I think that is possible as a union and it is an inherent part of being a union.*” The strategy to actively reach out to people that may not already agree with you and try to organise them anyway is similar to an issue advocate role as described by (Pielke, 2007). STUUR is engaged in advocating for a particular approach and attempts to convince both individuals and organisations to adopt it in an effort to improve conditions for students.

A trade-off that comes with this organising strategy is that it takes a lot of time and capacity, reducing your ability to focus on other things. However, mobilising and advocating also stand in the way of organising, according to Schut, he explains “*You operate on different basic assumptions, you are not centring students.*” Even with just the focus on organising, STUUR still depends on the self-selection of people. “*At the moment [STUUR] is mostly being approached by people. [...] We are trying to organise it in such a way that these people can then reach out to others, because capacity is always an issue.*” Increasing STUUR’s engagement with the wider network is thus a process that depends on the available capacity resulting from active members.

15.8.4 Position to the network

“When [students] come together, we call it a union, but it is not an external organisation.””

When asked to select which depiction of the three relationships to the network (Figure 24) fits best to STUURs current identity, Schut selects A, the decentralised and distributed relation. He explains his choice as follows: “The union and the workers, and in this case the students, are one and the same” When asked if this has changed compared to the previous, more advocacy and mobilisation approaches, he states that it definitely used be more like B. *“While [STUUR] was still part of the population, because it did have members, [STUUR] played a much more mediating role from the student population towards the people in power, but as an external organisation.”* This shift has had several consequences for how STUUR positions itself towards different actors in the network.

First, STUUR really is nothing more than the network itself. Schut describes it as follows: *“The union is nothing else but its members, or actually not even its members, but nothing else than the students that come together in a particular structure. When they come together, we call it a union, but it is not an external organisation.”* This means that STUUR now positions itself differently towards students. Schut: *“You need to centralise the people and explain that nothing will change without them. [...] A good counter example is the old title of the website ‘We take action for you’, well why would I still need to become a member then?”* The current website reads “make yourself heard” and “only together can we create change.”

Secondly, because STUUR no longer positions itself as an external organisation it no longer mediates between two parties, the students and people in power. *“STUUR is not an external organisation, it just isn't. It is about two parties with an antagonistic relationship: the government or university board, and the students. [...] In this case, STUUR has no bridging function in that sense.”* Schut explains.

15.9 Interview protocol Het NEWS

Introduction

After an introduction to the topic, Interviewees are walked through the informed consent form which includes. Once they have signed the form, giving consent to record the interview, the recording starts, and the interview begins.

Definition translational research: “*Research that aids in the translation of fundamental research findings into clinical research (and eventually implementation)*”

Contrary to the previous interviews, these will take a slightly different approach. Instead of interviewing multiple people from a similar background to find common themes, I will only be interviewing a small cohort of people, each from a different background. The goal is to discuss similarities and differences between the organization they were a part of and this hypothetical translational hub. We will look at how the context of their problem led to certain decisions and compare these to the translation hub's context.

Interview questions

Keuzes en context NEWS

- Kun je in je eigen woorden kort beschrijven wat je rol was tijdens de oprichting van Het NEWS
- Het NEWS werkt volgens drie strategische lijnen, expertise, verbinding en systeem. Kun je wat vertellen over in hoeverre dit onafhankelijke paden zijn of wanneer ze juist kruisen?
 - Zijn ze ooit in conflict met elkaar?
 - Zijn er punten waarop ze nauw overlappen?
- Hoe balanceer je die drie rollen?
- Als je prioriteit zou moeten geven aan elk van deze rollen, hoe zou de volgorde er dan uit zien?
- Heeft deze prioriteit een rol gespeeld in het opzetten van Het NEWS?
- Het missiestatement leest als volgt “Het centrum bevordert verbinding tussen wetenschap en samenleving door betere wetenschapscommunicatie.” is de verbinding expliciet het doel en de betere wetenschapscommunicatie het middel?

Expertise

- Kun je het verschil uitleggen tussen wel het trainingsaanbod verrijken, maar geen trainingscentrum zijn?
- In het rapport staat ook dat jullie er bewust voor hebben gekozen om hulpvragen met persoonlijk contact te beantwoorden ipv online databases of online hulpmiddelen. Kun je wat uitbreiden over de relatie tussen deze aanpak en de verbindende rol van Het NEWS?

- Wat is de balans tussen experts erbij halen en zelf de expertise aanbieden?

Verbinding

- Hoe pakt Het NEWS de verbindende rol op?
 - Welke middelen gebruikt NEWS
- Wanneer pak je zelf het initiatief om iemand te benaderen.
- Hoe zou je de positie van Het NEWS ten opzichte van het veld beschrijven?
- Welke van deze drie modellen past het best bij Het NEWS?
- Kun je uitleggen waarom?
- In welk opzicht verschilt de aanpak van Het NEWS op het punt van netwerken bouwen en onderhouden ten opzichte van een netwerkvereniging zoals scicom NL?

Systeem

- Hoe heeft de keuze om een constructieve partner op verschillende systeemniveaus te zijn de, vormgeving van de organisatie beïnvloed.
 - Eén van de pijlers is “Systeem” waar het volgende wordt gezegd: “NEWS werkt als constructieve partner op verschillende niveaus in het kennissysteem aan het wegnemen van drempels en optimaliseren van randvoorwaarden voor wetenschapscommunicatie.”
- Kun je iets meer vertellen over de reden om het NEWS helemaal onafhankelijk van andere partijen te houden. In het verslag worden deelbelangen genoemd, waar moet ik dan aan denken?
- Beïnvloed het meer helikopter perspectief het gemak waarmee Het NEWS in contact komt met het werkveld?

Organisatie

- Kun je kort schetsen in welke opzichten vergelijkbare centra in het buitenland overeenkwamen en verschilden?
 - Hoe had dit impact op de vormgeving van NEWS

Afsluiting

- Aan de hand van dit model, hoe zou je Het NEWS karakteriseren?
- Is er nog iets wat we niet besproken hebben, maar wel belangrijk is in deze discussie?

15.10 Interview protocol STUUR

Introduction

After an introduction to the topic, Interviewees are walked through the informed consent form which includes. Once they have signed the form, giving consent to record the interview, the recording starts, and the interview begins.

Definition translational research: “*Research that aids in the translation of fundamental research findings into clinical research (and eventually implementation)*”

Contrary to the previous interviews, these will take a slightly different approach. Instead of interviewing multiple people from a similar background to find common themes, I will only be interviewing a small cohort of people, each from a different background. The goal is to discuss similarities and differences between the organization they were a part of and this hypothetical translational hub. We will look at how the context of their problem led to certain decisions and compare these to the translation hub's context.

Interview questions

Keuzes en context STUUR

- Kun je in je eigen woorden kort beschrijven wat je rol was bij STUUR?
- Hoe zou je de rol van STUUR, en andere studentenbonden, beschrijven
- Hoe balanceer je die rollen?
- Als je prioriteit zou moeten geven aan elk van deze rollen, hoe zou de volgorde er dan uit zien?
- STUUR heeft een strategische shift gemaakt in het afgelopen jaar, kun je die toelichten.
- Kun je beschrijven hoe die strategische shift invloed heeft gehad op hoe STUUR zich positioneert ten opzichte van de samenleving

Expertise

- In hoeverre heeft STUUR een rol in het verzamelen, creëren, en distribueren van kennis?
- Wat voor kennis is dit dan?
- Hoe belangrijk is deze informerende taak ten opzichte van andere taken?
- Is het belang van deze taak veranderd na de strategische shift?
- Zijn er strategische of praktische trade-offs met betrekking tot deze expertise rol?

Verbinding

- In hoeverre heeft STUUR een rol in het verbinden van mensen met elkaar?
- Zijn dit veelal mensen met dezelfde achtergrond of juist ook tussen mensen van verschillende achtergronden (bijvoorbeeld studenten en machthebbers)?

- Hoe verhoudt de balans zich tussen benaderd worden door mensen en actief mensen benaderen?
- Welke van deze drie modellen past het best bij STUUR?
- Kun je uitleggen waarom?
- Is dat veranderd aan de hand van de strategische shift?
- Zijn er strategische of praktische trade-offs met betrekking tot deze verbindende rol?

Systeem

- In hoeverre heeft STUUR een rol in systeemveranderingen teweeg te brengen?
- Hoe heeft de strategische shift invloed gehad op deze rol?
- Hoe autonoom is STUUR ten opzichte van het netwerk?
- Hoe heeft de autonomie effect op de invloed die je hebt op het veranderen van het systeem?
- Op welke levels van het systeem heeft STUUR invloed?
- Hoe heeft de strategische shift invloed gehad op de autonomie en de levels waar STUUR invloed heeft?
- Zijn er strategische of praktische trade-offs met betrekking tot de systeem veranderende rol?

Organisatie

- Zijn er significante verschillen die STUUR karakteriseren ten opzichte van andere vakbonden op basis van hoe de organisatie gestructureerd is of te werk gaat?
- Wat zijn de strategische of praktische overwegingen die hieraan ten grondslag liggen?

Afsluiting

- Aan de hand van dit model, hoe zou je STUUR karakteriseren?
- Heb je het idee dat er een belangrijke eigenschap niet gevat wordt in dit model?
- Is er nog iets wat we niet besproken hebben, maar wel belangrijk is in deze discussie?

Informed consent – information

Dated: 04/07/2025

The following interview is part of my (Nathaniel germain) Thesis project. The topic will be the strategic organisation of intermediary organisations and how they handle their specific roles. The interview will be conducted by me, a TU Delft master student, and take approximately 30 minutes.

Questions will regard participant's professional experience with intermediary organisations. The studies aim is to understand which strategic choices were made based on the aims of the organisation and use this understanding to design a potential intermediary to facilitate more efficient translation.

To assure proper data collection, the audio will be recorded. These recordings will be stored on a secured storage environment of the TU Delft, are exclusively used for transcription, and will be destroyed once transcribed. Recordings and transcriptions will only be accessed by me and my primary supervisor (Caroline Wehrmanm). Transcriptions will also be destroyed once the project is concluded. Depending on the preference of the participant, personal information can be removed from the transcripts and left out of the final work. When requested, participants can see the transcripts from their own interview and ask for rectifications or erasure of particular segments. If the participant gives explicit consent, quotes may be used in the final thesis.

The aggregated results published in my final thesis will be uploaded in the TU Delft repository. When signed, this form will be stored in a database from the TU Delft.

Participation is voluntary and withdrawal is possible at any time. You are also free to not answer particular questions.

For questions, remarks, and requests of transcripts you may email me at [REDACTED]

Questions for my supervisor can be directed to [REDACTED]

Please tick the appropriate boxes

Yes **No**

- | | | |
|--|--------------------------|--------------------------|
| 1. I have read and understood the study information dated [04/07/2025], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction. | ☐ | ☐ |
| 2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions, and I can withdraw from the study at any time, without having to give a reason. | ☐ | ☐ |
| 3. I understand that any audio recordings and transcriptions will not be made available to anyone but Nathaniel Germain and their supervisor Caroline Wehrmann. | ☐ | ☐ |
| 4. I understand that the audio recordings are destroyed once the interview has been transcribed, and that the transcriptions are destroyed once the project is concluded. | ☐ | ☐ |
| 5. I understand that I can request access to the notes or transcripts from my interview and ask for the rectification or erasure of particular segments. | ☐ | ☐ |
| 6. I consent to being recording with Audio. | ☐ | ☐ |
| 7. I consent for my name and role during the establishing of “[organisation]” to be a part of the research outputs. | ☐ | ☐ |
| 8. I consent to my responses, views or other input to be quoted in research outputs. | ☐ | ☐ |

Signatures

Name of participant	Signature	date

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Researcher name	Signature	date