CBS COPENHAGEN BUSINESS SCHOOL
HANDELSHØJSKOLEN

Securing Access to Pharmaceuticals in Developing Countries

An interview-based study on access to treatment for sickle cell disease patients

MSc in Business Administration and Innovation in Health Care

Supervisor: Pedro Oliveira

Date of submission: 17th January 2022

Number of characters and pages: 112,239 / 65

Master's thesis

Zsofia Keszthelyi

Student number: 133305

ABSTRACT

This thesis is aimed at exploring the issues and solutions concerning access to treatment in developing countries, focused on a genetic blood disorder, sickle cell disease. The research launches from the issue statement that despite local and global efforts, access to essential medicines is problematic for more than two billion people worldwide.

To address this problem, the investigation is led by two research questions and a sub-question. The first two relate to exploring the causes and consequences of insufficient pharmaceutical access, as well as to researching existing solutions and potential solution ideas. The sub-question of this research is concerned with the feasibility of creating a solution that is sustainable financially, socially, and environmentally.

In order to find these answers, an inductive approach is followed, where a literature review serves as a supporting backbone to the primary data collection method, semi-structured qualitative interviews. In total, eight interviews are conducted with experts in several fields, such as supply chain management, access to care, and medicine. These interviews provide insightful data for analysis, which is conducted by finding common themes with the NVivo software.

The main takeaways of this research are that (1) the issue with accessing treatment actually starts with issues with accessing care, so the whole supply chain should be looked at holistically; (2) the most commonly mentioned issue was the lack of financial resources on both country and individual/family levels; (3) the lack of information, proper education and training, and awareness of specific diseases hinder the access to care; (4) reaching sustainability is a long way ahead, but steps can be taken to ultimately achieve well-functioning supply chains and extended pharmaceutical production in developing countries. Based on these and other takeaways, combined with ideas from already existing research, three recommendations are formed for stakeholders in the pharmaceutical supply chain. These are related to the need for solutions to be locally embedded; the importance of stakeholders moving away from their silo mindsets; and the tailoring of solutions to specific markets and disease areas.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

1 INTRODUCTION

1.1 Problem formulation

1.1.1 Personal motivation

As a student in health care innovation, I have learned about equity (or rather inequity) in health care, the difference between effectiveness and efficiency, bottlenecks in the supply chain, global trends affecting all health care systems, and several other topics that related to the understanding of how these systems work. As a professional in management consulting and then in the pharmaceutical industry in the Medicon Valley, I have developed a curiosity to analyze the issues I was facing and find solutions to them.

This lead me to a thesis topic focusing on the access to pharmaceuticals in developing countries, more specifically directed towards sickle cell disease. My goal with this thesis is to explore this problem field from issue to solution, and potentially find a sustainable angle to my recommendations in the end. I am hoping to deliver some outcomes of this research that would help stakeholders with prioritizing their efforts. Last, but not least, this thesis will also contribute to my learning journey. As I have only been personally exposed to health care issues and improvements in the developed world so far, I am eager to hear and read more about developing countries.

The importance of this topic can be seen by the large amount of research that has already been completed and the global discussions around it. In the upcoming sections, I will introduce the topic and its relevance in more detail, then discuss global steps that have already been taken to tackle these issues. I will then introduce my research by stating the research questions and defining the scope of the thesis.

1.1.2 Issue statement

The Constitution of the World Health Organization (WHO) states that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (Lee & Hunt, 2012). *Even though access to pharmaceuticals and*

care are fundamental for this basic human right, "access to essential medicines is problematic for one third of all persons worldwide" (Stevens & Huys, 2017 p. 1).

In developed countries, health care and access to pharmaceuticals is normally taken for granted, it is a part of life. However, as seen from the quote above, the availability of these services cannot be considered a given. Despite local and global efforts, for a lot of our peers, the security of a health care system is not evident. This inequity is visible not only in health care, but more specifically in the pharmaceutical sector too.

Health care systems around the world are all facing issues related to an aging population and increasing costs of health care. However, there are several characteristics dividing developed and developing countries in terms of the hardships they encounter. Developed countries are more affected by changes in their diets, urbanization, and sedentary lifestyles (Steele et al., 2019). Developing countries however are exposed to tropical diseases, issues with hygiene and bottlenecks in the infrastructure (Stevens & Huys, 2015). The latter are further hindered by the fact that they rely on donations to improve their facilities and in the recent years donors' attention is divided among several global challenges, leaving developing countries in uncertainty (Dieleman et al., 2016).

Steele et al. (2019) suggest that pharmaceutical companies are believed to be the key to public health growth, as they have the power to improve supply chains, provide medicines at affordable prices, and introduce new products and technologies. They further argue that these companies should aim to ensure that pharmaceuticals are available and accessible everywhere. However, pharmaceutical companies also face more challenges, such as a pressure from governments to reduce their drug prices, barriers to entry in emerging markets, and an increased usage of generic drugs (Gunasundari, 2018). The COVID-19 pandemic highlighted the dependence of developing areas (e.g. Africa) on the import of pharmaceutical and medical goods. The crisis has also shown the production potential of African companies, as they were able to adapt their facilities to manufacture medical products (disinfectants, masks, etc.) amidst the pandemic. However, there still remains the question of trust in local producers in terms of product quality (ECA, 2021).

1.1.3 Sustainable Development Goals

Sustainable development is defined as "development that meets the needs of the present without compromising the ability of future generations to meet their own needs" (UN, n.d.). Achieving sustainable development depends on global efforts to harmonize economic growth, social inclusion, and environmental protection.

The Sustainable Development Goals (SDGs) were agreed upon by the United Nations (UN) in 2015 as part of the 2030 Agenda for Sustainable Development. The Member States defined 17 goals (Appendix A) with the aim to end poverty and inequality, protect the planet in the midst of climate change and environmental degradation, and improve the lives of everyone by bringing peace and justice to all. While these goals are not legally binding, all stakeholders are expected to contribute to their realization, such as governments, the civil society, the private sector, and others.

Of these, Goal #3 is about ensuring healthy lives and promoting well-being for all at all ages. They have set several targets to be reached by 2030, mostly focusing on under-five and maternal mortality, communicable diseases, substance abuse, prevention and access to health care services, as well as the health workforce. Target 3.8 specifically relates to the topic of this thesis: "Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all" (UN, n.d.). While the member countries achieved great results in the first five years, the COVID-19 crisis disrupted these improvements. As health systems have been overwhelmed globally by the pandemic since the beginning of 2020, growth in the provision of health services must highly accelerate if targets are to be reached by 2030 (UN, n.d.).

The COVID-19 pandemic has further highlighted the disparities between countries' abilities to cope and recover from the crisis. The United Nations Development Program (UNDP) created a dashboard to illustrate the reasons for these differences, focusing on specific measures in the health care sectors (Appendix B). Table 1 below shows an extract of this dashboard to highlight differences between the Organisation for

Economic Cooperation and Development (OECD), developing countries, and least developed countries. Interestingly, much bigger differences can be seen in terms of the number of health workforce and hospital beds than in the number of mobile phone subscriptions. Unfortunately, Internet seems to be much less accessible in developing and least developed countries (UNDP, 2020).

Table 1
Extract of the UNDP Preparedness dashboard

	Health System			*Connectivity*	
	Physicians	**Nurses and midwifes**	**Hospital beds**	**Mobile phone subscription**	**Fixed broadband subscriptions**
Region	(per 10,000 people)			(per 100 people)	
	2010-2018	2010-2018	2010-2018	2017-2018	2017-2018
OECD	28.9	80	50	119.3	31.6
Developing countries	11.5	23	21	99.2	10.2
Least developed countries	2.5	6	7	70.9	1.4
World	14.9	34	28	104.0	14.0

Note: the darkness of the cells increases from low to high values, where light means low and dark means high (more favorable) values

Source: UNDP, 2020

A concrete example of working towards Goal #3 of the UN SDGs is a collaboration between the Access and Delivery Partnership, the Ministry of Health in Ghana, and other strategic partners. As a result, the Ministry of Health launched a revised National Medicines Policy, including a detailed 5-year implementation plan. The key goals of this policy are:

- "improving affordability and cost-effectiveness of health technologies through strategic pricing and procurement approaches (e.g. institutionalizing Health Technology Assessment);
- ensuring safety, quality and efficacy of health technologies through regulatory control strengthening and pharmacovigilance; and
- strengthening supply chain management for the effective delivery of health technologies".

The government's action is believed to improve access to health in Ghana by ensuring a more sustained access to safe and affordable medicines and other health technologies (Amankwa & Bhatnagar, 2018).

1.2 Research questions

As seen from the above introduction, pharmaceutical access is indeed influenced by both global and local trends in the fields of health care, economic developments, supply chains, etc. Furthermore, aspirations for improvements have also been on the agenda for quite a while now. However, despite all efforts, there are still more than 2 billion people who do not have secure access to treatment (Stevens & Huys, 2017).

Commencing from this issue statement, the following research questions and one sub-question will be investigated:

- *Research question #1:* What issues are present in pharmaceutical supply chains that hinder the access to treatment in developing countries?

- *Research question #2:* How can the issues around access to pharmaceuticals in developing countries be solved?
    - *Sub-question:* How can these solutions become sustainable financially, socially, and environmentally?

1.3 Scope and delimitation

As foreshadowed at the beginning of this chapter, the thesis is focused on pharmaceutical access in developing countries, especially targeting sickle cell disease. The research will aim to find answers to the above research questions through the analysis of related literature, experts' opinions, as well as my personal interpretation and knowledge gained during my studies and professional experiences. The goal of this thesis is to condense several viewpoints and deliver some substantial recommendations for research and practice.

The reason for having sickle cell disease as a focus area of this thesis is twofold. Firstly, being realistic about the timelines of a master's thesis, I had the intentions to narrow down the topic and be more focused within my research. Secondly, the initial conversations I had with experts in the field of access suggested that there are differences not only in access, but also in the issues around access to treatment among the specific disease areas. As a result, sickle cell disease was chosen as a condition highly prevalent in e.g. Sub-Saharan Africa, with the intention to serve as a proxy for other disease areas.

In the upcoming sections I will provide an overview of the two main components of the scope: developing countries and sickle cell disease.

1.3.1 Developing countries

For the clarity of this thesis, it is important to define which countries are referred to as developing. Nations are often referred to in specific groups based on some kind of common features (e.g. geographic location, level of development) in order to analyze them. Depending on the given characteristics, several different terminologies can be used and I will explain the most frequent ones below.

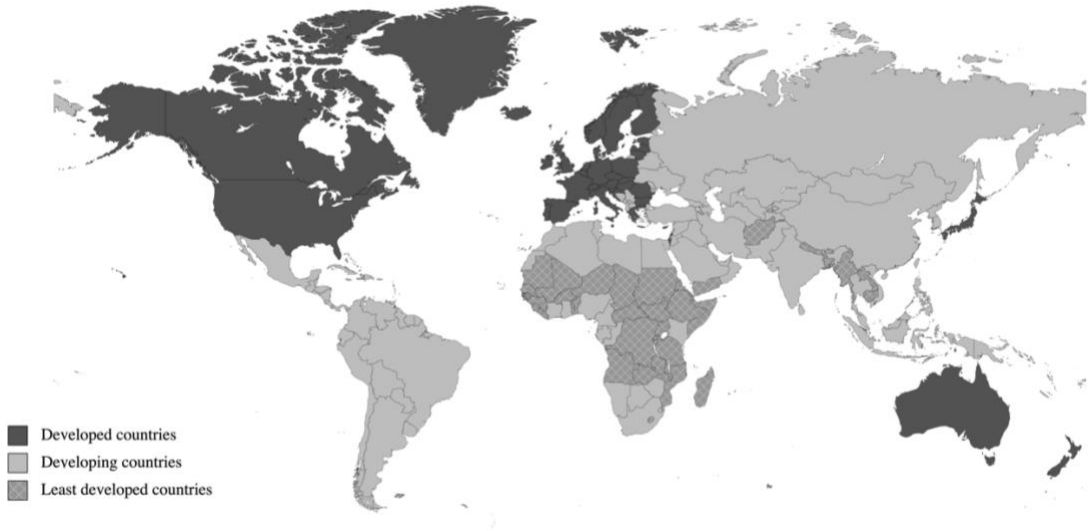
In the second half of the 20th century, the world was divided into four parts. The First World included the United States and Western Europe, the Soviet Union and its allies formed the Second World, and the rest of the nations were referred to as the Third or Fourth World. This division was created according to economic status (e.g. GDP) and other socio-economic metrics (e.g. unemployment rate). Due to its negative connotation

and irrelevance (i.e. the Cold War has long been over and the Soviet Union does not even exist anymore), there are more appropriate terminologies in use (Banton, 2020).

The World Bank uses a classification by income, and determine the following categories: low-, lower-middle, upper-middle, and high income countries. The low- and middle income countries (LMICs) together were also referred to as the developing world. However, due to the increasing dissimilarity among these countries, the World Bank started to use more specific categories in the recent years, e.g. low-income countries in East Asia (Khokhar & Serajuddin, 2015).

The International Monetary Fund only set two categories without a strict criteria: Advanced economies (similar to high-income countries) and Emerging market and developing economies. The UNDP use the Human Development Index to group countries into very high, high, medium, and low levels of human development. The index measures countries' wellbeing in terms of income, education, and health. The United Nations (despite not having a formal definition) use the terms developed and developing regions, with a specific sub-group of the latter being least developed countries (Khokhar & Serajuddin, 2015; UN, 2021).

Figure 1
Developed and developing countries



Source: created based on UN, 2021

For the sake of simplicity, this thesis will employ the UN phrases “developed country” and “developing country”, the latter including the least developed countries as well.

1.3.2 Sickle cell disease

Sickle cell disease refers to a group of genetic disorders caused by inherited mutant genes responsible for hemoglobin formation. Hemoglobin is a protein in red blood cells responsible for the transportation of oxygen throughout the body. These mutant genes cause red blood cells to become sickle-shaped and block capillaries (small blood vessels), inducing severe, recurrent, and unpredictable painful episodes. Pain may be located anywhere in the body and the pain episodes vary in terms of severity and frequency. With a global incidence rate of approximately 300,000 newborns each year, sickle cell disease is the most common inherited genetic disorder in Sub-Sharan Africa. Countries with the highest prevalence are Nigeria, the Democratic Republic of Congo, India, and Tanzania, in this order. As it is highly prevalent among people with roots in Sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries, migration from these areas raised the frequency of this gene in other parts of the world as well.

Signs of this disease start showing even in infants and young children, them being the most vulnerable to risk of death. However, due to the lack of systematic newborn screening, many parents are not aware of their children’s illness until the symptoms eventually lead to a diagnosis. Even though there is an increasing proportion of affected children surviving after five years of age, they are still at risk of premature death. Sickle cell disease in itself accounts for 5% of under-five deaths on the African continent, with an estimated 50-80% of affected children dying in developing countries before the age of five. Sickle cell patients are also at increased risk of severe malaria.

The prevention of sickle cell disease is possible by screening couples at risk of having affected children. Alternatively, prenatal screening can also be performed. The treatment for complications of this disease includes attempts to minimize intravascular sickling and to reduce pain. Aggressive narcotics are normally administered either orally

or intravenously, thus requiring frequent emergency room visits or even hospitalizations. However, for most patients the incidence of complications can be reduced by preventive administration of penicillin, avoiding excessive heat or cold and dehydration, and finding a specialist center. Thus, the most important challenge is to achieve early intervention for preventable issues with pain medication, antibiotics, proper nutrition and fluid intake, thereby reducing morbidity and mortality from the disease, as well as improving the quality of life of patients and their caregivers. Progress in health technologies has advanced the treatment opportunities for sickle cell disease. Long-term treatment with hydroxyurea (a generic drug) decreases the rate of painful crises; medical imaging can aid with screening for complications (e.g. stroke); bone marrow transplantation (though with risks) can cure sickle cell anemia; and regular blood transfusions combined with iron-chelation therapy (balancing the rate of iron in the blood) can prevent complications. However, these advances are mainly accessible in developed countries, further widening the gap between patients in different locations (WHO, 2006a; WHO, 2006b; WHO, 2018; Craighead & Nemeroff, 2004).

1.4 Example of access to care solutions

The following program is an example of joint efforts to make the care for sickle cell patients more accessible. The Novartis Africa Sickle Cell Disease program works through public-private partnerships between pharmaceutical company Novartis and local governments, and collaborations with universities, patient groups and other organizations. “A key element of our strategy is a holistic approach to disease management that encompasses screening, diagnosis, treatment, education, research, and advocacy” (Novartis, n.d.a). The program was launched in Ghana in 2019, and expanded to Uganda, Tanzania, and Kenya one year later.

The main goals of the program include making diagnosis more available, expanding the access to hydroxyurea and developing a version suitable for children, training the health care systems for the management of the disease, and supporting governments with the process of policy changes to prioritize the disease. The

collaboration also introduced two mobile applications, one focusing on data management from newborn screenings, the other is a clinical management app ensuring that hydroxyurea is administered safely (Novartis, n.d.a). Novartis has also started the preparations for a phase III clinical trial (STAND) that includes some African countries. Its aim is to assess the efficacy and safety of crizanlizumab in adolescents and adults with sickle cell disease. Crizanlizumab has already been approved in the United States after the SUSTAIN phase II trial showed that this biologic therapy significantly reduced the frequency of vaso-occlusive pain crises compared to placebo (Novartis, n.d.b; clinicaltrials.gov, 2020; clinicaltrials.gov, 2022).

1.5 Summary of introduction

To summarize, the topic of this thesis manifested from an initial wondering of why do approximately two billion people worldwide have to live without secure access to pharmaceutical products. While there are global agendas in place to solve this issue (among other pressing challenges), the progress achieved with the Sustainable Development Goals has been highly affected by the COVID-19 pandemic. The scope of this thesis is specifically developing countries (including least developed countries) and a blood disorder called sickle cell disease. This is a highly prevalent genetic disorder in Sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries, with an extremely high under-five mortality rate in Africa.

In the following chapter, I will lay the foundations of this topic through a literature review, then present the methodological choices. That will be followed by the analysis of the qualitative interviews and the thesis will end with recommendations, limitations, and conclusions drawn from this research.

2 BACKGROUND

This chapter introduces the main theoretical ideas behind this project, with the aim to provide a general understanding of the topic in question and a summary of previous research findings. This review serves as a brief background for the data collection and analysis process by presenting the underlying problem that is addressed in this thesis. The relevance of this review is later discussed in the Methodology (3) chapter.

The chapter is divided into two parts: a Theoretical framework (2.1) discussing supply chains and a Literature review (2.2) focused on available research within the area of access to pharmaceuticals in developing countries.

2.1 Theoretical framework on supply chains

This section will present three aspects of supply chains to serve as a background for the thesis. This deeper knowledge is required to gain a holistic overview of the topic and to put the research questions into perspective. Firstly, pharmaceutical supply chains are described on a high level. Then sustainable supply chains are introduced to see how these two branches of supply chains can be combined. Finally, supply chain vulnerabilities are presented to identify potential weaknesses, which can lead to the issues later discussed in the Literature review (2.2).

2.1.1 Pharmaceutical supply chains

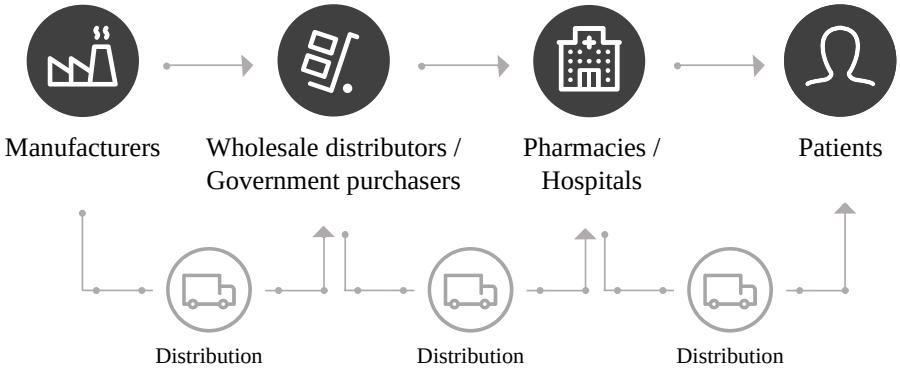
"A supply chain is a sequence of events intended to satisfy a customer and it includes procurement, manufacture, distribution and waste disposal, together with associated transportation, storage and information technology" (Asamoah, Abor, & Opare, 2011 p. 792). A pharmaceutical supply chain is the way through which prescription medicines are delivered to patients (The Health Strategies Consultancy (LLC), 2005).

There are three main types of flows served by supply chains that should be addressed: material, information, and financial (Asamoah et al., 2011; Van Wassenhove, 2005 as cited in Steele , Subramanian, & Tolani, 2019). The material flow includes the flow of the physical product from suppliers to end-users, including reverse flows for

returns, servicing, and recycling. Information flows supplement material flows with coordination of this sequence of events, e.g. by order transmission and order tracking. Financial flows include all aspects of compensation for the received goods, e.g. credit terms and payment schedules.

Figure 2 shows the basic structure of the material flows in a pharmaceutical supply chain without reverse logistics.

Figure 2
Basic structure of a pharmaceutical supply chain



Adapted from LLC, 2005; Asamoah et al., 2011

Prescription drugs are produced by pharmaceutical manufacturers, to then be transported to wholesale distributors or government purchasers. Manufacturers normally manage this transfer and potentially the whole supply chain until the product reaches the pharmacies or hospitals. They also ensure the safety of the material flow by creating information labelling for prescribers and consumers according to the granted conditions of the product's health authority approval. Some quality screening is performed during this process too.

There are two distinct business models of pharmaceutical manufacturers: those of brand-name drugs (e.g. Pfizer, Novartis, Novo Nordisk) and those of generic drugs (e.g. Mylan, Roxane, Barr). Brand manufacturers devote a part of their resources to scientific research and development of new drug therapies. Generic manufacturers start producing

generic compounds similar to the original branded versions once the brand product's patent protection expires.

Wholesale distributors, government purchasers, pharmacies, and hospitals might be able to influence their purchase prices through price negotiations. Branded pharmaceuticals are normally sold at a uniform price by wholesale distributors, but they usually negotiate with manufacturers for a discounted rate (e.g. volume discounts, prompt pay discounts, sale of products with short expiry dates). The difference between these two rates is the distributors' profit on the product. Generic product prices are quite volatile, depending on the competition and wholesale distributors' ability to increase the product's market share (Asamoah et al., 2011).

However, as mentioned above, this is just the basic structure of pharmaceutical supply chains. Many variations are possible in real life, as new players are appearing, and their relationships may differ significantly according to location, type of medication, and other factors (LLC, 2005). As an example, Shah (2004) adds main and local distribution centers to his model. These are warehouses storing inventories to be able to serve volatile demands. Local ones are smaller in capacity, but more wide-spread geographically to cover more areas of interest.

Pharmaceutical supply chains are unique in a way that they do not only entail the manufacturing and distribution of materials. Instead, the value-chain perspective is increasingly important in this sector. According to Booth (1999, as cited in Shah, 2004 p. 931), "there is a welcome move away from viewing the supply chain as merely having to deliver security of supply at minimum cost, to a recognition of its ability to generate both value for the customer and hence to the shareholder".

2.1.2 Sustainable supply chains

Sustainability has been a growing buzzword across industries, governments, and the general public, with different levels of engagement. "Sustainability is mainly referred to as a balance between environmental, social, and economic issues involved in human development" (Zahiri, Zhuang, & Mohammadi, 2017 p. 110). These three goals are also

called the triple bottom line. As awareness has grown, private companies have incorporated more and more sustainability measures in their operations, either by choice, corporate social responsibility (CSR) improvements, public pressure, or new legislations. Their supply chain management practices have been no exception to these changes (Ding, Liu, & Zheng, 2016).

The environmental aspects of sustainability have been thoroughly examined and communicated with regards to the global climate change. Companies´ environmental impact needs to be controlled, otherwise our climate and environmental systems may be subject to significant changes. Governments and global organizations (e.g. United Nations) have proposed guidelines and several restrictions to regulate these effects, e.g. by controlling the extent of greenhouse gas emissions (Ding et al., 2016). As a response, it is expected that companies adopt more energy-efficient technologies, equipment, and vehicles (Zahiri et al., 2017). Furthermore, they may also optimize production decisions, facility locations, transportation and inventory (Hua, Cheng, & Wang, 2011).

The social aspect has been addressed much less in the literature or in the media. In short, it pressures profit-oriented companies to consider and take responsibility for the social impacts of their actions. This means that companies operating in a socially responsible manner should be able to increase employment opportunities as well as provide a balanced economic development for local communities around the workplace (Zhalechian, Tavakkoli-Moghaddam, Zahiri, & Mohammadi, 2016).

The economic perspective can be considered the most classic of all: a company´s goal is to be profitable. Traditional metrics of economic performance in supply chains include e.g. cost minimization, reducing average inventory levels, and maximization of profits (Bals & Tate, 2018). Looking at the long-term financial sustainability of a company´s operations, applying a strategic point of view to supply chains is necessary. Porter (1996) argues that in order to achieve sustainable competitive advantage, companies need to do something different that is hard for competitors to match. In a supply chain, the more activities can be made self-reinforcing, or the more they are

intertwined in human relationships, the more possible it is to achieve sustainable competitive advantage.

2.1.3 Supply chain vulnerabilities

Sustainability and the accompanying rules and regulations (while being extremely important) pose new challenges to organizations in a supply chain. Supply chains are increasingly vulnerable to disruptions due to their growth in complexity, globalization, and constant market changes (Cardoso, Barbosa-Póvoa, Relvas, & Novais, 2015). Stauffer (2003) suggests that the higher risk is attributable to the pressure to increase productivity, reduce waste, remove supply chain duplication, and aim for cost improvement. Both internal and external factors can cause temporary stoppages resulting in delays and a direct impact on the stakeholders (e.g. profit, supply shortages, access to products). Internal factors can be e.g. labor strikes, technology malfunctions, and other events arising from the interactions between stakeholders in the supply chain. External risks are resulting from environmental, economic, political, or social causes, such as natural disasters, theft, terrorism, wars, and embargoes (Cardoso et al., 2015; Lysons & Farrington, 2006 as cited in Asamoah et al., 2011).

Asamoah et al. (2011) summarize that there are five main factors leading to pharmaceutical supply chain vulnerability:

- *Delays:* Delays can be caused in the supply chain by many risk factors, such as product discontinuity, product shortages, poor performance, and technological errors. Besides dissatisfaction and health system shortages, delays have an immediate impact on organizations´ finances (Breen, 2008).
- *Disruptions:* Disruptions hamper or stop the flow of pharmaceuticals through the supply chain, increasing patient risk (Breen, 2008). Disruption can happen due to the non-availability of raw materials, issues with transportation, lack of information flow within the supply chain, or theft.

- *Price increases:* Price increases are mainly attributed to cost inflation and companies´ anticipation of further inflation, which is why they tend to raise their prices by more than the cost inflation (Kotler, Armstrong, Saunders, & Wong, 2002 as cited in Asamoah et al., 2011).
- *Operations:* Operational risk is "the risk of loss arising from human errors, management failure and fraud; or from shortcomings in systems or controls" (Schwartz & Smith, 1997 as cited in Asamoah et al., 2011 p. 795).
- *Legislation:* The pharmaceutical industry is highly regulated by legislations, which organizations need to be aware of in all the markets they are operating. Regulations require extensive data collection and information exchange for traceability and monitoring across the supply chain (Zhang, He, & Tan, 2008).

To reduce the effect of unpredictable changes, supply chains must be built with the ability to respond rapidly and cost-effectively to such events (Cardoso et al., 2015).

2.2 Literature review on pharmaceutical access challenges and solutions

This section provides a summary of existing literature in the field of access to pharmaceuticals in developing countries. Its aim is to identify relevant previous research, which then could be compared to and potentially complemented by the findings of this thesis. It also functions as an aid to guide the interview process, more precisely the selection of experts and the flow of the interview questions. The literature search is performed with the help of online search engines, such as PubMed, Google Scholar, and the CBS Library database.

2.2.1 Challenges in access to pharmaceuticals in developing countries

The following challenge categorization is based on the work of Bendul, Rosca, & Pivovarova (2017), with specific examples added from other research articles.

2.2.1.1 Affordability constraints

Based on Steele et al. (2019), poor funding from health care systems is a significant constraint of access to pharmaceuticals. The lack of financial resources in

developing countries does not only refer to a reduced purchasing power, but also to quality issues along the whole supply chain. Furthermore, inefficient or expensive distribution practices increase the purchasing price for patients, putting another burden on family finances in the mainly out-of-pocket market for medicines in Africa (Ajepe, 2015).

The PATH (2015) however highlights that there are differences in terms of affordability across the different disease areas. As an example, the treatment for malaria being a priority of high-prevalence countries, malaria drugs have a fairly developed program in place. Whereas diabetes and other non-communicable diseases lack financing and support from the government, resulting in underdeveloped diagnosing- and treatment practices.

2.2.1.2 Infrastructure constraints

Generally, Steele et al. (2019) suggest that there is a lack of clear procedures in the supply chain, which generates other issues. Quantification and data collection on consumption is fairly poor, resulting in inadequate data and issues with forecasting, therefore a mismatch between demand and supply. This is further spoiled by inadequate methods of inventory control leading to overstocking/understocking.

The distribution function of the supply chain is faced with poor coordination between the central warehouses and health facilities, as well as a low availability of good quality public transport and a very expensive private fleet. Due to inaccessible locations and many rural areas, the frequency of distribution is low and last-mile delivery is severely affected (Steele et al., 2019).

The lack of adequate infrastructure is also visible in warehouses. Suppliers face poor conditions in storage facilities, accompanied by other constraints, such as the lack of sufficient temperature control (Steele et al., 2019).

Furthermore, Mustaffa and Potter (2009) add the issue of countries' disability to properly select, forecast, procure, and deliver health supplies. This is attributed to the lack of data on either an individual or a society level, which makes procurement practices

inconsistent (PATH, 2015). The caused erratic access contributes to patients losing their trust and confidence in the health care system.

2.2.1.3 Socio-cultural differences and constraints

Socio-cultural constraints mainly emerge from the unclear and not unified regulations within these complex supply chains. Regulatory initiations are often not well-planned or structured. This can be attributed to the governments' burden of facing several issues and at the same time having very limited resources. The result of these constraints often manifest in unnecessary bureaucracy and unclear guidelines for doing business (Chundru, 2015).

These regulatory issues result in counterfeit drugs crowding the health systems and a lack of transparency in the selection of pharmaceutical products in the health system. Another constraint is the low level of technology utilization, e.g. in the warehousing process. This reduces the security within the supply chain and paired with the insufficient human capacity, causes issues in access (Steele et al., 2019).

Asamoah et al. (2011) add in their article about anti-malaria drugs that most treatments are administered over-the-counter in general shops, pharmacies, and hawkers. The lack of proper regulation in these outlets results in significant variation among the distribution, quality, price, and administration of drugs. Furthermore, the inappropriate use of drugs, lack of medical supervision, and weak public health systems can cause the development of drug resistance in populations.

2.2.1.4 Education and training constraints

According to Steele et al. (2019), there is a general human resource shortage of well-trained workers in these supply chains, hindering the access to pharmaceuticals in developing countries through fragmentation and inefficiency of the public health systems. The lack of proper education and practice is also visible in cases of treatment failure, resulting in the extension of illness, adverse reactions, or in severe instances, disability or death.

2.2.2 Solutions for providing access to pharmaceuticals in developing countries

Previous research suggests that supply chains in developing countries need to follow a completely different approach compared to developed countries due to numerous existing constraints and institutional barriers (London & Hart, 2011). As an answer to the previous chapter, a summary of coping mechanisms by Bendul et al. (2017) is presented (Table 2). Then other researchers' ideas are gathered, which cannot be strictly included in only one constraint category.

Table 2
Sustainable supply chain models to cope with constraints

Constraint at the *base of the pyramid* (BOP)	**Sustainable supply chain models for BOP markets**
Affordability constraints	Focus on basic functionalities; Customer-centric design; Low initial and maintenance costs; Modular design; Labor-intensive assembly method; Reduced packaging; Low variance of basic product
Infrastructure constraints	Customer-centric design; Modular design; Locally embedded; Non-conventional distribution channels; Assembly, service and maintenance outsourced to local entrepreneurs
Socio-cultural differences and constraints	Customer-centric design; Local development teams through local R&D labs and cooperation with universities; Early customer involvement; Local suppliers; Supplier relationships; Locally embedded distribution channels
Education and training constraints	Customer-centric design; Tailored marketing with special focus on education and raising awareness
Raw material and production constraints	Local suppliers; Supplier relationships; Low initial investment costs through the use of cost-effective methods

Source: Bendul et al., 2017 p. 117

2.2.2.1 Decentralized procurement

As seen in the previous section, governments in developing countries balance scarce resources, which normally entails a prioritization of prevalent, infectious, and acute illnesses when decisions about funding are made. Therefore, building up the patient society and advocacy work could be a beneficial practice to raise awareness of a specific disease and achieve prioritization in annual budgets (PATH, 2015).

In order to improve procurement practices and speed up the procurement process, Ajepe (2015) suggests that purchases should be decentralized, performed by local governments instead of the state-level government. Another way to enhance procurement and overall supply chain practices is the use of mHealth (mobile health) strategies, which are practices enabled by wireless technology in health care. These can enable data collection and reporting, thereby planning and decision-making, training, and overall communication among stakeholders (Agarwal, Perry, Long, & Labrique, 2015).

Furthermore, existing supply chains for specific causes can serve as good tools to leverage for other disease areas by integrating these new disease areas into existing services (PATH, 2015).

2.2.2.2 Public-private partnerships

According to several researchers (e.g. Stevens & Huys, 2017), pharmaceutical companies need to take partial responsibility for finding solutions to treatment access issues. Public-private partnerships (PPP), as the name suggests, are collaborations between public (e.g. non-governmental- or international governmental organizations) and private players complementing each other with the goal of delivering healthcare and strengthen healthcare systems (Stevens & Huys, 2017). Involvement of local stakeholders in the supply chain operations is believed to increase acceptance and consequently market success of multinational companies both in terms of entering markets and creating social and economic benefits for the local communities (Bendul et al., 2017). A type of PPPs, product development partnerships (PDP) have the possibility to strengthen research capacity in developing countries by improving infrastructure at clinical trial sites,

providing equipment, and establishing training in good clinical practice and disease-specific research platforms. Besides pharmaceutical companies, local manufacturers, disease-specific control programs, national governments, and philanthropic organizations are normally present in these partnerships (Laokri, 2017).

An important feature of these partnerships must be patient-centricity, in that PPPs and their planned national health programs should be a response to local needs. Possible approaches include the "implementation of locally relevant tools and guidelines for practice, benchmarking practices, taskwork and teamwork training, learning projects to build mutual confidence between parts, early participation of coordinated stakeholders, actors' involvement in planning, process facilitator entities, contracting, and regulation" (Laokri, 2017 p. 9).

2.2.2.3 Intellectual property rights

Intellectual property (IP) rights from the perspective of the right holder are a guarantee for maintaining control over the use of their high-quality products. Patents are the most important IP protection tools in the pharmaceutical industry, "providing the owner exclusive rights to prevent use of the patented product or process without the consent of the owner for 20 years in a particular territory" (Stevens & Huys, 2017 p. 3). As discussed above, generic medicines may only be produced after the expiry of IP rights on the brand product.

However, there are some exceptions to this rule. The agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) by the World Trade Organization (WTO) introduces a phenomenon of compulsory licenses. Governments may impose these licenses based on supported reasons, which allows access to IP protected products and processes without the patent holder's consent. The aim of this flexibility is to support those countries that do not have the resources to manufacture or buy branded pharmaceuticals (WTO, 2017). According to Andreassen (2015) though, instead of flexibility in IP rights, protected patent terms should be extended. In cases where there is a widespread lack of access, patents could be used as a way of funding medicine access in

the least-developed countries. The extra profit derived from this prolonged period should serve as a source for drug donations to these countries.

2.2.2.4 Tiered/differential pricing

As seen above, the lack of financial resources is a significant burden for several countries in providing access to medicines in their health systems. However, producing and distributing medicines at a low costs is challenging. Furthermore, drug donations or purely financial support is unsustainable in the long term. Generic competitors and trade regulations play a role in driving prices down to some extent (Stevens & Huys, 2017).

When determining market prices, pharmaceutical companies can use several techniques, e.g. value-based pricing or cost-plus pricing. Either way, they must evaluate several factors, some of which are listed here. Firstly, whether there are any other products on the market treating the same condition. Secondly, they must consider the popularity and success of the competition, taking into account whether the new drug has any additional benefits compared to the current standard of care. Furthermore, they must evaluate their drug's potential or already proven effectiveness (Hawley, 2020). Finally, when they set a price for a specific market, they start their negotiations with the given regulatory entity. Normally, some kind of evaluation technique is used, such as a health technology assessment, or a cost-benefit analysis. Countries use different methods for negotiation. As an example, Germany utilizes a centralized drug assessment and price negotiation method. They motivate manufacturers to keep their prices lower by positive incentives (e.g. immediate coverage) and negative incentives (e.g. mandatory arbitration in case of the failure of negotiations). In the United States however, drug evaluations are not standardized and price negotiations are less structured, which leads to higher prices in the US (Robinson, Ex, & Panteli, 2020).

"Differential or tiered pricing means selling essential medicines in low-and middle income countries at prices below those in industrialized countries" (Danzon & Towse, 2003 as cited in Stevens & Huys, 2017, p. 4). Pharmaceutical companies need to evaluate the "lowest possible price" and the "fair price" for specific markets to provide the widest

access fairly. Income-related pricing may not be the best method for finding these values, as skewed income distribution in developing countries poses a challenge in calculating fair prices. Therefore, market segmentation is necessary across and even within national markets (Stevens & Huys, 2017; Williams, Ooms, & Hill, 2015).

2.3 Summary of background

To conclude, the basic structure of a pharmaceutical supply chain includes the manufacturers (pharmaceutical companies), government purchasers, pharmacies and hospitals, and patients as end-users. Two specific types of manufacturer business models are distinguished: those of branded drugs, and those of generic drugs. The former use part of their resources for research, while the latter produce medicine after the patent protection of branded drugs expire. The triple bottom line entails financial, social, and environmental sustainability of an organization's operations. However, this (and other factors) cause complexity and thereby vulnerability of supply chains.

Access to pharmaceuticals in developing factors is disrupted by several factors, such as affordability, infrastructure, socio-cultural constraints, and education. Existing literature mentions an array of potential solutions, e.g. decentralized procurement, public-private partnerships, intellectual property right alterations, and differential pricing models.

3 METHODOLOGY

3.1 Overview

This chapter describes the main assumptions, methodology, and tools employed to build and perform this research. The goal of this project is to create new knowledge for empirical use and to enrich currently existing research. Thus, the below sections explain this creation process, starting with the reasoning for an inductive research approach and the choice of van Aken, Berends & van der Bij´s (2012) field problem solving methodology. Then, continuing on a more granular level, the steps of the problem-solving cycle are delineated, including the chosen data collection and analysis methods. The primary data sources are semi-structured interviews, analyzed through a six-step approach using NVivo.

3.2 Research approach

Saunders et al. (2009) explain two main research approaches, also called modes of reasoning: deduction and induction. The choice of the approach depends on the relationship between theory and research that one is following in their project. Deduction refers to the testing of hypotheses that were created based on theory, while induction is the development of theory as a result of data collection and analysis.

During the deductive approach, the researcher collects knowledge from existing theory on a specific subject, then constructs hypotheses, which are to be tested empirically. Data collection and synthesis is followed by either the confirmation or rejection of the initial hypotheses (Bryman & Bell, 2003). However, as Bryman & Bell (2003) argue, the last step of the deductive approach involves a shift in direction: induction is used to find the implications of findings for the existing theory.

On the other hand, the inductive approach delivers theory as an outcome of research, commencing from individual observations with the aim to draw generalized conclusions (Bryman & Bell, 2003). Thus, induction starts with data collection on a specific (individual) level, to explore a phenomenon, identify patterns and create general

findings. The purpose of this approach is to gain deeper understanding of the nature of the problem through the analysis of data, which is based on participants' experience (Soiferman, 2010). As in the case of the deductive approach, inductive research also contains characteristics of the former, e.g. theory often supports the qualitative investigation as a framework or preceding knowledge base. Therefore, it can be concluded that deductive and inductive approaches are rarely applied on their own. Rather, they should be thought of as tendencies in the relationship between theory and research (Bryman & Bell, 2003).

Thus, this project applies an inductive tendency, starting from an initial wondering of an empirical observation, namely the lack of reliable access to medicines in developing countries. In the end, new knowledge is created by "looking for and analyzing significant patterns in data", instead of only utilizing the data to illustrate or support existing theories as in a deductive approach (Sabherwal & King, 1991 p. 192). However, theory and existing literature is reviewed to serve as a background for the investigation.

3.3 Field problem solving methodology

Even though this project is not performed in collaboration with a company, its aim is still to produce potential solutions to so-called field problems. Field problems are "situations in reality, which in the view of some influential stakeholders can or should be improved" (van Aken et al., 2012 p. 4). Thus, this research employs the approach of van Aken et al.´s (2012) design science paradigm and follows the steps of the problem solving cycle (Figure 3).

3.3.1 Field problem solving projects

Field problem solving projects emerge from a messy problem. According to van Aken et al. (2012), 'good' field problem solving projects bear the following characteristics:

- *Performance-focused:* The focus of the project is the potential for improvement in real-life performance, and analysis and design are purely means to this end.

- *Design-oriented:* The project comprehensively details the design and change process required to solve the problem, and the analyses that is needed to create this design.
- *Theory-informed:* The project applies state-of-the-art literature to solve the problem. This entails knowledge of the phenomenon, the realization of solutions, and analysis and design methods used for building the solution and the change plan.
- *Justified:* The way in which the proposed solution will solve the problem is thoroughly explained.
- *Client-centered:* Besides following the requests of the client, other stakeholders' views and interests are taken into account.

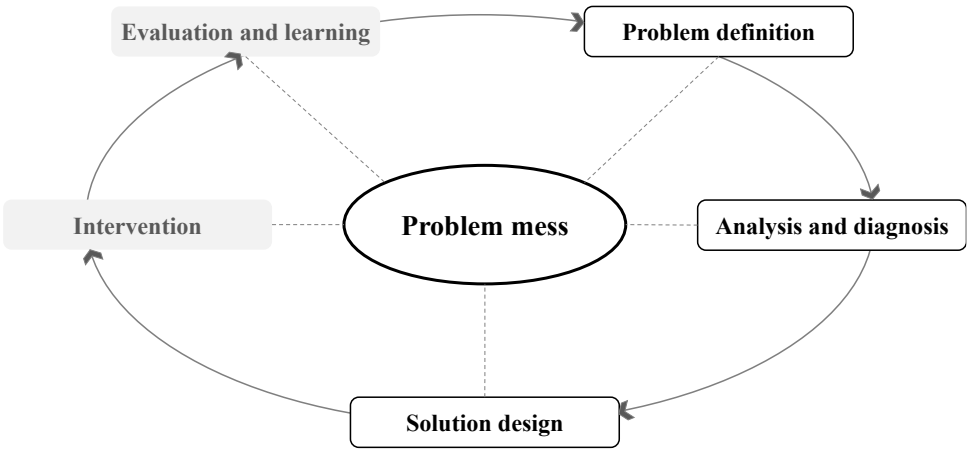
The performance-focused attribute is fulfilled by the origin of this thesis being a wondering about an empirical observation and its goal to find potential ways for improving access to medicines in developing countries. The design-oriented nature is presented in the Discussion (5), up to the level of comprehension defined by the scope of this project. Furthermore, the Theoretical Framework (2.1), Literature Review (2.2), and Methodology (3) chapters ensure that the project is based on existing and (if possible) recent literature, guiding it from beginning to end. Justification of the proposed solutions are included in the Discussion (5). Client-centeredness in this case is considered somewhat differently. As the project is not performed in collaboration with a host organization, there are no specific requests to consider. Instead, this thesis aims to view the initial problem from various viewpoints, including different stakeholders in the process.

Keeping these key guiding principles in mind, this project follows the problem solving cycle (Figure 3) within its scope. This cycle starts with the problem formulation, including the structuring of the problem mess into a problem definition. The next step consists of the analysis and diagnosis of the problem and its context to identify and validate the causes of the issue. This is followed by the solution design, which in this case includes the proposed recommendations, but more specific planning (e.g. implementation

plan) is not possible due to the lack of a host organization. These three steps combined form the design phase of the project. The last two steps of the problem solving cycle (intervention, evaluation and learning) are potentially performed by the stakeholders following this project, and as such, they are neither included in this chapter, nor in the scope of the project.

The structure of the problem solving cycle is built for iterations in order to constantly improve the solution design and therefore the outcomes. In this project, as testing an intervention is not possible, the iterative approach is utilized during the data collection process explained below.

Figure 3
Problem solving cycle



Source: van Aken et al., 2012, p. 37

3.3.2 Problem definition

The problem-solving cycle begins with an identified need buried in a problem mess consisting of potentially interrelated issues. This mess needs to be structured in order to identify a clear problem definition.

The process of finding a need in this thesis project was threefold. Firstly, my studies highlighted several issues within the field of unequal access to health care.

Secondly, discussions with my colleagues further broadened the problem mess, including the perspective of a pharmaceutical company. Finally, an initial literature search and iterations with my university supervisor guided the problem definition process.

3.3.3 Analysis and diagnosis

According to van Aken et al. (2012), there are three potential approaches to the analysis and diagnosis step that can be combined to produce a diagnosis. Empirical analysis means that the perceived problem, its causes, and consequences are identified and evidence is gathered to support the analysis. Theoretical analysis involves the review of scholarly literature. Process-oriented analysis focuses on exploring the current business system to connect it to the perceived problem. In this project, all three analyses are performed, allowing for the triangulation of multiple sources of data.

3.3.4 Solution design

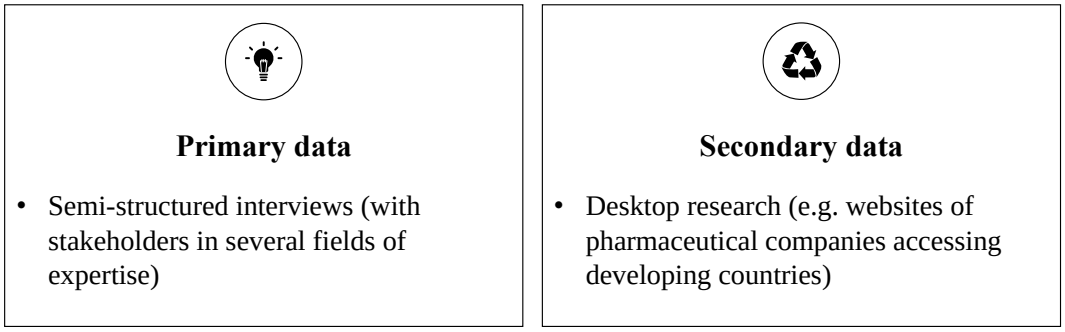
As previously mentioned, the solution design is included in the Discussion (5) chapter in the form of proposed solutions, but other design elements (e.g. implementation plan) are out of scope of this project.

3.4 Data collection

Following the above-mentioned research approach and the nature of this project, a multi-method qualitative study is performed. This means that more data collection techniques are utilized, but only within a qualitative world view. This method is beneficial in this project, as it allows for several viewpoints of the same issue to be included, leading to a more comprehensive understanding (Tashakkori & Teddlie, 2003 as cited in Saunders et al., 2009).

Researchers distinguish between primary and secondary data sources. Primary data is collected specifically for the research in question, while secondary data are those “that have already been collected for some other purpose” (Saunders et al., 2012 p. 304). The primary and secondary data sources in this project can be seen below (Figure 4).

Figure 4
Data sources



3.4.1 Literature review

In qualitative research, a literature review is "used to provide evidence for the purpose of the study and to identify the underlying problem that will be addressed" (Soiferman, 2010 p. 8), thus it is not explicitly a data collection method. According to Soiferman (2010 p. 8), a literature review is "brief and does not usually guide the research question" to prevent narrowing the information to be received from the respondents.

Therefore, as mentioned above, the Theoretical framework (2.1) and the Literature review (2.2) serve as a background for the data collection and analysis process. Topics of relevant theories and literature were found based on the initial wondering and were narrowed down and focused after an introductory understanding of the issue was achieved.

3.4.2 Semi-structured interviews

While theories and literature gave a structure to my understanding of the issue, the method of conducting semi-structured one-on-one interviews was chosen to investigate the empirical knowledge and potentially validate, contradict, and most importantly add to the existing understanding of the topic. Qualitative interviews allow for asking purposeful questions, ensuring meaningful participation of respondents, and carefully listening to their answers to be able to explore these further (Saunders et al, 2009 p. 372). Thus, this method enabled me to receive deeper insights about the respondents´ lived experience, as well as to open further discussion areas not previously considered (Saunders et al., 2009).

Some of the interviewees were chosen by convenience sampling, meaning easy accessibility (Bryman & Bell, 2003). These included my immediate contacts who helped me during my initial exploration for a research topic. From them, I received leads to other experts, whose participation were considered beneficial. The third group of interviewees were approached via unsolicited emails or Linkedin messages. These respondents were found based on theoretical, influential case sampling, as they are all relevant stakeholders in this project owing to their expertise and/or their occupation (van Aken et al., 2012). Naturally, the aim with this approach was not to complete the research on a statistically representative sample, but instead to include as many viewpoints as possible to get a broad understanding of the phenomenon. Kvale (2007a) recommends the interviewee count to be around 15 ± 10, but a relatively high ratio of non-response was expected due to the cold-calling nature of contact initiations (Bryman & Bell, 2003). This resulted in the following interviews:

Table 3
Conducted interviews

#	Name / Anonym title	Location
1	Expert in supply chain management	Denmark
2	Medical doctor #1	Denmark (experience in Tanzania)
3	Industry expert #3	Switzerland
4	Pediatric nurse	The Netherlands (experience in Malawi)
5	Industry expert #2	Switzerland
6	Industry expert #1	Denmark
7	Expert in access to care	Switzerland
8	Medical doctor #2	Kenya

The interviews were conducted online, despite the potential risk of less interactivity and more challenges for engagement (Saunders et al., 2009). This approach allowed for a more efficient process (no travelling required, recording is solved by the videoconference platform, etc.) and also decreased geographic limitations.

Saunders et al. (2009) and Kvale (2007a) highlight the importance of pre-interview planning, which supports the quality of the interview, therefore also the prospects of acquiring valuable information. First, the goal of the interviews were defined based on the scope of the project and the literature review. Then, an interview guide (Appendix C) was outlined, including the main themes to be covered during each interview. Briefing and debriefing sections were also developed to ensure proper facilitation (van Aken et al., 2012; Kvale, 2007b). Following the nature of semi-structured interviews, follow-up, interpreting, probing, and structuring questions were also posed besides the planned ones (Kvale, 2007b). The interview guides were also slightly adjusted based on respondents´ backgrounds, field of expertise, and the insights gained during the data collection process so far. Therefore, an iterative process was accomplished, while also keeping in mind that a common theme needs to be followed to get comparable results.

3.4.3 Desktop research

Desktop research in this process refers to the search for relevant cases, news pieces, or reports of projects, pharmaceutical companies, or other organizations who in some way contribute to the access to health care in developing countries. These were considered relevant as examples for potential solutions to the initial issue with the aim to learn from them. Explicit examples of this research are seen in the Introduction (1) chapter.

3.5 Data analysis method

Qualitative research normally results in a large amount of raw, unstructured material that needs to be synthesized before conclusions can be drawn from it (van Aken

et al., 2012). To provide a structured approach for my analysis, Braun & Clarke's (2006) step-by-step guidance was followed (Figure 5).

Figure 5
Phases of analysis

Source: Braun & Clarke, 2006, p. 35

Firstly, the interviews were transcribed by Microsoft Teams' built-in transcription functionality and checked manually for accuracy. This process in itself contributed to familiarizing myself with the data and preparing it for the analysis. The transcriptions were also anonymized during this phase. All transcriptions can be seen in Appendix D.

Then, general codes were created in NVivo, a qualitative data analysis software. Braun and Clarke (2006) suggest basing the codes on the theory, therefore, the Theoretical framework (2.1) and the Literature review (2.2) were used to identify main codes. While coding the texts in NVivo, new codes were added and the existing ones modified to organize the data better and subtract insights more efficiently. NVivo allows for structuring the codes with the help of so-called top-level and children codes, which drafted the key themes from the data.

Reviewing these themes emphasized the main ideas from the interviews and the secondary data, which lead to a skeleton of the analysis. NVivo was a useful tool to clarify how the empirical data collected relates to the theories and literature. Data was then used in the writing process to illustrate and exemplify these relations.

3.6 Quality criteria

Van Aken et al. (2012) and Bryman & Bell (2003) consider three quality criteria to be the most important in research: replication (controllability), reliability, and validity.

Replication is ensured in this project by describing the methodology in detail, so that other researchers could repeat the research.

Reliability entails the consistent nature of the results (Saunders et al., 2009). Thus, the replication of the study by another researcher, with a different research instrument, with different respondents, or in another situation should produce similar results (van Aken et al., 2012). For this to be achieved, several different biases are reduced. Researcher bias is reduced by standardization, e.g. preparing an interview guide, using NVivo for an organized analysis. Instrument bias is decreased by the small iterations during the data collection process. Respondent bias is inevitable, but involving participants from different fields of expertise is aimed to serve this purpose. Lastly, situation bias was reduced by providing a relaxed atmosphere during the interviews.

Validity in a research setting means that the way results are generated is a warranty for the results being true and adequate (van Aken et al., 2012). Iterations throughout the data collection and analysis process and including numerous viewpoints ensured that the findings of this research are valid.

3.7 Ethical considerations

As the project includes respondents from numerous fields, ethics and confidentiality played an important role during the research. Silverman (2014, p. 148) provides a summary of the main points to consider with regards to ethics in research: "ensuring that people participate voluntarily; making people's comments and behavior confidential; protecting people from harm; and ensuring mutual trust between researcher and people studied".

To ensure that respondents' rights were preserved, they were informed that their participation is voluntary and I explained how the contents of their interviews would be used.

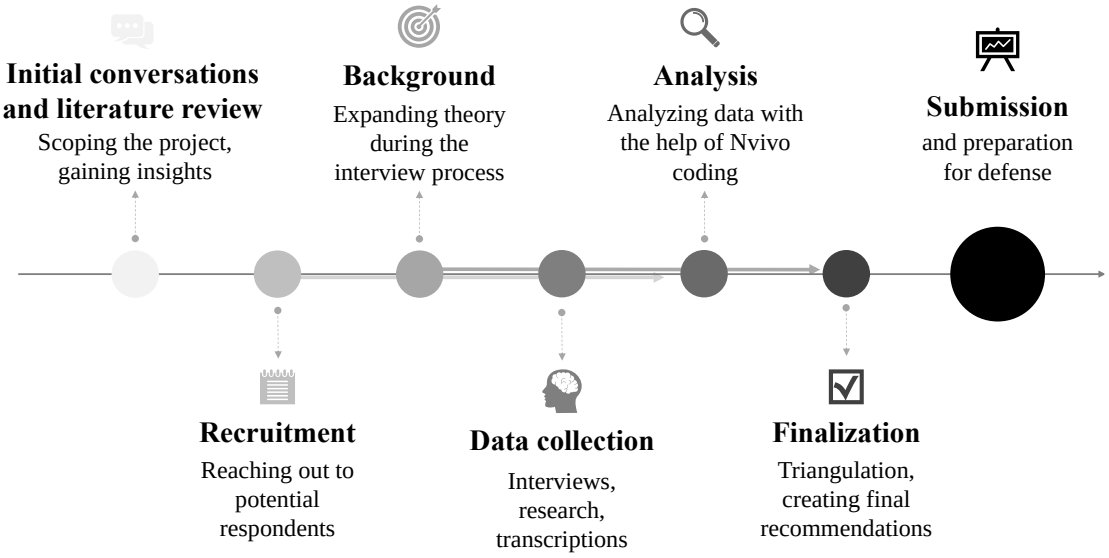
3.8 Summary of methodology

In summary, this thesis will apply an inductive approach, delivering generalized conclusions from the research. On a more practical level, a field problem solving methodology is followed, along with the steps of the problem-solving cycle: problem definition, analysis and diagnosis, and solution design. The primary data collection

method is interviewing experts in this broad field. Further cases and examples are used as secondary data for this research. Data analysis is performed with the help of NVivo, by coding data according to pre-defined and developing themes. These themes are then organized for providing detailed insights into the research and form recommendations based on the gathered knowledge.

Figure 6 shows an overview of my thesis process:

Figure 6
Overview of the thesis methodology

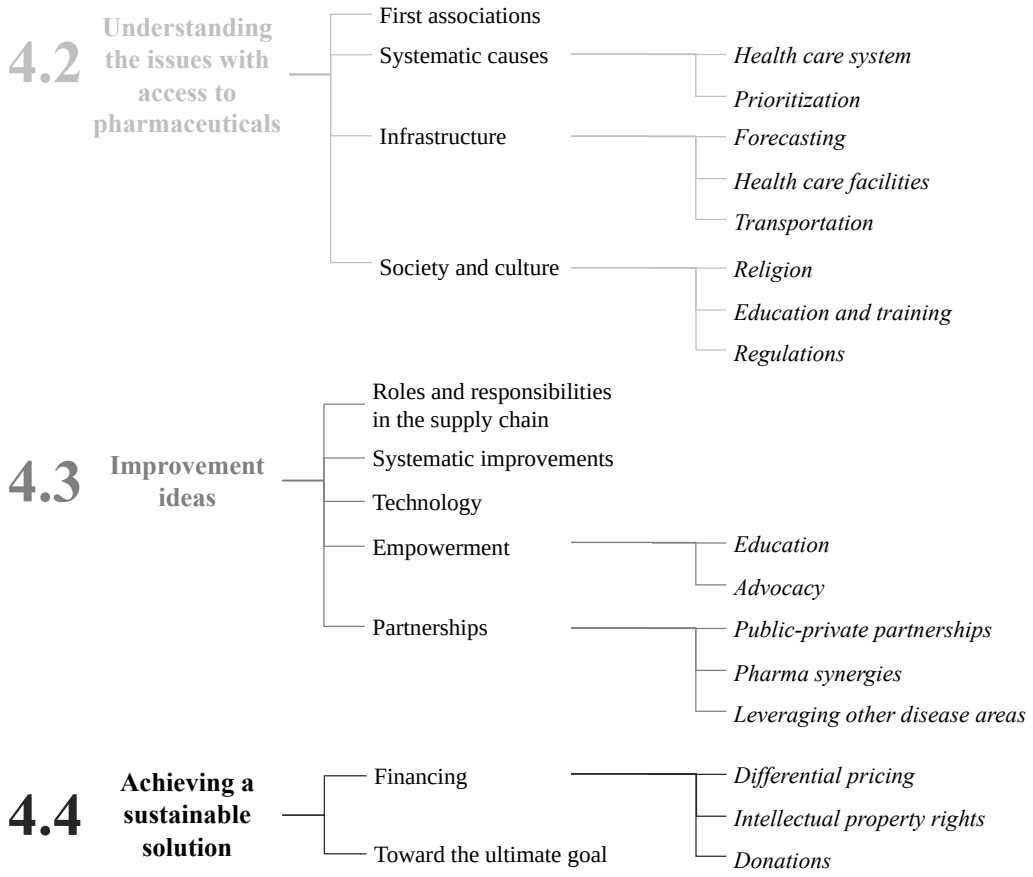


4 ANALYSIS

4.1 Overview

This chapter presents the empirical findings of the research, based on semi-structured qualitative interviews analyzed through the computer program NVivo (Appendix E). As discussed in the Methodology (3) chapter, data was structured along themes in an inductive way following the steps of Braun & Clarke's (2006) approach (Figure 5). Accordingly, the Background (2) chapter served as an initial structure for these themes, and others were added as the respondents steered the conversation to new interesting areas. The findings are presented along these themes, as illustrated in Figure 7:

Figure 7
Themes generated from interviews



The findings are substantiated with relevant quotes from the interviews to allow for easier interpretation. Insights gained from interviewees' personal and professional experiences then lead to implications and recommendations to health care research and practice, detailed in the Discussion (5) chapter. Information about the care for sickle cell disease patients are highlighted when relevant and to the extent that disease-specific data collection was possible. Interview respondents will be referred to according to the created IDs below (Table 4):

Table 4
Interviewee IDs

No.	Anonym title	ID
1	Expert in supply chain management	SCM
2	Medical doctor #1	MD 1
3	Industry expert #3	IND 3
4	Pediatric nurse	NUR
5	Industry expert #2	IND 1
6	Industry expert #1	IND 2
7	Expert in access to care	ACC
8	Medical doctor #2	MD 2

4.2 Understanding the issues with access in developing countries

4.2.1 First associations

At the beginning of each interview, respondents were asked the following question: "When you hear this phrase "access to pharmaceuticals", what is the first thing that pops into your mind?". Even though the respondents' educational backgrounds and professional experiences influenced their answers, the most common answer included some affordability-related hardships (SCM, MD1, IND1, IND2, IND3). Others mentioned stock shortages (NUR), inequality among different parts of the world and among different

diseases (ACC, IND3), issues with infrastructure (ACC, SCM), cost-benefit dilemmas (MD1), and the healthcare system in general (IND1, IND2).

Even at the beginning of the interviews, several respondents started to explain how this issue is multifaceted. They mentioned that as there are several factors and stakeholders having an important role, the issue itself cannot be understood or treated by only focusing on one underlying cause, such as expenses. Some experts even highlighted that the biggest issue is not access to pharmaceuticals – it is in fact the overall access to care (IND1, IND2, MD2). This means that even if the pharmaceutical products get to the patients, there is much more to be addressed in the whole supply chain and this holistic perspective is necessary to reach better health outcomes (SCM, IND1). Additionally, the pharmaceutical products may not get to the patients because of these other systematic hindrances (IND1).

„The drug is playing a big role, but there are other elements that also have a big influence on the final outcome. (…) Even though [pharmaceutical] companies would like to help, it might not be feasible to provide that treatment because of the infrastructure. So you could say in those situations access to care in general is where we can all help, but access to treatment itself is more of a challenge."

Quote 1, IND1

4.2.2 Systematic causes

Health care systems were reoccurring topics during the interviews. We normally distinguish between the most common models, such as Bismarck, Beveridge and private insurance models, and their combinations. These entail different levels of government provision versus private out-of-pocket contribution. Compared to the developed world, in developing countries the tendency is more towards out-of-pocket financing, occasionally as a co-pay system with a minimal amount of government coverage (IND3). While this poses a huge challenge for families especially in rural areas, it is also a consequence of the government's restricted resources. These constraints play a big role in health care

provision, as for many governments the highest priority is not necessarily providing medication, but basic hygiene, clean water, reliable electricity, etc. (IND1, SCM).

Therefore, governments need to prioritize when allocating their budgets to different causes. As highlighted by some respondents, besides evaluating unmet need, awareness of specific diseases also serves as a driver for prioritization (e.g. IND3, MD2). Then some disease areas receive more support than others, so the issues mentioned by respondents cannot be generalized across all diseases. Naturally, some basic medication and location-specific diseases receive the most resources: anti-malaria medication, some antibiotics are normally available at the facilities (e.g. NUR, MD1). Whereas medication for anesthesia, heart diseases, diabetes, etc. are harder to obtain, but may be available at bigger hospitals (e.g. NUR, MD1). As a general distinction, governments tend to focus more on communicable diseases, at the expense of non-communicable conditions (MD2).

Lack of availability of several pharmaceuticals and tools often results in mistreating a disease with other, available medications or re-using tools, thereby risking e.g. antibiotic resistance and serious infections (NUR).

Another interesting aspect of several developing countries' health care systems is the appearance of the church as a provider. They may be part of the supply system, manage health care facilities, or even serve as faith-based healers (IND3, NUR).

4.2.3 Infrastructure

The infrastructure around getting a pharmaceutical product from the manufacturer to the end user (patient) includes several aspects from transportation and warehousing to health care facilities and supporting (digital) technologies. In developing countries, where the basics may not be in place, even keeping the medicine at certain temperatures is a challenge, causing extra costs or damage to the products (SCM).

Transportation may not only be an issue for the distribution of health care products, but also in relation to physicians and patients reaching facilities, or health care staff travelling to meetings (NUR). Patients and caregivers may also miss out on school or workdays due to travel time (ACC).

"- Are you saying that they actually walk to the hospital if they are sick?
- Yes, so most people walk. Some of them have a bike of course, but most people walk.
- And what if they are so sick that they cannot actually walk?
- They stay home."

Quote 2, MD1

However, as MD2 pointed out, this is not a general problem in all developing countries. He suggested that a relatively good network of transportation is in place in Kenya, even in rural areas where people have different means of transportation.

On the other hand, the availability and equipment of health care facilities is a more general issue. Even if they have the equipment, the complementary services, such as electricity, maintenance, reagents may be lacking (SCM, MD2). Almost all respondents mentioned that there are not enough facilities, let alone enough well-equipped facilities, except for bigger or capital cities. A lot of developing countries also lack enough experts to manage specific disorders (e.g. MD2, IND2).

While in the developed world we see more and more digital health technology solutions (electronic patient registers, mobile health tools, etc.), this is not the norm in the developing countries. When asked whether the governments used any technologies to capture data on supplies or usage for planning purposes, the answers were not too positive. MD2 stated that they do have some information channels to the Kenyan government, but NUR highlighted an important aspect of why planning is not so organized in countries such as Malawi:

"Planning is not really a thing that I was seeing there. (...) you know, if you are struggling every day, you don't think about next year."

Quote 3, NUR

The above mentioned issues with infrastructure also impact the personnel and their dedication during their workday. NUR and MD1 both provided examples of health care professionals who were struggling to find their motivation in these circumstances, as they

did not feel like they were able to make a big difference. Patients may be reluctant or cannot afford to buy medications, they may not take the necessary precautions, so doctors and nurses may feel helpless and their enthusiasm may fade over time. As NUR pointed out, a system where the government decides on health care professionals' work placements may also hinder these professionals to feel motivated.

4.2.4 Society and culture

All interviewees mentioned some kind of interactions between members of the society in developing countries as having a role in accessing care or treatment. NUR mentioned that access and availability of supplies may be dependent on personal relationships a facility has with the government. High levels of bureaucracy and corruption were also mentioned as a hindrance to access (MD2, SCM, NUR). Though MD2 also added that in some places, corruption has been repressed – not eliminated, but improvements can be seen as people are becoming more vocal by the availability of information.

The lack of proper treatment and care can be seen as a vicious circle from a societal perspective. Without treatment, patients suffer from the side effects of their conditions, they may even not be able to attend to their regular duties. If the patient is a child, at least one of their parents would not go to work to take care of the patient. Besides the caused salary loss, these hardships often disrupt families, and it is quite common that mothers are left alone to provide for the children. This leads to the vicious circle of increasing poverty, thereby less and less access to care (ACC, MD2).

An important aspect of care in some developing countries (especially in rural, disadvantaged areas) is the presence of traditional medicine techniques represented by local healers. Their importance lies in residents' trust towards them and their agriculture-based remedies. Besides these being more affordable, they are also often better understood by the families than Western medicine, therefore they are less resistant to receive care (IND3). However, these healers' knowledge does not normally come from attending medical school, so it is mainly their experience or reputation that brings patients to them

(SCM). MD1 adds that in her area, the hospital worked together with some of these healers. The nurses and the doctors would visit the healers and explain what symptoms to look out for, when they should immediately refer the patient to the hospital. The challenge in some areas appears to be a disbelief in Western medicine and hospitals being viewed as a place to die. This is further encumbered by the costs of hospital beds and care in general. MD1 also encountered a curious regulation in rural Tanzania: patients were not allowed to be discharged before they could pay their medical bills. This resulted in them staying longer, their debt growing, and them potentially getting infected by other patients in the hospital facility.

4.3 Improvement ideas

4.3.1 Roles and responsibilities in the supply chain

Moving on to the solutions during the interviews, respondents were asked about the different players in the supply chain, who they thought were the most important, and who had the highest responsibility for providing access to treatment in developing countries. Almost all respondents highlighted the governments or health authorities (ministries) as being the stakeholders with the highest responsibility. They are the ones that need to arrange drug availability after the medicine agencies' approval (e.g. NUR, MD1, IND1). They are elected as trusted decision-makers to understand the country's health care context, explore patient needs, prioritize, ensure other aspects of the healthcare system to be in place, be open for dialogue with other stakeholders, reach out to companies or organizations for help, and through all be accountable, visible, and transparent in their decisions (IND1, IND3).

Pharmaceutical companies were also frequently mentioned, as they carry the responsibility of establishing and maintaining the supply chain from the factory to pharmacies or hospitals (IND2). They may benefit from having affiliates or third party representatives in the targeted countries. IND1 added that pharmaceutical companies also have a role in raising awareness of a disease. NUR mentioned that these companies should make medication cheaper for developing countries (i.e. differential/tiered pricing) or

enable these countries to produce drugs on their own. MD1 had the viewpoint that differential pricing would not be realistic, because then it is either not beneficial for the company, or other countries would question why they have to pay more if the same products can also be consumed for less in developing countries. IND3 concluded that companies need to respect the characteristics of the environment they are targeting:

> *"First of all, we must respect that the position of command and control must be local. (…) I think if a company comes in who has a very clear interest to sell a particular medication and then they want to give a lot of money and a lot of support to a country for that medication, it sounds like a great idea, but (…) it's very important that we help the governments and we don't just drive our own agendas of what we think is most important."*

Quote 4, IND3

According to industry experts (IND1, IND2), patient organizations and non-governmental organizations also have a role in providing the patient perspective or solution ideas to governments. NUR also mentioned that hospitals and pharmacies could explore new solutions to find their own ways of getting access to pharmaceuticals. Healthcare professionals need to have a good education and earn patients' trust (IND2, IND3). Besides providing care, they have a role in being advocates, negotiators, handle stakeholders on all levels of the healthcare system (ACC).

4.3.2 Systematic improvements

Under the umbrella of systematic improvements, two main topics were mentioned by the respondents: the importance of diagnosis and the establishment of a well-functioning referral system. Receiving a diagnosis early is of high importance for patients, as this is the first step towards understanding the reason for their suffering and getting into a system of care (ACC, IND3). From a societal perspective, the importance lies in the fact that treating a more developed condition is normally more expensive and the potential health outcomes of the patient are worse (e.g. their quality of life, future contributions to

society). This is the reason for a greater focus on provision of care for children in terms of diagnosis and medication, to enable an early intervention (IND3). However, access to diagnosis is a big challenge in several developing countries, mainly because neither are there screening programs in place, nor is there capacity for screening beside the huge patient count per doctor ratio (MD1, MD2). Therefore, patients normally have to wait until complications arise to receive a diagnosis and care. Unfortunately, this results in an unidentified need and a lack of governmental focus on specific disease areas:

> *"Of course they have no patients if they don't have diagnosis in place. Of course there's no unmet need if they haven't identified the unmet need."*

Quote 5, IND2

Furthermore, even if symptoms start to show, the lack of diagnosis protocols may lead to mistreating the condition, but once diagnosed, further tests and targeted medications may be too expensive and not readily available:

> *"Sickle cell presents with sudden symptoms that initially people would think you have malaria. (…) They'll start treating you for all sorts of things, and then they would pile you up with drugs that would literally poison you, especially drugs to replace iron. (…) But once diagnosed, then people would tend to be very basic in terms of care. (…) Sometimes we start patients on hydroxyurea, but it is not always available."*

Quote 6, MD2

The need for a well-functioning referral system between different levels of health care providers were mentioned especially in relation to rare blood disorders, such as hemophilia and sickle cell disease. As these disorders require specialized and multidisciplinary care, they are not available in every single health care facility. For example, through involving experts, Kenya has established a system where treatment centers' locations were optimized in the country. Then patients would be referred to these centers from first level facilities. However, due to restricted resources, patients in developing countries still have to travel hours to get to these centers (ACC, IND3).

4.3.3 Technology

In some countries, technology as a supporting tool for health care is completely unrealistic, as residents in rural areas cannot access digital tools or other complementary assets (e.g. electricity) are not at their disposal (NUR, MD1, SCM). However, in other developing countries, these issues seem to be fading as more and more people have access to basic but useful tools, such as smart phones. MD2 explained that the majority of Kenyans are now familiar with newer methodologies for communication, serving as a basis for telemedicine to appear. Teleconferencing with patients allows for symptomatic diagnoses and disease management even in small villages. While this solution is not very well established yet, the COVID-19 pandemic has accelerated this learning curve even in developing countries. ACC provided an example from Mexico, where a large hemophilia clinic has already achieved to significantly reduce the number of hospital visits. Patients and caregivers have been educated by health care professionals to administer their treatment at home, and they can also use telemedicine for remote guidance. Thus, they only need to visit the center when they pick up their medication or in case of urgency – resulting in an increased quality of life for both the patients and their caregivers.

MD2 further argues that even basic digital technologies, such as telemedicine, electronic patient records, scheduling systems, consumption records, etc. will improve the quality of care in developing countries too. Not only will they reach more patients through remote visits, but with structured data they can also improve efficiency and availability of medication and tools in the facilities (MD1, MD2).

4.3.4 Empowerment

Topics around empowerment that the respondents mentioned refer to the education of physicians and patients so that they can better advocate and care for the patient populations. Empowerment in the health care sector can manifest in better effectiveness and efficiency of care in developing countries:

> *"I do not think it's a very good idea just to put free medication into a country where you do not have the health care professionals in place to be able to administer and distribute that medication."*

Quote 7, IND3

For diseases like sickle cell disease, the proper training of a multidisciplinary care team is of high importance. However, in some countries, certain specializations are simply not available, doctors need to go abroad to receive specialized education in that field. According to ACC, it would be quite important to help these countries with setting up the required infrastructure for these trainings instead of sending professionals abroad where they will learn from people who do not come from the same circumstances as they do. Another goal of training specialized doctors is for them to become passionate about certain disease areas and become champions for the mission of improving access to care (IND2).

Education of physicians does not necessarily has to happen in an institutionalized format. An example from Tanzania illustrates how professionals can also learn from each other. An anesthesiologist decided to teach a neighboring hospital's staff about post-operative care after seeing how many patients were lost due to ineffective post-operative monitoring. This way they achieved better outcomes and even in a cost-efficient manner (NUR).

The respondents suggested that educating patients is equally important so that they can feel safe, make informed (and better) decisions, and have an improved quality of life (e.g. IND1, MD1). In hemophilia for example, teaching the patients and their caregivers about how to prevent bleedings, what to do if a bleeding occurs, who to contact in case of emergency are all important pieces of knowledge when living with this condition (ACC). In case of sickle cell disease, simply distributing the standard of care (hydroxyurea) is also not an option. Patients need to be told some information on how to take the medication, its mechanism, potential side effects, etc. Understanding the disease will likely stop the taboo around it, thereby bringing the community together (IND2). MD3 explained that access to

the Internet in and of itself had brought great change to the lives of patients in Kenya. As they can now access more information before getting care, they have started to converse with doctors, know their rights better, and demand certain services.

> *"Education is one of the most important things to help a developing country further."*

Quote 8, MD1

Providing education from a very young age, teaching them English and passing on knowledge about the rest of the world may cause brain drain (educated people leaving the country), but tendencies show that several of them do return after a while to support their home countries with the experience they gained (MD1).

If the population in general is more knowledgeable, together with the patients, patient advocates, organizations, they need to educate the people in the decision-making system about the diseases. They need to spread the word not only about pharmaceuticals, but also about distribution of human resources, budgets, research labs, etc. to get decision makers' approval and commitment (ACC). MD3 explains several ways of how they advocate for treatments to become part of the "essential drug list":

> *"…advocacy using media, policymakers, we also go to community leaders, just trying to engage them, we also talk to religious leaders just to try and see whether we can make an impact. For scenarios where we think people have misunderstood diseases, we also try to educate and we use different mechanisms to do that. We actually go to parliaments and petition parliaments and say this disease requires attention, (…) and then of course working with the different international groupings and supporters, funders."*

Quote 9, MD3

However, not everyone is able or has the skillset to handle all these tasks. Thus, it is important that these individuals are empowered, e.g. through a world-wide network arranged by a global organization, where strong members can share their experiences to inspire less-experienced peers (ACC). IND3 highlighted physicians' advocacy work by

suggesting that health care professionals are the ones who can articulate the current situation in a disease area, its priority compared to other diseases, and the solutions that would be the most beneficial.

4.3.5 Partnerships

Several different types of partnerships were mentioned during the interviews, such as public-private partnerships, company synergies, and cooperation between disease areas.

Public-private partnerships were viewed as beneficial for several improvements, such as increasing access to treatment (NUR), establishing diagnosis protocols, building a patient registry, building medical capacity (training health care workers, educating patients), raising awareness, building patient communities, and advocacy (ACC, IND2).

The importance of synergies between pharmaceutical companies lies within the assumption that companies working in their own silos waste resources, whereas they could find synergies in their financials, expertise, geographical reach, etc. (ACC, IND2). Naturally, competition is somewhat of a barrier for these synergies, but the respondents suggested that companies should focus on common aspects instead of what differentiates them (e.g. ACC). Since pharmaceutical companies engage separately in advocacy work, raising awareness, they are decreasing their efficiency. As these activities are not product specific, they should collaborate to advocate for changing a system (ACC, IND2).

> *"I think when you are open to recognize the work of others and to also just not being territorial… I think that is very important. Then you contribute to a bigger goal."*

Quote 10, ACC

Besides pharmaceutical companies, countries are also encouraged to find a common ground. MD1 believes that these collaborations would contribute to a more significant negotiation power of countries when discussing with e.g. pharmaceutical companies.

Some respondents also mentioned a collaboration between disease communities. The specific example they explained was a program in Kenya, Tanzania, and other

African countries, where the communities in hemophilia and sickle cell disease were working together. The rationale of this collaboration is that the care for these diseases faces similar challenges: late diagnoses, lack of awareness and advocacy, insufficient training of health care professionals, and some physicians treating these diseases are even the same group of people (ACC). The intention is to try and use a common disease (sickle cell disease) to support a less common disease (MD2).

> *"When you want to develop capacity for a clinician, if you just went with one disease, hemophilia is not always the common problem. So when you capacity build a clinician to manage a sickler and you capacity build them to also manage a hemophilic, you use that clinician better. (…) the labs can be developed to manage both disease entities and so there´s better utility of services and the personnel within a facility."*

Quote 11, MD2

4.4 Achieving a sustainable solution

4.4.1 Financing

Since financial resources were assumed to be the biggest constraints for developing countries during the interviews, this was also one of the most discussed topics in relation to achieving sustainability. Different strategies were mentioned regarding differential pricing, intellectual property rights, and donations.

Respondents' answers were not unified in terms of differential pricing. Some of them suggested that companies should offer lower prices to developing countries (e.g. NUR), while others had the standpoint that differential pricing is already in place and in several countries the price is set by the authorities, but it still does not solve the issues (IND2). Some others mentioned the example of access programs as good solutions, but they also acknowledged that countries may be upset by having to pay more for the same medication as the ones included in the access programs (e.g. MD1).

As mentioned above, NUR suggested that pharmaceutical companies should share their compound details even before the patent expires. Another respondent found that lengthening the patent protection would be quite beneficial – and not only for companies.

IND1 further argued that when a company has production facilities set up and gains the experience from working with a disease and a specific compound, their efficiency is constantly increasing, and the cost of production is decreasing. However, when the patent expires, there is an immediate impact on the company and its finances. Thus, it would be beneficial for both the companies and developing health care systems if companies could focus more on partnerships and access programs instead of being challenged by potential competition.

Developing countries are also recipients of different kinds of donations, may it be money, facility building, or others. And while respondents said that donations are necessary at some point to help these countries (SCM, MD2, IND3), some of them also warned about the potentially not-so-selfless helping hands that in fact plan to exploit the country for gaining political power (NUR, MD2), or the intermediaries along the supply chain who only care about their own profits when the donation may not even reach the end users (SCM).

4.4.2 Toward the ultimate goal

As mentioned above, "donations are not the final destination, but they are definitely a chapter in the book" (IND3). However, the dilemma in these situations is the unforeseeable duration of donations, potentially leaving the patients without secure access to their medications in the long run. Even with very good intentions at the beginning, companies may need to re-prioritize their own resources, they could be taken over by another company, or simply go into liquidation (IND3). MD2 suggested that donations are indeed beneficial for sensitizing people about the availability of new medications. He continued further, that the ultimate goal would be building production capacities in developing countries as well, so that they could produce their own medications. This would not only provide benefits financially, but could create new workplaces for local communities, and serve the environmental purpose by reducing long-distance shipments. However, this may be a long way ahead. Pharmaceutical companies planning to invest in

these regions need to be guaranteed safe and transparent environments and this requires a change in developing countries' political functions (MD2).

Naturally, solving the other infrastructural issues would still be a task where different partners could help, otherwise the production facilities would still not solve the challenges in access. Even though partnerships may accelerate progress in developing countries, almost all respondents warned against being too consumed in an external organization's mindset.

> *"I was alluding to people making very smart decisions in offices in Switzerland. Yes, from a supply chain perspective, those decisions were very smart, but they were forgetting everything around… all the environment. I think that's a big-big problem"*

Quote 12, SCM

The developed world does not have all the insights of living with a disease in a specific country that might not be that developed, so it is important to start with understanding the patients and their journeys (IND1). The local community needs to work together, so the pull for action has to be there locally (IND2), but partners can help them become a champion for their needs (IND3).

> *"If society, politicians are not deciding that this has to be a priority, then nothing will drive that forward. Then there will be healthcare organizations, companies trying to help with donations maybe, but it will not be successful if it's lacking in ownership of trying to make things change."*

Quote 13, IND1

Furthermore, there are huge differences between countries, so the support needs to be tailored to fit for purpose (ACC, IND2). However, new strategies take time and resources, so we should find ways that benefit the most people (IND1).

> *"I think what we need to realize is that we can't help everybody and we can't help them at once. But we can try to make a big impact and try to find a good solution that can hopefully help many to better lives and to also better treatments."*

Quote 14, IND1

5 DISCUSSION

5.1 Overview

This chapter brings together the knowledge gained throughout the whole thesis process, including the information in the Introduction (1), Theoretical framework (2.1), Literature review (2.2), and Analysis (4) chapters, formed by my interpretation. It summarizes the main findings, highlights implications for research and practice, touches on limitations of the thesis, and suggests future research areas. By answering the research questions, it also provides recommendations for stakeholders in the health care supply chain.

5.2 Implications for research

Even though the topic of this thesis is quite practical, some implications for research can also be drawn. The thesis was set out to bring together the literature available on pharmaceutical supply chains and aspects of access to treatment in developing countries. The unique angle that was chosen is the sustainable supply chain perspective in pharmaceutical access. Instead of focusing on one stakeholder's perspective, I believe that this holistic approach was justified by the complexity and intertwined nature of the field.

Two of the findings imply that this research could be channeled into further investigation applying Michael Porter's value-based health care approach, where value is defined as the achieved health care outcomes that matter to patients relative to the money spent (Porter, 2008). Firstly, very scarce resources need to be distributed across several aspects of health care. Secondly, developing countries have differing priorities and react differently to specific interventions, since they cannot be generalized as one geographic area. Therefore, specific interventions are perceived with different values in these countries and as resources are highly limited, the return (i.e. health outcomes) on investment could serve as a good measure of efficiency. I believe that researching this field through Porter's approach would aid practitioners with finding a united interest among stakeholders' sometimes conflicting goals (Porter, 2010).

Learnings related to the research approach and future research areas are discussed in the Limitations and future research areas section (5.4) below.

5.3 Implications for practice

5.3.1 Answer to research question #1

What issues are present in pharmaceutical supply chains that hinder the access to treatment in developing countries?

While the answer to this research question cannot be directly used in practice, I believe it is important for practitioners to understand the issues in detail before thinking about the solutions.

It is established at the beginning of this thesis that health care sectors in general (not only in developing countries) are faced with increasing challenges due to an aging population, lifestyle diseases, etc. However, developing countries are burdened with even more challenges due to their scarce resources. As explained in the Theoretical framework (2.1) section, pharmaceutical supply chains also differ from regular supply chains in a way that besides the distribution of pharmaceutical products, they entail a value-chain perspective. Respondents also shared this opinion that the real issue in developing countries is not the access to pharmaceuticals, but in fact the access to care, so the whole health care infrastructure is lacking some aspects of provision in these geographic areas. Thus, as one of the most important learnings, further implications focus on access to care instead of access to treatment.

The underlying cause of insufficient and unequal access to care in developing countries is multifaceted. The overarching theme mentioned by respondents and by previous research too is affordability on both a health care system and an individual level. Developing countries tend to have a mostly out-of-pocket market for medicines, putting an even higher burden on family finances. Another cause appearing from this research is infrastructure. This includes the lack of well-equipped health care facilities, clear procedures in the supply chain, adequate warehousing and transportation, consistent

procurement practices, etc. Furthermore, several medical specialties and disease areas suffer from an insufficient number of experts, lack of awareness, and overall underinformed population. These less-than-optimal solutions often lead to late diagnoses, misdiagnoses, or mistreatment, resulting in severe problems, such as drug resistance and the vicious circle of certain diseases. Since it takes large financial resources and time investment for patients to get care, they may not be able to work, resulting in even less purchasing power and an even more decreased access to care for society.

5.3.2 Answer to research question #2

How can the issues around access to pharmaceuticals in developing countries be solved?

As seen from above, the issue of accessing care in developing countries is very complex and interconnected. The Background (2) and Analysis (4) chapters highlighted several examples of potential solutions. Thus, this section explains some recommendations as a result of this research. The recommendations focus on the stakeholders in the basic structure of a pharmaceutical supply chain as shown in Figure 2.

Recommendation #1: Solutions must be locally embedded for a successful change

Bendul et al. (2017) suggest a customer-centric design and local solutions as suitable supply chain models for all their identified constraints at the base of the pyramid. This is further justified by the research of this thesis, as most interviewees mentioned this aspect in one way or another. I find the following quote by IND1 extremely important, as it captures the essence of this recommendation: *"If society, politicians are not deciding that this has to be a priority, then nothing will drive that forward".*

The actual implementation of this recommendation involves all stakeholders of the supply chain. Patients and patient organizations have a very important role in building a patient group which can advocate for themselves and raise awareness around a certain disease and issues of care. Pharmacies, hospitals, and all health care professionals should

support the forming of patient groups and serve as trusted advocates in all possible online and offline channels. They should also aid governments with channeling in their needs in terms of resources, priorities, or improvement ideas.

Governments and policy makers have the most important, but also the most challenging and complex tasks in this process. Therefore, their dedication and accountability above all is crucial, and the examples below should be viewed as parts of potential tasks necessary in a given environment. They should also acknowledge that all this cannot be performed alone – thus they need to be open to dialogue with others to define a future health care agenda. Systematic changes are needed in several countries, such as the optimization of health care facility locations. I would recommend looking into Porter and Lee's hub-and-spoke model explained in their 2013 paper, The Strategy That Will Fix Health Care. This refers to the establishment of expert facilities (hubs) supported by a satellite system of smaller treatment centers. Governments also need to engage in providing complementary services, ensure sufficient training and employment opportunities for health care professionals, and establish protocols to standardize quality of care. They also have a responsibility to reduce harmful practices, e.g. corruption and high levels of bureaucracy. A further step could be to secure the requirements for digital health technologies, such as internet coverage.

Manufacturers/pharmaceutical companies are responsible for establishing and maintaining the supply chain from factory to pharmacies or hospitals and they could also aid with their expertise and knowledge in raising awareness. Their ethical contribution is extremely important, however, they should let the government be in control.

Recommendation #2: Stakeholders should move away from their own silos

Partnerships and different kinds of cooperation are highlighted as one key takeaway from this research. Collaborations among local players or between local and global stakeholders ensure embeddedness in the country, but also bring in good practices, expertise, and potentially financial and other resources to catalyze change. However, for

these collaborations to function, a common ground needs to be found instead of the often present silo mindset.

As private companies can function because of the profit they make, this common ground does not entail sharing of confidential information. Rather, it should be viewed as a change of mindset: instead of finding aspects of an organization that is not to be shared, potential synergies should be highlighted. This research already mentioned ideas, such as a collaboration between companies for raising awareness and advocacy, or the division of geographic regions included in access programs.

Other examples, like collaborations between countries or disease areas with similarities, are also worth exploring locally.

Recommendation #3: Pharmaceutical companies should tailor their strategies to the given market and disease area

The interviews included respondents who had differing levels of experience in (among others) Kenya, Tanzania, Malawi, and Mexico. Their impressions of the health care systems in these countries and more specifically, of the access to care in these countries further highlighted what several respondents suggested: each and every country needs to be targeted separately. The most impact can be achieved if approaches are tailored to specific countries and disease areas or disease area groups. However, this does not mean that a completely new strategy needs to be built for each market. Instead, all stakeholders need to keep in mind that these strategies need to be overviewed according to the countries' health care system (e.g. payment structure), infrastructure (e.g. health care facilities, transportation, warehousing), disease prioritization, governance and regulations, patient advocate groups, etc. Then the aim should be to create a strategy that can benefit the most patients, not only within, but also across countries.

Digital technologies may be solutions that are possible to be transferred from one market to another as they do not necessarily require much alteration (besides e.g. translation). Furthermore, as seen in the UNDP's Preparedness Dashboard (Table 1, p. 9),

it can be assumed that mobile phone solutions would have a relatively high utilization rate.

5.3.3 Answer to the sub-question

How can these solutions become sustainable financially, socially, and environmentally?

It is quite clear from this research that achieving sustainability across all three areas is a long process with several steps along the way. A respondent even concretized this end-goal as having local production facilities in developing areas. However, for this to become reality and function in the long term, commitment is required from all sides. Pharmaceutical companies outsourcing their productions need to share their knowledge with local stakeholders and ensure that the quality is constantly kept at a high level. Governments need to be open for long-term collaborations with these companies and create a politically stable, safe, and transparent environment for external investors.

When discussing financial sustainability, several respondents mentioned that external donations must be a phase in this process, but this is not a sustainable solution. One example that could be utilized is the intellectual property right alteration explained by Andreassen (2015). As discussed previously, if global policymakers extended patent protection on pharmaceuticals, the companies could use the extra profit for donations or access programs, while not having to focus their resources on potential competition. However, I believe there is a risk with this solution of restricting the competition too much, thereby monopolizing specific markets.

Social sustainability can be achieved by ethical operations in these countries. Furthermore, by building the infrastructure and potentially outsourcing parts of the production to these areas would open new employment opportunities and a stable economic development for local communities (e.g. decreasing poverty). Socially sustainable solutions should also ensure uninterrupted, long-term access to care by building supply chains that can flexibly respond to the supply chain vulnerabilities

explained by Asamoah et al. (2011) as seen in the Supply chain vulnerabilities (2.1.3) section of this thesis.

As for the environmental sustainability, it is not enough to adapt to global and local regulations. I believe that both external and internal players should reduce their environmental footprints by e.g. energy-efficient technologies and optimizing facility locations and inventory (Zahiri et al., 2017; Hua et al., 2011).

5.4 Limitations and future research areas

As all research, this thesis also has several limitations, owing to the methodological choices or some other factors. Firstly, the chosen topic was a slice of a wide-spread theme, but still it turned out to be highly complex, affecting a lot of stakeholders. This posed challenges in terms of time and access to enough experts in the field. This shortcoming was further deteriorated by some no-shows and a low response rate to unsolicited messages.

Secondly, I faced a dilemma at the beginning regarding scoping. The insecurities were twofold: the thesis could have been narrowed down to a specific disease and a specific country, or kept open, or as it finally happened, focused on a specific disease, but in all developing countries. The reason for this dilemma was the question whether the issues explored in the thesis would be general or specific to each situation. Then I made my decision according to the initial research conducted, which highlighted that indeed different disease areas have differing issues with access, but several countries are facing the same or similar challenges. As it turned out from my results, it may have been beneficial to also narrow down the research to one specific country. However, I was still facing the issue of finding enough respondents working with sickle cell disease and this would have further complicated my search for interviewees. For future research, I would recommend finding a narrow scope for deeper analysis and potentially utilizing other data gathering methods besides interviews.

Finally, the choice of data collection also entailed some bias. The respondents' experience mainly related to African countries, leaving other developing areas unexplored.

Furthermore, the patient voice was missing from the research. Field visits (even virtually) or patient interviews would have been very beneficial.

Further to the results of this thesis research, I would recommend two concrete research areas. Firstly, as mentioned in the Answer to the sub-question (5.3.3) section, supply chain vulnerabilities need to be treated during the process of supply chain optimization. It would be worth exploring how to treat these in developing countries, e.g. by building resilient supply chains starting from the works of Zahiri et al. (2017) and Silvestre (2015). Secondly, it would be interesting to analyze how the COVID-19 pandemic affected global supply chains, and whether these effects are only temporary or will have long-lasting effects (e.g. ECA, 2021).

6 CONCLUSION

In this thesis, both theory and practice is applied to form substantial recommendations for securing access to pharmaceuticals in developing countries. Starting from an initial problem statement that one third of the population does not have access to treatment, two research questions and one sub-question were stated. Accordingly, the aim of this research was to investigate the reasons for insufficient access to treatment in developing areas. Furthermore, I aimed to explore potential solution ideas for these issues. Finally, the research also intended to find solutions that are sustainable financially, socially, and environmentally. The outcome of this thesis was presumed to find specific steps for stakeholders in the pharmaceutical supply chain that they can follow for gradually achieving sustainable access to treatment.

In the first part, the topic and its relevance was introduced in detail, with special attention to the scope being developing and least developed countries, and sickle cell disease. As a background to the whole research field, relevant theories were presented about pharmaceutical- and sustainable supply chains, as well as supply chain vulnerabilities. Then a review was done on the currently existing literature about the challenges and potential solutions for providing access to pharmaceuticals in developing countries. Then the methodology was thoroughly explained, including the inductive research approach, the field problem solving methodology, and the main data collection method, semi-structured qualitative interviews.

The second part of this thesis included the analysis, where the conducted interviews were synthesized through three bigger themes and several smaller topics. Then this data was triangulated with the existing literature, resulting in three recommendations for practice. These referred to the solutions being locally embedded, stakeholders moving away from their silo mindset, and the tailoring of solutions to specific markets and disease areas. As the thesis process has constantly formed the scope and outcome, in the end recommendations for the future were discussed.

Even though the thesis initially set out its focus to be on developing countries, as seen from the Developing countries (1.3.1) section, recommendations should be viewed differently for countries with different levels of development. Despite their similarities, the markets included under this term cover an extensive range, therefore narrowing this group may result in more focused solutions. While the focus on sickle cell disease has aided the research with finding a target and specific examples, and led me to interview respondents thereby improving the quality of the analysis, the recommendations are not only suitable for this disease area. Instead, sickle cell disease should be viewed as a proxy for other disorders.

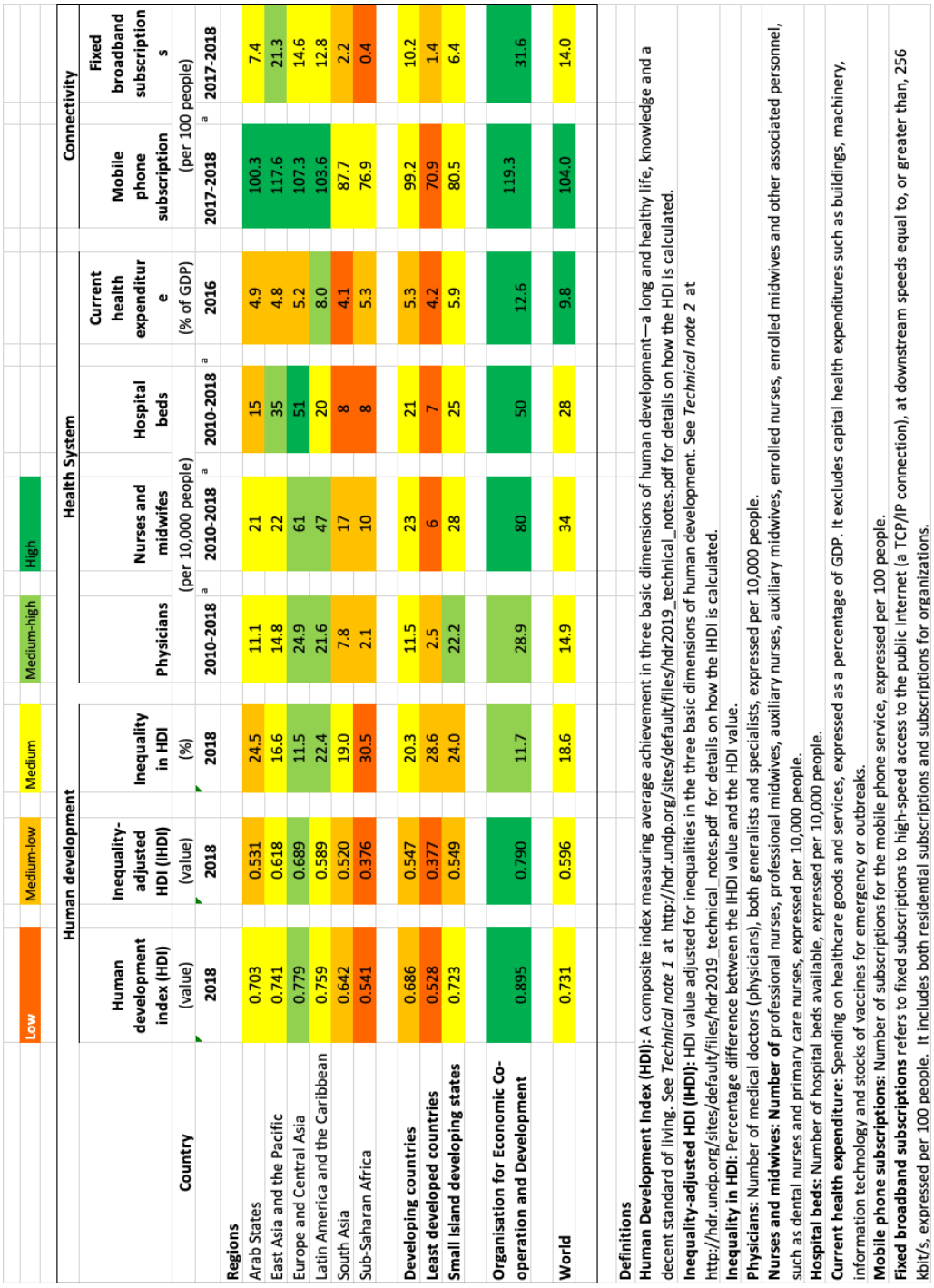
Based on the results of this thesis, it is clear that sustainable access to pharmaceuticals and health care in general cannot be achieved with short-term investments. However, these are also part of the journey, e.g. in the form of drug donations. Arguably the most important takeaway for all parties included in the pharmaceutical supply chain is that focusing on one aspect only and working individually is not the path to follow. In order to improve access in developing countries, a holistic approach is necessary, not only in terms of stakeholders, but also of disease areas, care priorities, other industries, etc. Indeed, this is where the real challenge lies.

While the thesis in itself marks the end of my master studies in health care innovation, I am hoping to continue contributing to this field for quite a while. Along with my professor and supervisor in this process, we have received an invitation to write a case study about this topic in a case collection named *Managing Sustainability: State-of-the art and Mini-Case Studies Series*. Therefore, the work continues firstly by ensuring the ethical use of the data included in this thesis.

7 APPENDIX

Appendix A - Sustainable Development Goals

Appendix B - UNDP Preparedness Dashboard



	Low	Medium-low	Medium	Medium-high	High								
	Human development			Health System						Connectivity			
Country	Human development index (HDI) (value) 2018	Inequality-adjusted HDI (IHDI) (value) 2018	Inequality in HDI (%) 2018	Physicians (per 10,000 people) 2010-2018 [a]	Nurses and midwifes (per 10,000 people) 2010-2018 [a]	Hospital beds 2010-2018 [a]	Current health expenditure (% of GDP) 2016	Mobile phone subscription (per 100 people) 2017-2018 [a]	Fixed broadband subscriptions (per 100 people) 2017-2018
Regions									
Arab States	0.703	0.531	24.5	11.1	21	15	4.9	100.3	7.4
East Asia and the Pacific	0.741	0.618	16.6	14.8	22	35	4.8	117.6	21.3
Europe and Central Asia	0.779	0.689	11.5	24.9	61	51	5.2	107.3	14.6
Latin America and the Caribbean	0.759	0.589	22.4	21.6	47	20	8.0	103.6	12.8
South Asia	0.642	0.520	19.0	7.8	17	8	4.1	87.7	2.2
Sub-Saharan Africa	0.541	0.376	30.5	2.1	10	8	5.3	76.9	0.4
Developing countries	0.686	0.547	20.3	11.5	23	21	5.3	99.2	10.2
Least developed countries	0.528	0.377	28.6	2.5	6	7	4.2	70.9	1.4
Small Island developing states	0.723	0.549	24.0	22.2	28	25	5.9	80.5	6.4
Organisation for Economic Co-operation and Development	0.895	0.790	11.7	28.9	80	50	12.6	119.3	31.6
World	0.731	0.596	18.6	14.9	34	28	9.8	104.0	14.0

Definitions

Human Development Index (HDI): A composite index measuring average achievement in three basic dimensions of human development—a long and healthy life, knowledge and a decent standard of living. See *Technical note 1* at http://hdr.undp.org/sites/default/files/hdr2019_technical_notes.pdf for details on how the HDI is calculated.

Inequality-adjusted HDI (IHDI): HDI value adjusted for inequalities in the three basic dimensions of human development. See *Technical note 2* at http://hdr.undp.org/sites/default/files/hdr2019_technical_notes.pdf for details on how the IHDI is calculated.

Inequality in HDI: Percentage difference between the IHDI value and the HDI value.

Physicians: Number of medical doctors (physicians), both generalists and specialists, expressed per 10,000 people.

Nurses and midwives: Number of professional nurses, professional midwives, auxiliary midwives, enrolled nurses, enrolled midwives and other associated personnel, such as dental nurses and primary care nurses, expressed per 10,000 people.

Hospital beds: Number of hospital beds available, expressed per 10,000 people.

Current health expenditure: Spending on healthcare goods and services, expressed as a percentage of GDP. It excludes capital health expenditures such as buildings, machinery, information technology and stocks of vaccines for emergency or outbreaks.

Mobile phone subscriptions: Number of subscriptions for the mobile phone service, expressed per 100 people.

Fixed broadband subscriptions refers to fixed subscriptions to high-speed access to the public Internet (a TCP/IP connection), at downstream speeds equal to, or greater than, 256 kbit/s, expressed per 100 people. It includes both residential subscriptions and subscriptions for organizations.

Source: UNDP, 2020

Appendix C - Initial interview guide

Interview title	Interview with XYZ, Organization
Date, time	XX December 2021
Location	online

Goals:

- To be informed about
  - problems and needs
  - potential solutions
  - sustainability of pharma access
  - examples

Theme	**Relevant theory/literature**	**Interview questions**
Briefing 5´	N/A	• Asking for permission to record • The interview transcript will be included in the appendix of the thesis, unless otherwise requested. This means that it will be visible in the CBS thesis library. Do you agree to this? Would you like to be anonymized or shown with your name and title in the thesis? • Purpose of the interview and letting the subject know how I will use this data (transcription, use of quotes) • Timeframe: How long it is going to take (~45 minutes) • *Talking about confidentiality* • Asking if the subject has any questions before we begin
Introduction 5´	*Pharmaceutical supply chains* *Challenges in access*	• Could you introduce what you do in just 1-2 sentences? • What is the first thing that pops into mind when you hear "Access to pharmaceuticals" *(only focused on pharma and not care)*? • When you think about patients anywhere in the world – what do you think their most important need is in terms of accessing pharmaceutical products? What would be the first thing they say?
Issues with access 10´	*Pharmaceutical supply chains* *Supply chain vulnerabilities* *Challenges in access*	*The first questions are general, without having a specific treatment area or disease in mind:* • Based on your experience, how is access to pharmaceuticals // a pharma supply chain different in developing countries compared to the developed world? • What do you think are the 3 main causes for these differences?

		• Do you think there are differences in access among the different diseases or are these general issues in developing countries? (Examples for communicable diseases: HIV, ebola) *Optional for the ones having experience with sickle cell disease:* • How would you characterize the access to treatment for SCD? Are there any specifics of these drugs compared to other non-communicable diseases in terms of access?
Solutions to access 10´	*Pharmaceutical supply chains* *Solutions for providing access*	• Who are the stakeholders within providing access to pharmaceuticals in developing countries? Who do you think are the most important players in this supply chain? • How do you see different stakeholders´ roles and responsibilities in finding a solution to these issues around access? • What would be your strategy to solve the issues you have mentioned before? • How would you start working on this solution?
Sustainability 10´	*Sustainable supply chains* *Solutions for providing access*	• We can hear a lot about the triple bottom line of companies, which includes the environmental, social, and financial sustainability. Do you think that your solution could be sustainable considering all 3 aspects? Why (not)? o *Follow-up with challenging questions if they say yes, e.g. Would it require constant financial donations from an organization?* • Have you encountered a solution that you think would be sustainable? Or maybe with a little modification, it could work well? • What challenges do you expect regarding the sustainability of access to pharmaceuticals in developing countries?
Debriefing 5´	N/A	• Reinforcing/summarizing the learnings of the interview • Asking if the subject has anything else to add • Thanking the subject for the interview • Asking if they will allow me to contact them again for follow-up questions (if necessary)

Appendix D - Interview transcripts

Interview title	Interview with an Expert in supply chain management
Date, time	10 December 2021
Location	online

00:01:18.060 --> 00:01:23.380
ZSOFIA KESZTHELYI
As you know, my thesis is about securing access to pharmaceuticals in developing countries.
And the reason why you're here is because I believe you're a great expert in supply chain management in the healthcare sector, so I would like to hear your thoughts on different topics.
But first, could you introduce in one sentence what you do?

00:01:42.800 --> 00:01:55.320
EXPERT IN SCM
So I do different things, I'm a professor at the university… at several universities in fact, one of my fields is actually supply chain management… operations management. One of my areas of interest in health care, pharma. And I have a number of other projects related with innovation in health care. Yeah, so I'm a researcher, but also practitioner in the sense that I have helped creating several companies in this space. I'm partner in several companies that I created in sometimes… in some cases with students, so that's more or less what I do.

00:02:27.560 --> 00:02:35.490
ZSOFIA KESZTHELYI
Uhm, when you hear the phrase “access to pharmaceuticals”, what is the first thing that pops into your mind?

00:02:38.170 --> 00:02:41.920
EXPERT IN SCM
Well is that people should have access… right? Access to pharmaceuticals is not very different from access to other goods and services, and we all know that in some parts of the world is access doesn’t exist, because the goods don't get there for a number of reasons. Sometimes it's because people cannot afford them. In other cases it is because regardless of the purchasing power, these people or these places cannot… do not have the infrastructure to get these products or services. From simple things like roads or trains to you know sometimes different types of infrastructures… telecom infrastructures. Uh, you know, wireless, Wi-Fi, blah blah blah. So for a number of reasons. Sometimes political, by the way, right? Not everyone has equal access to goods and services.

00:03:46.860 --> 00:04:06.050
ZSOFIA KESZTHELYI
And when you think about patients, I know you are quite close to patients because of [xxx] for example. So when you think about patients anywhere in the world, what do you think their most important need is in terms of accessing the pharmaceutical products, what would be the first thing that they say they need?

00:04:08.920 --> 00:04:19.900
EXPERT IN SCM
It's a bit hard to say it's a… it's a very broad question, but uh, because different patients need different

things, but so for the broad question maybe a broad answer is enough: access. Right? I mean you use it first, but access to medical devices, to medicines, to knowledge. Uh, so there's also not enough knowledge in part of… in some parts of the world about what people should do right? So people don't often even understand the problem that they have. And so they of course sometimes have local doctors with sometimes limited knowledge and sometimes the wrong knowledge about what can and should be done. But yes, so that there are a number of resources that lack… patients don't have access to medical professionals, medical support, social support. Uh. And of course, medical professionals would be required for them to then get medicines. Sometimes you know that even means that people are taking the wrong medicines. Uh, because they take whatever is available sometimes.

00:05:34.710 --> 00:05:35.020
ZSOFIA KESZTHELYI
Yeah. Right, uhm. So based on your experience, how is a pharma supply chain different in developing countries compared to the developed world? You already mentioned some examples but do you have a specific idea of how these pharma supply chains are different?

00:05:58.490 --> 00:06:05.790
EXPERT IN SCM
Yes, so they are different in health care as they are different in in other areas, right? And for instance, I always recall that Nokia at some point…like talking now about the cell phones, they realized that they could sell millions of phones in parts of the globe where there is no electric power. And this was interesting because you know how did they charge the phone, right? And you sometimes realize that now I'm talking about the product that it's actually similar, regardless of where they are. But what they did was to find different ways of charging the phone. So there are some **complimentary services** that are required for you to use a found like electric power that was not available. So they had to come up with new ways, interesting ways, innovative ways of actually charging their phones. For instance, in some places there were people that were delivering power by using batteries from cars. And because you know, there were some cars and some entrepreneurs, let's call it. That way you know some entrepreneurs realized if they were careful they will be able to extract the energy from the battery of the car and actually charge the phones and soon realize that in fact they didn't have enough cars to charge the batteries, because this became a big business of those guys that use motorcycles with car batteries to go around villages and charge the phones. So this is to explain that sometimes what is provided is different. So the services available end up being a bit different even for products that are that are common right? If cell phone is about the same you know, in Denmark or in South Africa or in Central African Republic, except that in some of these locations, there's no access to some of the complementary assets that are necessary. Now thinking about the health care. You know, sometimes that means that even when there is a service available, not everything is available. I mean my mother tells me… so I grew up in a very poor country. I grew up in… I was born in Central African Republic. It has been often considered the poorest country on Earth. Uh, and at the time was not, in fact, it… at the time was not that bad compared with other countries at least. But it's a fact that at some point when I was a baby, I had an infection in my leg and they wanted to… and they had to do surgery to fix that infection. And there was no anesthesia right? So they considered transporting me to Paris or to even to Russia apparently, to Moscow, but you know, it turns out that this was not viable. So what they had to do was a surgery where there was no anesthesia. That means that my parents had to use their hands to sort of hold me. So this is to say… I mean, I guess it was… it wasn't in the in the end… it was basically something in a leg, right? It was not that serious, because if it was of a different nature, uh the fact that there was no supporting medicine could they've been very serious. So this is to say sometimes they will have part of it, right? And then they're providing some services, not everything. So part of it is incomplete. In this case I don't think it was because there was no infrastructure it is more because

somehow it didn't get there. I mean, I don't really know why they run out of anesthesia but yes, resources are scarce. And the supply chain is not there. Human resources are also not very sophisticated, so their ability to plan ahead is not very good sometimes right? And so yeah, so it becomes a bit problematic to be able to provide health care services in some parts of the globe. In particular health care services.

00:11:14.540 --> 00:11:18.780
ZSOFIA KESZTHELYI
Do you think that these differences or issues… So are there any differences in access among the different diseases, or are they like… are these general health-care related issues that we're talking about?

00:11:31.610 --> 00:11:39.000
EXPERT IN SCM
I think so. First of all, because some diseases are not even recognized as diseases in some parts of the globe, right? Uh. I mean mental health. Just to give you a… mental health in developed countries is it's becoming a big deal. It's already a big deal. In other parts of the of the globe, it is a luxury in the sense that they would not worry so much about mental problems and the treatment of mental problems because they have other stuff…more serious problems that they need to handle right away. Uh, otherwise people die right? So that's why I'm saying more serious. So I think yes so the recognition of the importance of the disease is very different in different parts of the globe. That's for sure, yeah.

00:12:32.240 --> 00:12:33.970
Zsofia Keszthelyi
Great, umm. Then moving on to... So now we discussed the issues and moving onto the solution side of it all. Who are the stakeholders that you think are most important in this supply chain? Who are the stakeholders that are providing access to pharmaceuticals in developing countries? So how is the chain built up?

00:13:00.380 --> 00:13:01.270
EXPERT IN SCM
Yeah so then of course it's a bit hard to generalize right? Because when we talk about.. it's developing countries we are talking about… very poor situations where, I mean, I always hear stories like the dentist, what's the dentist in a rural area in central Africa? Well. It's not really as a health care professional, right? It's someone that uses all sorts of techniques from mechanical tools that's typically are used to fix cars to sort of remove the teeth. Uh, with techniques that you would never consider acceptable. So it's still a health service in theory, right, uh? Removing the tooth but the... so this is to say I, I think sometimes what you see is that the resources are different, the stakeholders are very different. You know, many of the doctors are not really doctors, right? Or the nurses are not nurses, so those are people that in theory or the community at least believes that they have some knowledge of what they are doing. That knowledge doesn't necessarily come from attending medical school or studying a topic, maybe it comes from experience, from reputation and you know… they already helped my father so they might be able to help me… And you have all sorts of non-educated people with the with…you know, streams of knowledge associated… or let's not even call it knowledge, but basically strange backgrounds doing health care practice in many parts of very poor countries in particular. Uh, of course then you also have, uh, other practices that… because these countries are typically characterized by very high inequality… I mean, I think the best hospitals, the richest hospitals by any means that I've seen in my life are in Brazil. And Brazil is one of those cases where you have all

sorts of things from the best of everything… and believe me, at some point I had the chance of visiting the best hospitals say in Boston, right? The Harvard Medical School, the Harvard Hospital, in other places in the US as well. And then I went to Brazil and it's like "Oh my God". The Brazilian hospitals are so much better that it sort of tells you that it's a bit hard to generalize, right? Of course, if you are in San Paolo is one thing… well, if you are in San Paolo, it's one thing if you have access because San Paolo is huge and if you are poor in San Paolo then it's about the same right? So your neighbor access is not just because in some of these countries… like I mean you live in Denmark. We can say that everyone has access… same sort of access if you are part of the system in particular. Yeah, if you have a CPR card, you have access. Most people do have that. It's very interesting that the other day I was talking with the ambassador of my country and she was saying that people don't know this, but for some weird reason ambassadors don't get a CPR number and without the CPR number it's very hard to get access to health care. So you know, in a way if there's someone in Denmark that is not getting access to health care services, even if they have access to a lot of other impressive things… are the diplomats. So this is to say that of course sometimes you are in a place, so so… and this was actually about vaccines. Diplomats are having a hard time getting the vaccines in Denmark. Of course this is a rich country problem right? Now if we go to a poor country problem, then the problem is a lot more serious. There's nothing… there's not even water sometimes right? Water is essential for hygiene. So there are hospitals that are running without water, without electric power or, or at least they have power a number of hours per day, so yeah. And as a result lots of different stakeholders emerge. And sometimes individuals that yeah, should not be practicing medicine. But you know, in a way, because there's no better option. Yeah, and they end up helping I guess.

00:18:27.520 --> 00:18:35.820
ZSOFIA KESZTHELYI
So I think now we talked about the end of the supply chain, so the ones that are actually in contact with the patients. When you think about the beginning of the supply chain or the front of it, do you see influential players in that part of the supply chain?

00:18:48.600 --> 00:18:50.990
EXPERT IN SCM
Yes, so of course there are... you know supply chains have different tiers from those that are, you know, reaching out… are in the distribution of the goods and services right for medicines in in Africa. Uh, before that, you know, sometimes you need warehouses. Sometimes you need warehouses that are refrigerated. Think about the vaccines, right? The distribution of the vaccines for COVID, it is quite difficult for some of them that require refrigeration, and of course the complications of the supply chains are not just the distribution. And that's in a way is easiest, but making the vaccine arrive there in a good shape is super complicated. And then there is another problem I think. That often for instance companies have no clue about… you know companies have no clue about what they're trying to do in… and what they are trying to bring to some of these markets They don't know the markets that well. You know, some of these strategies for delivering medicines in rural Africa are you know, designed in sophisticated offices in Switzerland or in Copenhagen. And it turns out that quite often the end implementation is a disaster because they have no clue about what are the real conditions in the field, so I think that's another big problem that that we have. I actually have seen statistics you should look at those from the World Health Organization, talking about….it was more related with innovative problems for solving uh, you know developing country problems like you know, malaria right? All the tips to fix malaria, it fails. I mean not because we don't know how to treat malaria, but because we don't understand that the people that suffer from malaria are in very poor rural areas. You know they don't even have resources to buy the protection for the mosquito right, and quite often what we think about is to provide them a bit more expensive and sophisticated medicines, which makes no sense, right? If they

have a hard time keeping the mosquito that will bite them and that will kill them away. Of course, this means that whatever we do will fail. And my point is if… we should look at that literature that crossed my mind now… so many things have failed. Uh, so many of them. So many resources have been wasted because… even I'm now thinking about humanitarian efforts, right? The idea is very good. The goal is very good. To help people in Sub-Saharan Africa. But in the end there's nothing there. There's nothing there, so it's a problem. So which means we end up wasting a lot of resources in the intermediaries. And that's often a problem, right? Sometimes there's even a lot of corruption…some people don't care, in fact, because they will be the intermediaries and they will be getting their part. Will this ever reach the end user? No. And of course it's true for you know, everything. It's true for medicines, it's true for foods. Uh, you know, food in a way, has… some food right… has similar complications if you… if you need to keep it refrigerated, of course it's going to be hard to reach some parts of the planet, and that's why some parts of… some people around the globe will never touch fish or meat because you need the refrigeration to provide those goods. Or any other things that we sort of need… uh, complicated storage or more difficult storage.

00:23:28.590 --> 00:23:29.000
ZSOFIA KESZTHELYI
Right. So I believe you've mentioned a lot of issues now, also locally, but throughout the global supply chain as well. Now my question would be to you, how would you solve this issue or what would be your strategy to start actually to solve these issues?

00:23:48.260 --> 00:23:49.960
EXPERT IN SCM
That's a difficult one. It's uh, and I'm not very optimistic about solving it anytime soon. Uhm, because for instance quite… so once I did a project with a company in Angola. And Angola is both a very rich country and a very poor country. And Angola is a big producer of oil. And if you go to Luanda, the capital city you will see some of the most expensive stores and restaurants on Earth. In fact, sometimes you see those statistics about the most expensive cities and Luanda is typically there. And it was actually about supply chain…the problem that we were trying to solve. And we realized that, you know…products were not reaching the final destination because of corruption. Because there's always many roadblocks, you need to pay for everything. Dirty money is used for everything, you know. And we went there thinking that maybe what we know about supply chain management can help these people. But then realized, oh, this is not about supply chain management. You know the overall political situation, the overall context is so much more difficult. That it's not that they don't know how to manage stocks. You see what I mean? Uh, in this case they even have some of the infrastructures to store stuff that needs, for instance, refrigeration. Now the problem is that things arrive to the airport, and if you want to take them out of the airport…you know the guy… you go to the storage where you are supposed to pick up the orders that have arrived and the guy will tell you, "oh, I cannot find it. Oh I've been searching around I'm sorry. I mean we have to give up. I cannot find it" and suddenly of course the other guy is already understanding what he wants is like "OK, but how much does it cost for you to find the package" right? And even now talking about respectable companies. And suddenly if you give them money, you will find it right. But then… and this happened 2 to meet or to us, right? Then you are driving to any place right and the police stops you. It's like "So what are you taking there?" oh, it's like we, uh. it's some sort of… it's something right whatever… it doesn't matter because the police will get you in trouble because… Doesn't matter if you have all the documents or no documents… It matters if you have some money, right? So we really need to have money all the time to bribe people along the way. So you see, it's like it's a little bit hard to make a supply chain like that work. So it's a miracle when finally some of these goods reach the destination. Which doesn't happen often, by the way, right? And it costs a fortune. And you see, it's not in the end… It's not about

anything related with supply chain, it's related with a corrupt system where everyone is trying to take the most out of it. That you know… in a way when it works, it's because there's enough money flowing around to bribe the police, to bribe the guards at the airport, to bribe everyone. And it's a disgrace so maybe Angola is worse than average, although it's worse because… I mean there are much poorer countries, Angola could be a very rich country, right? It's a it's a disgrace because it's a country that produces oil. So Angola could be Norway. Because at least they have some of the same resources, in a way you know, it's a beautiful country in many ways, beautiful it could be a very touristic country, for instance, but it's a place where everything is about corruption…from getting a visa to get there. I mean, people even… I don't know how it works in in Denmark, but in the place where I took the visa, there's a huge line at the embassy, it's impossible to stay in line to get the visa unless of course you pay. And then you have priority, right? So Zsofia, what I'm saying is that… I think it's so… the problem with supply chains is that they touch a lot of different dimensions of a country right? From the political system to the transportation system, to the level of corruption… so the difficult part for some of these companies in… you know, pharma or construction, or transportation, or aviation or anything… Some of these guys that have to deal with developing countries… and now I'm probably talking about some of the worst case scenarios, right… it is not so much that we don't know exactly how to… you see what these people… before I was sort of alluding to people making, you know, very smart decisions in offices in Switzerland. Yes, from a supply chain perspective, those decisions were very smart, but they were forgetting everything around… all the environment. And I think that's a big-big problem.

00:30:38.450 --> 00:30:39.000
ZSOFIA KESZTHELYI
Right. So uhm, do I understand you well, that you're saying we are kind of thinking with our developed mindset instead of the developing country mindset?

00:30:51.090 --> 00:30:56.890
EXPERT IN SCM
Exactly exactly, and because it's a bit hard to sync with their… it's hard and sometimes illegal, right? The truth is that if you want to have a supply chain delivering goods to rural communities, you may have to play their game and you may have to practice corruption. Right and then… well and companies do it OK, so it's not… we should not be naive about it. The companies understand that they have to do that. Of course it will be hard for a company… pharma company in Denmark to admit that. So what they have to do is to find a local partner that does the dirty job. But, but that's when it becomes complicated, right? Because only you have… you know…yeah, you have companies that have to play with the rules that they would never consider… that no one ever would consider acceptable. If the public opinion in Denmark knew what needs to be done to take a medicine to the end user, and probably we would not accept it. And it's a fact that companies that are successful…. it's impossible for a company to be successful in a developing country without playing by some of their rules. So they have two to adapt.

00:32:37.710 --> 00:32:45.340
ZSOFIA KESZTHELYI
So do you think that this partnership so partnering up with a local company, would be a way to go?

00:32:47.260 --> 00:32:50.250
EXPERT IN SCM
It is. It is the way many things are done. Right, you always need to find local brokers that will help you doing some of these things. But then sometimes it's also, you know….again, it depends on what we are

talking about. If you need to deliver basic health care supplies to... in a hospital in Bangladesh, that's one thing, right? But if it's about the vaccine that needs to be refrigerated at minus 80… then it's a different story.

00:33:34.370 --> 00:33:37.070
ZSOFIA KESZTHELYI
From what aspect do you think it's different?

00:33:37.480 --> 00:33:40.650
EXPERT IN SCM
It's different in the sense that maybe it will never get there. And if it gets there, it will probably be damaged. Uh. I mean, it's… it will never get there because they there is no… there are no refrigerators, and if there are… if suddenly you decide "OK, so let's buy them a refrigerator"…well then the problem is that maybe they will not have power to refrigerate it, or they do have power a number of hours per day, right? So, it's better than nothing, but if you have a refrigerator that can have… that has no energy a number of hours per day… that means that the level of refrigeration that you can do… it, it's going to be very, very poor. Yeah, and then there is no knowledge sometimes what is really frustrating is that even when you give everything, then they don't know exactly how to do it. So let me share this. Together with a big foundation, we have been involved in giving a 3D printers to 25 different locations in Africa. And the idea for the 3D printers was to have…you know these guys… and these guys were in different places. Some of them were in hospitals, others were in universities… and to actually provide them with 3D printers so that for instance they could print prosthetics. We trained them, but then in fact what happened was… corona came, right? And it was hard to travel etc. But the printers got there and we did some training via Zoom and we… in theory… helped them printing the first couple of things. And then it became very difficult and the general difficulty is… you know these guys now have a printer. They are happy with the power that the community perceives that they have because they have a 3D printer, right? In the middle of nowhere you can print objects. But then you know the supplies don't get there on time when it breaks. Nobody knows how to fix it. In fact, nobody really knows how to print in the first place. Uh, or to use a computer you know in other cases it's already broken and it will take months to… so you see, it's like a bit complicated to make it happen. Uh. This one was even designed by people that knew the field very well. They knew these guys already. They didn't know the people, but they knew these institutions and they thought they were the most respectable ones. And in a way, I mean, yeah, that's what it needs to be done this way, but it's going to be always very inefficient. I don't know exactly how many prosthetics these 25 printers will actually print that will help anyone. Maybe none… you see what I mean… is like it's a huge investment that eventually will contribute to train people assemble them… will learn how to use these skill. But in the end, it's going to be very… so what I mean… what is it that many… what is it that works? In many places… and it's a bit humanitarian, but you see, for instance, in Portugal, right? We have lots of different colonies, some of them very poor. When you are in a serious condition, what can you do to help? The only thing that you can do to help is to bring those people to Portugal. And they are… you know airlines etc. have partnered to make it happen in the sense… if you need surgery, yeah…it's not going to happen there, they will bring you to… they will come to Lisbon and they will get health care services in Lisbon which then becomes also very complicated because of course if you need surgery, if it's a difficult one then you probably need to stay for three months. Right and then like, oh, how is… who's going to pay for it? And if it's in the hospital, well yes…if it's… then the state pays right? If after two weeks you have to leave the hospital and you just need to go back once per week. Who's going to pay? I mean yeah, in theory there are solutions for this, but so providing the services… bringing them over to developed countries is also a bit complicated. It has challenges. Uh, yeah.

00:38:52.370 --> 00:39:10.680
ZSOFIA KESZTHELYI
I think you already very well touched upon my last topic, which would have been sustainability so, but if I hear you correctly, you say that we are not there yet to call this in any way sustainable, even if we find a solution to solve the issues in developing countries.

00:39:12.970 --> 00:39:16.380
EXPERT IN SCM
No, I don't think we are there. Uh, I think we're doing some good things and for sure there are many success stories, right? Because yeah, life expectancy has been increasing…. in many countries around the globe. You know, but the fact… But if you if you visit some of these places, you will see that just the fact that they are now starting to get water or sewage systems is probably what is happening the most. In terms of healthcare provision, I think we still have a long way to go.

00:40:00.750 --> 00:40:08.960
ZSOFIA KESZTHELYI
Alright, thank you so much. We discussed a lot of issues, probably more issues than potential solutions so.

00:40:09.570 --> 00:40:10.080
EXPERT IN SCM
For sure.

00:40:10.010 --> 00:40:15.140
ZSOFIA KESZTHELYI
I think it's important to see the big picture in a realistic way, so thank you for that. Uhm, do you have anything else to add about the topics that we discussed so far?

00:40:22.490 --> 00:40:26.460
EXPERT IN SCM
No, thank you so much for your interest. Best of luck for your thesis.

Interview title	Interview with a medical doctor with experience in Tanzania
Date, time	10 December 2021
Location	online

00:02:16.950 --> 00:02:29.440
ZSOFIA KESZTHELYI
Great so let's start then. I would just like to ask you to introduce what you do in like one sentence or two.

00:02:30.900 --> 00:02:32.360
MEDICAL DOCTOR 1
So what I'm doing currently.

00:02:32.760 --> 00:02:33.140
ZSOFIA KESZTHELYI
Yes.

00:02:33.340 --> 00:02:46.760
MEDICAL DOCTOR 1
Yeah, so I'm currently working as a [ ] and that means that I'm working with the communication around our clinical results and internal education.

00:02:48.250 --> 00:02:49.070
ZSOFIA KESZTHELYI
Great, thank you. When you think about this phrase, "access to pharmaceuticals", what is the first thing that pops into your mind?

00:03:02.660 --> 00:03:16.750
MEDICAL DOCTOR 1
Actually a lot of things, so I studied access to pharma or pharmaceuticals in my masters and what I'm then thinking about is that it's all… It's an economical skill where we look at things, and then depending on how beneficial it is, and how expensive it can be that we get access to these pharmaceuticals.

00:03:43.940 --> 00:04:00.920
ZSOFIA KESZTHELYI
You are quite close to the patient perspective I would assume, so when you think about patients anywhere in the world, it doesn't have to be developing countries right now, what do you think their most important need is in terms of accessing pharmaceutical products?

00:04:03.200 --> 00:04:17.430
MEDICAL DOCTOR 1
I think for most patients it would still be the costs because luckily we are of course living in a country where medication is relatively cheap, although sometimes you have to pay a small out of pocket prize. In a lot of countries, like if we look at one of the biggest countries, America, still a lot of patients struggle with getting their medicine because of pricing.

00:04:32.800 --> 00:04:41.450
ZSOFIA KESZTHELYI
OK. So the next question is will be general without having any specific treatment area or any disease in mind.
Based on your experience, how is access to pharmaceuticals or a pharma supply chain different in developing countries compared to the developed world?

00:04:53.850 --> 00:05:06.080
MEDICAL DOCTOR 1
So I think that from a negotiation standpoint, developing countries have a more difficult position when negotiating with pharma industry. Plus on top of that, new pharmaceuticals are extremely expensive. And developing countries often do not have the funds to meet those. And then if you look at the patients, that means that all patients have to pay a big out of pocket price, which of course a lot of patients do not have the money for. But also that sometimes the treatments are just not available because the country is not making them available for people, because they are simply too expensive.

00:05:42.320 --> 00:05:47.190
ZSOFIA KESZTHELYI
And what do you think are, let's say, the three main causes for these differences?

00:05:49.670 --> 00:05:51.670
MEDICAL DOCTOR 1
Uh, so money. I would definitely say, so pricing is one of them. And infrastructure. So how do we actually get the medication to the patient. Uhm, and then I think. The third one is probably also the lack of knowledge of doctors, or the lack of knowledge of new treatments available.

00:06:25.640 --> 00:06:28.210
ZSOFIA KESZTHELYI
And why do you think there is a lack of knowledge there?

00:06:30.830 --> 00:06:47.540
MEDICAL DOCTOR 1
It is because a lot of the education is targeted to the Western world, where a lot of the medication is available. Plus on top of that medication that is being promoted is medication that often has a patent that is expensive and because it's expensive, a lot of the pharmaceutical companies might not invest in these developing countries as much as they will in developed countries.

00:07:02.780 --> 00:07:14.230
ZSOFIA KESZTHELYI
And is the education playing a role? So the education of the doctors? How is that in the developing countries compared to the developed world in your perspective?

00:07:17.560 --> 00:07:26.450
MEDICAL DOCTOR 1
So what I noticed when I was working in Tanzania, I think the biggest difference is that they have a lot of book knowledge and a lot of knowledge that is very established, so they are in general very knowledgeable, especially when it comes to tropical diseases. But because they do not have the necessary tools like, they don't have machines that can make an X-ray, or that can do a CT scan or something like that, they often miss diagnoses, which means that a patient goes undiagnosed and untreated because of that as well.

00:08:46.340 --> 00:08:57.270
ZSOFIA KESZTHELYI
Do you think that they are more knowledgeable about the diseases that they have in developing countries compared to, for example, the developed world?

00:08:58.760 --> 00:09:05.790
MEDICAL DOCTOR 1
I think they are more skilled in treating them, simply because they see more of those cases. I do not necessarily think they are more knowledgeable. But they are very good at treating patients with the tools they have.

00:09:23.840 --> 00:09:28.380
ZSOFIA KESZTHELYI
And do you think there are differences in terms of the access to care or to pharmaceuticals among the different diseases?

00:09:34.940 --> 00:09:55.980
MEDICAL DOCTOR 1
Uh, so among the different diseases, definitely. Yeah, yeah, it is very clear that if you go to the local pharmacy where I worked that there is medication available for the typical diseases, so the tropical diseases like malaria for example. That is I think the most common. And there was a there was one patient with diabetes and there was, for example, no medication available except for insulin. Uh, and then also not all the types of insulins. So if you look at a treating a patient here and Denmark or in Holland where I'm from, you would have a wide range of different insulins and there you only had the human insulins available. Uhm, plus on top of that it is just more difficult to manage a patient with a disease that is not so typical because they might not have the right monitoring systems available either.

00:10:37.970 --> 00:10:53.920
ZSOFIA KESZTHELYI
Yeah, that's true. And in terms of… if you compare communicable and non-communicable diseases, is there a difference or did you see any difference of the treatment of those? Or is it just a general issue and it doesn't really make a difference what kind of disease that is?

00:10:58.380 --> 00:11:03.810
MEDICAL DOCTOR 1
I think you see more of the communicable diseases, and that causes that they are in a way better at treating those and diagnosing those. Like they have the tools to diagnose those diseases, but they do lack the tools to maybe have the non-communicable diseases detected. So I think you do see a difference.

00:11:27.780 --> 00:11:43.190
ZSOFIA KESZTHELYI
I also read in some articles that there is an issue with identifying diseases at childbirth for example, so there is no such screening as we are used to in Europe for example. Do you have any experience about this?

00:11:44.520 --> 00:11:57.690
MEDICAL DOCTOR 1
I know that they do their best with the tools they have, but if you look at how many patients you have here for one doctor, I don't know the numbers, but it is probably a lot fewer patients then you have in those countries. Uhm, and in the hospital I was working there were two docs is available for... I think it must have been 250 patients. So you can imagine that if a child gets born and it looks healthy, of course there's not going to be a heart scan or blood tests. They do get their vaccinations, some of them. But of course there's also a part that it's called religion, which also plays a big role in people wanting to have their child vaccinated or not, which is something that you see happening more, but definitely diagnosing is not happening when a child is born.

00:12:44.010 --> 00:12:46.130
ZSOFIA KESZTHELYI
Do you know if there are any downsides of not vaccinating a child? Because I think there are some consequences here in Europe if you don't vaccinate your child with the with the vaccines that have to be given.

00:13:05.240 --> 00:13:13.710
MEDICAL DOCTOR 1
No, I don't think so. I don't think they have like a very well organized system and a vaccination little book. I don't think that you have any downsides from not being vaccinated. Of course you have the downside of not being vaccinated, right? But not community speaking wise.

00:13:27.430 --> 00:13:29.300
ZSOFIA KESZTHELYI
Right, do you have any experience with sickle cell disease?

00:13:37.210 --> 00:13:46.770
MEDICAL DOCTOR 1
That was not in Tanzania actually, uh, because those cases went to the University Hospital because they're very difficult most of the time. So not really, no. Uhm, it was not really something that we typically saw at the hospital.

00:13:59.180 --> 00:14:05.690
ZSOFIA KESZTHELYI
And that's simply because they were sent to some facilities that were better equipped?

00:14:08.100 --> 00:14:08.380
MEDICAL DOCTOR 1
Yeah.

00:14:08.330 --> 00:14:18.560
ZSOFIA KESZTHELYI
OK, and did you hear anything else about this? Whether there are any specifics related to sickle cell disease and access to care in sickle cell disease?

00:14:20.400 --> 00:14:27.190
MEDICAL DOCTOR 1
No, access to care sickle cell disease is… I do not have any knowledge of. Yeah it is not something that we saw a lot or that was not diagnosed like there might have been patients that had it right? But that was just not diagnosed.

00:14:40.000 --> 00:14:41.430
ZSOFIA KESZTHELYI
Right, right OK. Then we talked a lot about the issues that we are facing in terms of access. But when you think about the supply chain, for example, who do you think are the main stakeholders within providing access to pharmaceuticals in these countries? Would you say are the key stakeholders?

00:15:11.380 --> 00:15:15.650
MEDICAL DOCTOR 1
So of course it is the agency that sees if treatment should be available, like we have to EMA and FDA. But then it's of course also the government, because as soon as the medication is registered as… in the EMA or FDA, it should be available, but that becoming available as a step that the EMA and FDA are not arranging. It is of course a step that is taken inside the country by the respective organs that are going around that. So of course that is also one. So it is probably the government in those countries as that will be arranged centrally. So I think then of course you have an important role for the pharmaceutical industry because new treatments are expensive so there should be a way of supplying developing countries. But that has proven to be very difficult I also know.

00:16:23.990 --> 00:16:34.900
ZSOFIA KESZTHELYI
OK, and you already started to touch upon this, but how do you see the roles and the responsibilities especially, of these stakeholders that you just mentioned?

00:16:36.170 --> 00:17:05.220
MEDICAL DOCTOR 1
Yeah, so I think what you should have is a review of new drugs that's becoming available very quickly so that medication can become quickly available. But then of course you should have a strong negotiation and maybe that it should be arranged differently for developing countries. And I'm not completely sure how it is arranged at this moment, if that is arranged in a central organ that is, for example, doing some of the countries in Africa. But if it is per country that they negotiate, maybe it is an idea to collaborate in that negotiation because they will be stronger in a collaborative model than they are being by themselves. And then I think if government promises something to the people in the country then they should keep their promises. Like what we had for example, is that they in Tanzania promised free health care until the age of five. And so that means that medication should be available freely to children. But the problem is that the hospitals are not having enough of these medicines in their stock. So that means if a hospital runs out then it's not free anymore for a child because the mother has to go to the pharmacy and has to pay it there. So they try to, of course say that we have these rules in place... and it is a difficult question, because if there's no money there's no money but.

00:18:14.990 --> 00:18:21.700
ZSOFIA KESZTHELYI
And why do you think the stocks run out in the hospitals? Was it purely a financial reason?

00:18:22.920 --> 00:18:25.260
MEDICAL DOCTOR 1
I think it's financial and also as I said before, it's infrastructure, how to get the medication there. I think that is also a big part because… and then I'm not only talking about that, the roads are not good, but the whole system is not good. Like do they have an online system where you can say “hey now we are running out of this medication and then they order something new”? I don't think that's how it's going. I think it's somebody filling in a little form and seeing what they can get out of that form. So it is the whole infrastructure around getting the medication to the patient that is very difficult and challenging in those countries.

00:19:04.680 --> 00:19:08.200
ZSOFIA KESZTHELYI
And how do you see the responsibility of pharma companies in this whole thing? You mentioned that we should do something about pricing, but how realistic is that?

00:19:15.910 --> 00:19:29.570
MEDICAL DOCTOR 1
Yeah, and that is the problem because I don't think that that is realistic because of course for pharmaceutical companies it should still be beneficial to invest in inventing new medication. So as soon as they start handing out their booming products nearly for free, then of course it is very difficult. And why should Denmark pay a higher price than a country in Africa? Because they can apparently make it for that cheap. So it is a very difficult question and it is not something that is easily solved, but I think how they can help is that you can have access programs. You're gonna have people enrolled. And of course people need to know these access programs. And I think one of the most important things is education, not only education after doctors would also education of the patients so that patients can also know "what can I ask and what can I expect from the health care in my country".

00:20:21.420 --> 00:20:27.860
ZSOFIA KESZTHELYI
When you say access programs, how would you define an access program or what would it entail?

00:20:29.740 --> 00:20:36.000
MEDICAL DOCTOR 1
Uh, so that´s a good question because I know that we have access programs, but I'm not completely sure how it is set up. Uhm, but it is so that some pharma companies offer medication for a relatively cheap price, which is normally a product that is not under patent anymore, but that is a generic drug. Uhm, and somehow set up a system where people can sign up. I actually have no idea how they arrange it because I know it now, but when I was working in Tanzania, I didn't know it. And I think the communication may be lacking or maybe they are only collaborating with university hospitals are not with very small hospitals I was working in.

00:21:27.360 --> 00:21:39.790
ZSOFIA KESZTHELYI
And do you think there would be a bigger need in smaller hospitals? Or is it still kind of almost equally lacking the access in comparison to the university hospitals?

00:21:40.470 --> 00:21:46.670
MEDICAL DOCTOR 1
So I haven't worked in a university hospital, but I have been in a hospital that was in a bigger and I would say wealthier area then I was living in and they definitely had more tools to help a patient. They had more technical tools but also more medication available. But patients on the other hand were also richer so they could actually afford buying their medication if you prescribed them something. So I think that it might be possible that they have better access to things in a university hospital, but in the end, most people do not live near university hospitals in these countries. Most people are living out there in the middle of nowhere where they might be lucky if there's a hospital let's say in 50 kilometres circle around them where they can walk to if they are sick. And I think education is needed in both. But probably university hospitals they are a little bit before the before the regional hospitals, so the area hospitals.

00:22:58.600 --> 00:23:03.100
ZSOFIA KESZTHELYI
Are you saying that they actually walk to the hospital if they're sick?

00:23:03.570 --> 00:23:10.230
MEDICAL DOCTOR 1
Yeah, so most people work. Yeah yeah, some of them have a bike of course, but most people walk.

00:23:11.460 --> 00:23:19.340
ZSOFIA KESZTHELYI
And what if there are so sick that they cannot actually walk like they cannot stand up? When you would normally call an ambulance here. What do they do there?

00:23:22.500 --> 00:23:23.230
MEDICAL DOCTOR 1
They stay home.

00:23:22.690 --> 00:23:23.560
ZSOFIA KESZTHELYI
Is there a way?

00:23:24.130 --> 00:23:31.470
MEDICAL DOCTOR 1
No, no no. So that is really hard in those countries. There's no way unless your neighbour might be able to bring you, but most people do not have a car. There are of course some buses going, and of course there's people that can help you, right? If they see you next to the road, there's a lot of people that will help you, but the question is, is somebody passing then? You cannot depend on anything, So what they always said was... if you would ask them when the bus was going, for example, they would be laughing and they would say "Yeah, maybe tomorrow maybe?" And then maybe it was leaving in 10 minutes. Maybe it was leaving in three hours. So then you would just be sitting on the town square as they called it and you would just be waiting so there were enough people so it would be going. So if you're really sick in those areas then most people will stay at home. One because it costs a lot of money to get better. And two, because they simply cannot reach hospital.

00:24:36.040 --> 00:24:36.530
ZSOFIA KESZTHELYI
I see. Uhm we did discuss a lot of issues. Uh, so now I would like to ask you how you would start solving these issues, what would be your strategy?

00:24:52.390 --> 00:24:54.430
MEDICAL DOCTOR 1
For me, I think it would be education. I think education is one of the most important things to help a developing country further. In a sense of like where we are at, right? Guess you can go in a lot of directions, but I think past has shown that **giving a bunch of money is not helping,** it often ends up in the wrong hands, because there's a lot of corruption in those countries, and I'm not always saying that everything that goes there will not end up at in a good place because luckily there is also a lot ending up in a good place and there are beautiful projects done in those countries. But it is a difficulty with if

you just give a bunch of money there and then I think that's also why a lot of people may be in the Western world hesitant to give them money to these organizations that help developing countries. And I can see that, but I think if you support them with education from a very young age, you teach them English, you teach them about the world about how is it in other parts of the world… Of course, you will have a lot of people leaving. That's what you see now with the part of the population that is very well educated often leave to a country where they can be more successful in their career and they have a better future for themselves… But what you see is that at a later stage they often come back to their country to actually help support their country of getting better. So, of course you will see a lot of people leaving if they are highly educated, but I think you will also keep a lot of good people in the country that can help the country further.

00:26:53.560 --> 00:27:08.130
ZSOFIA KESZTHELYI
And still I just have this idea that even though they might know what to get, they still have this issue of money and infrastructure and corruption that you mentioned. So how would you go about those issues?

00:27:15.490 --> 00:27:20.240
MEDICAL DOCTOR 1
It's a very, very good question. So now we are talking about if people would have been educated that they would still not be able to access in the infrastructure. But I think if you educate people in a broad spectrum, so not, it's not only education about doctors I´m talking about it, but it's education about everybody in the country. I think you will have people that start taking ideas from maybe where they have worked for a while back into the country and help develop the country further that way. And of course there will always be corruption like this, there´s even corruption in Denmark, there's even corruption in Holland here, just don't see it that well, it's way better hidden. But it's not a thing that you could easily change by doing one thing. I honestly don't know how you could change something like this. No. Corruption will always be there.

00:28:40.190 --> 00:28:50.030
ZSOFIA KESZTHELYI
Right, uh, but it's also an idea if we say that this is just too complex to have a solution, so that's also completely fine. Uhm, actually my third area or third research question would refer to the sustainability of different solutions. So we can hear a lot about the triple bottom line of companies, I believe you've also heard it, so that it includes the environmental, the social and also the financial sustainability. And you have already mentioned that you think that pharma companies are of course companies so they are running on money, they cannot just do everything for free, but do you think there would be a solution in any way, or maybe just a small part of a solution that is sustainable to give better access or to move forward to potentially have better access in developing countries?

00:29:50.530 --> 00:29:56.280
MEDICAL DOCTOR 1
Yeah, so I think then you come back again to that negotiation that people can have, that countries can have. And once again I have no idea how it's arranged in Africa at the moment or in other developing countries for that matter. But I think it's about arranging the infrastructure of how to get the medicine. So building that infrastructure which is a giant task… it's not over a year and also not over 10 years probably, but it is about getting that infrastructure right. So how do we get the medicine to the country? And I think pharma can help in that, can help establishing that. But I also think that the countries need to find a way of collaborating with each other, but also with pharma and say OK we are need of this,

how will we get there and how we will reach that point? So I think it is about negotiation and I think in the end that will be sustainable because if you have a good platform where you can negotiate as partners then that might end up in a good collaboration. And I think that's in the end what is needed to get that infrastructure right.

00:31:15.300 --> 00:31:26.650
ZSOFIA KESZTHELYI
In terms of collaboration, how would you imagine this? Like, let's say there are three countries who are collaborating together and then also collaborating with a pharmaceutical company. Uhm, but if so, the pharmaceutical company would need to have something out of it as well, so it's not just the countries that need to benefit from a collaboration. So what do you think that these countries could offer?

00:31:43.010 --> 00:31:49.360
MEDICAL DOCTOR 1
So I think in the end it's about how much can we sell for a pharma company - not always and of course this is also… if we look at what pharmaceutical companies are doing, it's not always to make money. Luckily it's also about giving back to society. And I think this is the part where they can give back to society, but I think if you are not selling below product price or if you're selling on product price, you will not lose. You will maybe not win a lot, but at least on product price or something like that. And this is of course for new medication. Because if we're talking about generic medication which has also a lot of pharma companies that are specialized in that… it is of course often easier to get access to those medicine because they are cheaper. And I think it's not one pharma company that they are collaborating with, it is the pharmaceutical industry that they have to collaborate with because how do we get all these medications that are available maybe in the western world or anywhere else on the world? How do we get that to Africa? That is the big question that you have. It's not only about this innovative medicine that we are talking about, it's not about the newest heart failure pill that came out. It is about how do we get aspirin? How do we have enough aspirin in Africa to treat children with fever or pain or whatever? And for that to work together, I know that there are some platforms in the pharma industry world. There are platforms like that that pharma companies are working together. But it will be a very big task if they have to collaborate with each country in specific. And that's why I was saying like they need to collaborate as well. So that is not a collaboration with a few countries and then what about the other countries?

00:33:57.040 --> 00:34:12.700
ZSOFIA KESZTHELYI
Right… when you think of your time in in Tanzania, was there anything in the hospital that you were pleasantly surprised about? So some kind of innovation or anything that you didn't expect to see there?

00:34:16.670 --> 00:34:17.130
MEDICAL DOCTOR 1
No… I was surprised about the knowledge of the doctors. Then I think I was surprised about and the determination of the… some of the nurses as well. Uh, but in a positive way I was not surprised about many things, no.

00:34:43.170 --> 00:34:47.240
ZSOFIA KESZTHELYI
When you say the knowledge of the doctors, what is it that you were surprised about?

00:34:47.680 --> 00:34:55.370
MEDICAL DOCTOR 1
So I think as I said, they have a lot of book knowledge. They are very knowledgeable in what they've studied about. Uh, the only problem is that what you studied about is not always what you see in practice. And I think they weren't very knowledgeable in that way.

00:35:08.670 --> 00:35:13.440
ZSOFIA KESZTHELYI
And then OK, then let's look at the other side. So what was it that you were shocked by or you had a cultural shock when you got there?

00:35:20.910 --> 00:35:24.470
MEDICAL DOCTOR 1
Yeah, I think it was the amount of people on one doctor. And also the doctors not showing up. No dedication and like sometimes we would be in the hospital and we would be alone. And then nobody knew where the doctor was or when he would come. And, for example, so that patients were not allowed to leave the hospital if they couldn't pay. But they were paying per day, so the longer they couldn't leave the more they had to pay. So some patients were just stuck in the hospital for weeks. And then they were just walking around doing nothing, sometimes getting sick again because of the sick patients around them. So that was shocking as well. And then, of course, that it felt like a life meant less. So for us it's a… I would say in the in the Western world it is very impactful if a child is passing away. But over there it was something that was usual business. So if a child passes away, then we just go to the next. That was how it was going there and I think that was the most shocking.

00:36:54.520 --> 00:36:56.470
ZSOFIA KESZTHELYI
And did you see this to be maybe a reason for the doctors not showing up or their accountability to be lacking?

00:37:05.060 --> 00:37:10.770
MEDICAL DOCTOR 1
I think so. I think if you can do so little as a doctor in a hospital like that... the courage that you maybe have when you come out of medical school and the enthusiasm will fade. Because if you see that even though you are really trying your best, but then you find out two days later that the mother didn't buy the medication, or that they indeed didn't do what you asked because they couldn't afford or they didn't understand or they for whatever reason they don't want to. Then I can imagine that over time you are getting less motivated to go to your work and to go out there and help because it doesn't feel maybe like you make a big difference. And I think that is what a lot of the doctors had there… that even though they showed up, people were still dying. People still didn't have the money to buy the medication. People still didn't believe what they were saying. From my understanding that was because it was not that they were living far away, they were living around the corner.

00:38:24.490 --> 00:38:41.650
ZSOFIA KESZTHELYI
I can remember that in our previous conversation you mentioned that the people would not first go to a doctor, but they would go to somewhat of a healer. Maybe a more traditional? How does that look like or what did you experience in terms of this?

00:38:41.880 --> 00:38:53.730
MEDICAL DOCTOR 1
Yeah, so we actually visited one of those. Each village almost has a healer. Normally patients go there first, because then they…. Yeah, it's funny sight because it looks like a kind of farm where there's one hut for the healer. And then there's several little small huts surrounded where then people can be when they are ill they get treated. I don't know how many times a day, but at least they get treated by the healer. And what the hospital did in our town was that the nurses and the doctors went into conversations with these healers and told them it is OK. Because it is a tradition, you can't just scratch out that tradition that they have because a lot of people don't believe in Western medicine as we call it. They don't believe in a modern medicine. So then you have the problem that people don't go anywhere, they will just stay home. So now at least they went to a healer and then the nurses and the doctors would go and visit. And that they would have conversations with the healers. They would see the sick people as well. And in a conversation with the healer they explained "OK if a patient has these and these and these symptoms, you cannot heal this patient, but you really have to refer this patient to the hospital". Then the best choice of the patient if the patient goes to the hospital, the patient stays at the healer or the patient disappears, so goes home. That also happened. But there was still a collaboration between the healer and the hospital. Because the healer also understood… or this healer at least... and there's many different ones, right. Some are a little bit stricter than others. But this healer understood that some of the diseases he could not cure himself. So, and that was… mainly spoke about HIV when I was there, but they also spoke about for example, hepatitis and other diseases that are a lot in those countries.

00:40:48.920 --> 00:41:14.330
ZSOFIA KESZTHELYI
This is very interesting. Obviously, I've never encountered something like this, so it's really interesting to hear. Do you feel like there's a generational difference in terms of how they think about medicine? So are the newer generations, the younger ones more open to Western medicine? Is there a tendency around this?

00:41:20.220 --> 00:41:24.430
MEDICAL DOCTOR 1
I think so, yeah, I think so. Yeah, I think the younger people might be more in favour of Western medicine or modern medicine. But it's, uh, not all of them. Uh, and for sure still many that do not want to go to hospital and do not want to get pills.

00:41:55.000 --> 00:42:01.980
ZSOFIA KESZTHELYI
I think you mentioned that they don't want to go to hospital because that costs a lot of money, but is there another reason as well?

00:42:03.360 --> 00:42:06.490
MEDICAL DOCTOR 1
It's because they don't believe in it and it costs a lot of money. There's a lot of people dying in the hospital like you should not forget that. I think it's a big part… you go to a hospital to die. That was back in the days the belief. So if you go to the hospital, you die and that was why people went to a healer first and then if they were so sick that they could not be saved, they would go to the hospital. So the hospital was seen as a place to die. And I think that was the difficulty in getting patients there that you could also walk out and be healthy again as long as you arrive in the hospital in good time. And the

problem is because it is expensive, because people do not have a lot of money, because if you look at how much a hospital bed costs there… compared to here it was not a lot. But still, for those people it was an insane amount of money and it meant "OK I could choose to take care of my eight other children or to bring my one child to the hospital this month". And then that choice is, I think, an easy to make choice for a lot of parents. Because of course, if you can save 8 instead of 1 it is a balance that they are making. And I think the trust in the hospital is slowly growing, because they see that you can leave it as a healthy person and continue a happy life, but it is a very slow process.

00:43:42.940 --> 00:43:48.010
ZSOFIA KESZTHELYI
Just out of curiosity, and this has nothing to do with the thesis at all. How did you see birth control as we know it here? How did you see that in Tanzania?

00:43:55.250 --> 00:43:56.130
MEDICAL DOCTOR 1
They don't have it… not in the area where I was living. Some women got it in secret, because they just simply did not want to have any children anymore. And they took anti-conception secretly, so they normally had the implant on, the little stick in their arm, or they had a spiral, something like that, something that was not visible for the husband, at least because that was often the problem. And then there's also a woman that was sterilized when they had a C-section. So they would just say just do it in one go... So that happened quite a lot as well.

00:45:04.810 --> 00:45:08.850
ZSOFIA KESZTHELYI
And is it a religious thing that they don't want to have a burden against a natural cycle of life or?

00:45:14.350 --> 00:45:20.360
MEDICAL DOCTOR 1
I think it is a religious thing for some, but for most it's also that children are still seen as something that can give you richness, like you will be taken care of in the older age, but why women just simply did not want it is because it is a lot of work to have eight children. And if you see that your other children are suffering, because you are getting two more children than for most women, it's probably not worth it to go for those two more children. And if it's already difficult to feed eight mouths, then they're just looking at it from a very practical point of view normally. There were a few that let it do after two children. But there weren't that much… not many.

00:46:11.040 --> 00:46:17.690
ZSOFIA KESZTHELYI
And the dads, the fathers, they just don't see it this way? They don't see the work in raising those children?

00:46:19.190 --> 00:46:22.300
MEDICAL DOCTOR 1
I don't think in many families they did. Uh, often the father was not in the picture. The father was seeing other women, the father was working on the land and simply did not see the burden that they had at home. So I think it was mainly the women that thought about "Maybe I don't want to have more children anymore". I haven't seen a father there, but probably they are there as well. That fathers are saying now it's enough.

00:46:54.380 --> 00:46:54.770
ZSOFIA KESZTHELYI
OK so we discussed a lot of issues, a couple of solutions that could work but we also established that it's a really complex issue so maybe it won't happen by tomorrow. But thank you for all your insights. I just wanted to ask you whether you have anything else to add, anything else in your mind that you think would be relevant.

00:47:26.780 --> 00:47:28.950
MEDICAL DOCTOR 1
No, I will think about another solution, if I can think about something, then I will email you. But it is extremely difficult. I wish I had the solution, I would implement it tomorrow. But I do not.

00:48:25.770 --> 00:48:30.320
ZSOFIA KESZTHELYI
Alright, thank you so much for this interview. It was really great talking to you again.

00:48:30.620 --> 00:48:31.890
MEDICAL DOCTOR 1
Yeah, thank you so much.

00:48:32.380 --> 00:48:33.760
ZSOFIA KESZTHELYI
And have a nice weekend.

00:48:33.990 --> 00:48:35.020
MEDICAL DOCTOR 1
Yeah you as well.

00:48:35.490 --> 00:48:36.040
ZSOFIA KESZTHELYI
Bye bye.

00:48:36.330 --> 00:48:36.800
MEDICAL DOCTOR 1
Bye bye.

Interview title	Interview with Industry expert #3
Date, time	10 December 2021
Location	online

00:00:03.130 --> 00:00:13.730
ZSOFIA KESZTHELYI
So thank you so much for agreeing to do this interview with me. As you know, this will be for my master thesis about access to pharmaceuticals in developing countries. So the purpose of this interview is to… for myself to gain knowledge from experts like yourself and potentially gain… use this as data and also use quotes from this conversation to support my suggestions at the end of my thesis. So just some formalities for you to know. I will transcribe this interview and unless you request otherwise, this

transcription is normally included in the thesis as an appendix. Is that OK for you or would you like me to leave it out?

Industry expert #3
It´s fine by me.

Zsofia Keszthelyi
So this means that it will be available in the CBS´s thesis library so it will be visible for everyone to see at CBS.

Industry expert #3
I have one question. Will it be possible to redact any parts that I may advert I say something and then I realize perhaps I shouldn't have divulged that cause it´s company information, but to stop you from deleting everything you can just redact certain parts.

Zsofia Keszthelyi
Yes that´s absolutely fine. My next questions would´ve been anyways to ask whether you would like to be presented with your name, title, and the company that you work for or should I anonymize the whole?

Industry expert #3
No I´m fine with you divulging my name.

Zsofia Keszthelyi
OK. Then how about I send you the document once I'm done with the transcription and then you can look through it and if there is anything you want to remove, then we can remove that.

Industry expert #3
Yes exactly, that´s a good solution.

Zsofia Keszthelyi
OK. Great. So it will take about 45 minutes, depending on how much we have to talk about and as I told you before, [xxx] please don´t say anything that's confidential [xxx].

Industry expert #3
That's fine as I said, as long as it can be redacted before it goes to press that's fine.

Zsofia Keszthelyi
Great. Do you have any questions before we begin?

Industry expert #3
No.

Zsofia Keszthelyi
OK excellent. Then please introduce yourself in just 1 or 2 sentences about what you do.

Industry expert #3
Sure. My name is [XXX], I have worked for [xxx] for the past 25 years. In my current position I work together with 7 of the geography regions around the world, basically all regions except North America, in the area of rare blood and also rare endocrine disorders. My responsibility is more commercial, but I also work together with the Medical Affairs colleagues on many projects.

Zsofia Keszthelyi
Thank you. When you hear this phrase "access to pharmaceuticals", what is the first thing that pops into your mind?

Industry expert #3
Affordability.

Zsofia Keszthelyi
Uhm. Affordability in a sense of…?

00:04:14.390 --> 00:04:19.200
INDUSTRY EXPERT #3
So it is very much of a country fit situation, so what is affordable to a family or a patient in one country is completely out of question in another. And then what is often more troublesome is that different families in one country can afford different medications. So access is perhaps a social good in an ideal situation, but in many countries it's a privilege.

00:04:21.190 --> 00:04:31.020
ZSOFIA KESZTHELYI
It's great that you mentioned patients because my next question would be about them. So if you think about patients anywhere in the world, it doesn't necessarily have to be developing countries, so just a general patient, what do you think their number one most important thing is in terms of accessing pharmaceuticals that they need?

00:04:42.280 --> 00:04:58.690
INDUSTRY EXPERT #3
I think trust in the health care provider who recommends the medication to them, that it is the right medication for their needs, that the benefit and the risk assessment for their individual case has been correctly assessed by their health care provider of trust.

00:04:59.270 --> 00:05:02.490
ZSOFIA KESZTHELYI
Mm-hmm yeah fair point. Um, alright, so the next questions that I would like to ask you, they are general so please don't think of anything any specific treatment area or any disease. Just think about them in general in terms of healthcare or pharmaceuticals. So um, based on your experience, how is the access to pharmaceuticals or the pharma supply chain different in the developing countries compared to the developed world?

00:05:32.640 --> 00:05:47.310
INDUSTRY EXPERT #3
So in most countries in the developed world, you either have a complete access to health care and to medication provision, which is a social good. So it's provided by the government. Uh, it is paid for by

the tax system typically, and it takes care of an equitable distribution of medications based on medical need. Um, you also have very developed countries where there is perhaps a baseline of health care and medication provision for what might be classified as essential needs. But then there would be over and above the basic need for patients and they have to find the money themselves or to supplement the reimbursement provided by their government. Uh, and then again in some developed countries uh, many aspects of medical care provision have to be paid out of pocket. In developed… or less developed countries you tend to find that the direction is much more towards out of pocket. There may be a minimal amount of coverage. That is where we describe a co-pay system, so the government pays part, the patient pays part for even essential medications. Um or there is simply no government provision that at all.

00:06:58.620 --> 00:07:13.170
ZSOFIA KESZTHELYI
Alright, um, and if you think about issues or hardships in access to pharmaceuticals, how do you think there is a distinction between the developing and the developed countries.

00:07:14.430 --> 00:07:38.590
INDUSTRY EXPERT #3
So apart from the obvious distinction of affordability, what, uh, a mother or a father or a patient, can afford in their family, there's also a question of the families' ability to assess or to judge for themselves. Do I need this medication? How long do I need the medication for? Do I have to take it for a long period of time? If I feel better, can I stop taking it? Um, so I think that the awareness, the education, the ability to judge… I have a prescription in my hand. Do I go and fill it? That's often different in developing countries to developed countries. Obviously in a developed country you can be handed a prescription by your doctor and you don't even have to think about it. You can go and fill it at the pharmacy it's paid for, you think about it later, and if you don't feel like taking the medication, you throw it away. This is not an option in a developing country.

00:08:10.890 --> 00:08:15.960
ZSOFIA KESZTHELYI
Why do you think it is so? Is it just a purely financial reason?

00:08:17.240 --> 00:08:29.560
INDUSTRY EXPERT #3
No, it also has to do with education. You know, to my point about the ability for a family to judge, do I need this? How much do I need it? For how long do I need it? Um, so yeah, I think it is also linked to socio-economic and educational infrastructure in the country.

00:08:41.840 --> 00:08:50.270
ZSOFIA KESZTHELYI
Um, when you say infrastructure… Is there anything else infrastructure-wise that you think are missing or are different?

00:08:55.740 --> 00:08:56.550
INDUSTRY EXPERT #3
Uhm…Perhaps…You know in more developed countries you have very basic things like school nurses. Uh, so even if the family is in a poor situation to be able to make good healthcare calls for their children, you actually have the school where there is a healthcare professional on hand to look at things

like vaccinations, treatment of contagious diseases, uh, you know trauma that may happen to the child, nutrition. All these things can be taken care of or looked at… out for by the school nurse. And actually the good thing is even in many developing countries you have these school nurses or sometimes faith-based health care providers who go from one village to another educating and giving very basic health care provision to the communities.

00:09:58.030 --> 00:10:01.480
ZSOFIA KESZTHELYI
Sorry you were saying faith-based, uh?

00:10:01.280 --> 00:10:03.000
INDUSTRY EXPERT #3
Yeah, often linked to churches.

00:10:03.520 --> 00:10:08.280
ZSOFIA KESZTHELYI
Oh OK, so that has to do with religion in a given country?

00:10:08.660 --> 00:10:19.150
INDUSTRY EXPERT #3
Yeah, I mean it…it's just that the church finances it right? Uh, as an NGO. So in Africa you find a lot of this… many African countries.

00:10:19.910 --> 00:10:28.320
ZSOFIA KESZTHELYI
Do these people actually teach the Western medicine or the modern medicine?

00:10:27.920 --> 00:10:46.160
INDUSTRY EXPERT #3
That´s a very, very good question. They typically represent the western medicine, but actually I was about to say in many of the less developed countries you actually have traditional medicine techniques as well, and these are often more affordable. But more importantly, they're often better understood by the families than Western medicine.

00:10:47.070 --> 00:10:53.780
ZSOFIA KESZTHELYI
Do you think it's because it's more linked in their culture and tradition? Is that why they understand it better?

00:10:54.090 --> 00:11:12.350
INDUSTRY EXPERT #3
Yes, that is true and also traditional medicine tends to be much more localized… it is my perception. So you know you have someone in the village who is responsible for the provision of that care, whereas Western medicine you may have to go to the next major town to a hospital or to a clinic.

00:11:13.150 --> 00:11:19.040
ZSOFIA KESZTHELYI
Yeah, yeah, and if you have any insights into this traditional medicine, do you think that's a competitor to going to a hospital, for example, or visiting a doctor? Or is it somewhat a complementary asset that they have?

00:11:29.420 --> 00:11:30.430
INDUSTRY EXPERT #3
It can be both. I mean, a family will have to make a decision about what intervention they choose to look for and embrace. Their first step may be to go to something local, something they better understand, like traditional medicine. Also, perhaps more affordable because traditional medicine is often based on remedies which are agriculture based. Um, easily accessible without paying any money. Um, they may then decide only to go to Western medicine provision as a fall back.

00:12:09.680 --> 00:12:26.990
ZSOFIA KESZTHELYI
Um, when you think of this issue of access to care or access to pharmaceuticals, do you think there are any differences in access to pharmaceuticals among the different diseases, or are these just general issues in the developing countries?

00:12:28.080 --> 00:12:47.440
INDUSTRY EXPERT #3
There are differences, so depending on the public health policy of any country, even many less developed countries will actually ensure certain basic medicines are provided. For example, antibiotics (penicillin), vaccines. These are often supported by organizations like the WHO. Or international NGOs that help to provide these very important medications.

00:12:56.210 --> 00:13:03.440
ZSOFIA KESZTHELYI
Do you have a specific example that you have encountered in your work, like a specific country or?

00:13:05.300 --> 00:13:37.970
INDUSTRY EXPERT #3
Um, so I think many African countries you often hear about penicillin being provided for patients living with sickle cell disease. This is extremely important because these children, these new-born infants are at high risk of infections and then what we call splenic sequestration. So penicillin is very, very important to protect these children. The other aspect that is important to remember it's it's not only about medication, it's also about diagnostics. So prenatal screening, post-natal screening, assay testing to lead to a differential diagnosis. These are also important that these are also accessible as you say, and perhaps even more important sometimes than the medication. Uh, you know, even for a family, it helps a lot if they understand what is wrong, there's nothing worse than having a sick child or being sick yourself and not understanding what's wrong. So the whole diagnostic element is also extremely important in terms of access.

00:14:15.730 --> 00:14:18.640
ZSOFIA KESZTHELYI
And do you think this diagnostics is available in general?

00:14:20.210 --> 00:14:50.170
INDUSTRY EXPERT #3
Yeah, in in many… again like the medication where I was describing something like penicillin. Some basic diagnostics are made available by the governments. One example for you is in congenital hypothyroidism. There's just a very basic ankle prick test or heel prick test that can be done. It's a dry paper test and it's very cheap to administer, very fast, not distressing for the family or the infant, but if it's done uh, in time and it should be done with all infants, then we can prevent a missed diagnosis.

00:14:58.690 --> 00:15:13.120
ZSOFIA KESZTHELYI
I heard that you had a couple of ifs in your sentence, so do you think that it is actually provided so it is? I understand that the government provides these kind of tests, but is it actually performed?

00:15:13.770 --> 00:15:32.360
INDUSTRY EXPERT #3
Yes, so countries like India, countries like Brazil, countries like even Kenya… I mean many of these sort of less developed countries… Brazil maybe not being less developed, but they… the government have a healthcare policy and they define what healthcare provision elements should basically be available and accessible for all. You'll probably find a greater focus on provision of care for children in these countries… prioritization of children in terms of diagnosis and medication. Uh, because so much can be done if the intervention is early.

00:15:56.240 --> 00:16:13.850
ZSOFIA KESZTHELYI
Yeah, yeah, it's great that you already mentioned sickle cell disease because we are actually moving onto that now, um, so maybe you know more, but how do you characterize the access to treatment for sickle cell disease in developing countries?

00:16:14.600 --> 00:16:33.470
INDUSTRY EXPERT #3
In developing countries, so there are many different tiers of developing countries. Um, you know, I think at the most extreme case, if you take a country like the Democratic Republic of Congo, right? You'll have around the capital city, Kinshasa… Uh, you will have hospitals. You will have tertiary, secondary hospitals where the families can go, they will find a doctor or health care professional who will help them understand, help them with the diagnosis, even help them with treatment if required. Uhm… If you're living in the east of the country, in the Outback, in the very rural areas, the remote areas, um, you probably learn in your village that this disease exists. It's probable… there are traditional medicine remedies. You learn basic truths like the child should not go and jump in the river, or the child should be careful when drinking, you know Coca Cola out of the fridge or an ice cream or whatever. They should be careful to environmental factors which could put them at risk. Um, beyond that, uh, you know you're gonna have to make a journey very often to either a regional primary level institution where some basic care can be provided, or if your child is, or you're the patient, is actually experiencing more severe symptoms, then they will have to go to a larger city, the capital city maybe. And that's a long journey which costs money and time and effort. Uh, and that's not always a given, right? So in many of these developing countries, it's not just a question of a government saying “I'm gonna make this accessible”, you need the healthcare infrastructure in place and for an efficient healthcare infrastructure, you need actually a tiered system where you can migrate from basic provision

of health care services, including prevention, including education, then that can be escalated to secondary and tertiary institutions as required.

00:18:36.850 --> 00:18:55.640
ZSOFIA KESZTHELYI
Mm-hmm um when I did my research, I actually heard about Novartis creating this program for sickle cell disease in Africa, so they just expanded it to several more countries than their originally plans. Have you heard of this program?

00:18:56.050 --> 00:18:56.300
INDUSTRY EXPERT #3
Yes. So I have heard of it. As I understand it there providing hydroxyurea which is a basic drug used for prevention or prophylaxis of vaso-occlusive crises and they're trying to provide it at a very low cost or 0 cost this medication.

00:19:15.160 --> 00:19:16.350
ZSOFIA KESZTHELYI
Yeah, um. So this was just, uh, to lead you to the next topic, which is basically about the stakeholders within providing access to pharmaceuticals in these developing countries. So who do you think are the most important players in this supply chain?

00:19:34.310 --> 00:20:06.440
INDUSTRY EXPERT #3
Well, certainly the procurement agency in the country, so the government. Also the Ministry of Health. Because what is important with providing drugs, medication is that there are many other important things that have to be in place first. And the most important is back to what we started our conversation about which is a doctor, a patient or a family can trust or a nurse. Someone where they know that they will get good education, good advice, most importantly a differential diagnosis. Uh, and they will be shown what can be done to make themselves or their children feel better so that whole healthcare infrastructure has to be in place and it has to be done in an efficient way as I was just describing. And then we can move onto medication because I personally… I do not think it's a very good idea just to put free medication into a country where you do not have the health care professionals in place to be able to administer, distribute that medication.

00:20:40.510 --> 00:20:44.120
ZSOFIA KESZTHELYI
From what perspective do you not think this is a good idea?

00:20:45.190 --> 00:21:04.850
INDUSTRY EXPERT #3
I think it… I do not know enough about the Novartis programme to find out if they make sure some of these basics are in place before they just lavish, you know, box loads of hydroxyurea upon a country. Um, so many things can go wrong if you do not put medication either procured and purchased or donated into a country's healthcare system. That medication can get to the wrong people, it can be administered incorrectly, which can result in certain safety problems. It can be wasted, discarded, used, inappropriately, like after expiry. So my opinion is there should be a sequential approach to improving the welfare of patients in any country. Basics first, then move on to you know the later steps which can

involve provision of medication as a donation, leading… and that's quite important… to provision of medication through proper procurement channels by the local government.

00:21:53.510 --> 00:22:11.700
ZSOFIA KESZTHELYI
Um, so if I understand you well, your first step would be the educational part and the health care practitioners´ part so that they are trustworthy towards the patients and then can you elaborate a little bit on the next steps on how you would follow?

00:22:12.620 --> 00:22:32.530
INDUSTRY EXPERT #3
So usually what you find in these less developed countries is that they will welcome donations and the Novartis program is an example of this… and donations are fine if the basics are in place, but donations can be a double edged sword, because if I'm a patient living in one of these developed… or less developed countries, I need sustainable solutions and I need local solutions. I need to know that my own government is prioritizing some level of financing towards my disease or condition, because a donation can be here this year and it can be gone in five years´ time. Uhm… Whereas if my… if I know my government has set aside a budget to prioritize my disease, or at least acknowledge my disease and put it in some kind of hierarchy for payment prioritization, then I know that the government has got a system established. The Ministry of Health… my disease has the attention of the Ministry of Health. Um, they are putting all of the elements in place in my country. They are making sure that the provision of medication is being done in the right way and the…obviously, if I'm a government paying for medication, I'm much more motivated to make sure that it's being done properly.

00:23:42.750 --> 00:23:49.100
ZSOFIA KESZTHELYI
So you mentioned stakeholders such as the government and um, of course the pharma companies. Um, do you see a responsibility split among the stakeholders of who are playing a big role in providing access? Are they equally responsible or is there someone who should take the lead?

00:24:04.820 --> 00:24:16.880
INDUSTRY EXPERT #3
No, the ultimate responsible in any country, in my opinion, is with the policy makers, the elected representatives in that country who represent the health and the welfare of their citizens. Um, this is very, very important that they are in the position of command to determine what gets done, what does not get done. Of course, it's important that these ministries of health, these policymakers, these government officials are open to dialogue. They're open to learn, to have other stakeholders make suggestions to them, but they are ultimately responsible for prioritization and provision of health care in their country. Because they understand better than anybody, the context of their own country.

00:24:53.220 --> 00:24:53.570
ZSOFIA KESZTHELYI
Yeah.

00:24:53.960 --> 00:24:55.930
INDUSTRY EXPERT #3
And they're accountable to their population.

00:24:57.090 --> 00:24:57.720
ZSOFIA KESZTHELYI
That's right. Um, do you think that us in the developed world have some kind of responsibility towards the developing countries?

00:25:08.200 --> 00:25:20.050
INDUSTRY EXPERT #3
Yes, I think first of all, we must respect that the position of command and control must be local. Um, we must respect that uh, the improvement, the escalation of healthcare provision in the country should go along a logical sequence that it also has to be established in a whole ecosystem where there are lots of diseases, lots of public health initiatives that require attention, um, and that you know, we do recognize and acknowledge that. I think if a company comes in who has a very clear interest to sell a particular medication and then they want to give a lot of money and a lot of support to a country for that medication, it sounds like a great idea, but it's… the company obviously has a very strong focus on what they want to achieve, and it's very important that you know, we help the governments and we don't just drive our own agendas of what we think is most important.

00:26:24.730 --> 00:26:46.630
ZSOFIA KESZTHELYI
It's actually great that you mentioned this because this just leads to the next topic, which is basically sustainability. So we hear more and more about the triple bottom line of the company's. Now, let's think about pharma companies, so this includes the environmental, the social and the financial sustainability from a company perspective. Um, do you think that the solution that you envisioned would be sustainable considering these three aspects?

00:26:58.200 --> 00:27:05.200
INDUSTRY EXPERT #3
I think it can be. I mean, we've seen many countries around the world on this journey and develop and progress. Um, so it does make sense, I think.

00:27:11.050 --> 00:27:11.870
ZSOFIA KESZTHELYI
Uhm… Do you think then based on your solution, would that require cost and financial donations from an organization?

00:27:23.200 --> 00:27:36.500
INDUSTRY EXPERT #3
Yes, that always has to be in place. Um, I mean, as I said, it's a journey, so while donations for me are not the final destination, they are definitely a chapter in the book. Um, but we just have to remember, it's not the prologue, and it's not the epilogue, right? It's somewhere in the middle. Um, so yes, things that you describe are very important. They just need to be applied in the right context. From an economics point of view, but also from an ethics point of view.

00:27:57.100 --> 00:28:04.810
ZSOFIA KESZTHELYI
That's right, so um, you mentioned previously that maybe a company would want to invest in a market. Um, and then maybe provide big batches of their drugs. But then what happens if the company cannot

afford this anymore or…I don't know… maybe they put the priorities elsewhere. So then was it really a good thing that they went there with their drug in the first place? Or did they do more harm by going there and then just leaving the country after a while?

00:28:33.800 --> 00:28:44.100
INDUSTRY EXPERT #3
You're absolutely right, because the harm is a breach of trust, right? Um, and I think in many African countries and communities, this trust is fragile because of that… a sort of a smash-and-grab approach by many commercial organisations, uh most often, with a very good intent at the outset, but you're right, the guarantee of sustainability with all the good intentions in the world at the beginning may not be there. Yeah, um… because other factors and contexts may prevail upon the decision makers in these commercial organisations to basically change their minds and refocus and re-prioritize or something as simple as a company is merged or it is taken over or it goes into liquidation. I mean all of these things can happen.

00:29:13.140 --> 00:29:13.480
ZSOFIA KESZTHELYI
Yeah. So you mentioned that OK, um, these donations will be a chapter in the story? Um, how would you step from the donation-based affordability in our country to actually being able to afford somewhat of a pay or payment for these drugs?

00:29:45.560 --> 00:30:03.610
INDUSTRY EXPERT #3
So this is where medicine and economics meet. It is a next step, because once a policymaker is in a position to say… and I have another example that we're going through right now with this… , "OK, I have this population with this disease. Please characterize this population for me. Are there different kinds of patients living with the disease? For example, are there mild forms, are there severe forms? What is the impact on children? What is the impact on adults? What about males versus females? What about patients who've had certain risk factors and other patients who don't carry these risk factors?" This all helps the policymaker to prioritize. I give this medication of what I can afford to these groups first. To these groups, second and to these groups, 3rd and may be in Group #3, I want to spend more money on prevention. So this is really where judicious application of scarce resources is required. That's how you go from donation… this is where you can rehearse all of this... because you're giving it away, but you still should be applying good principles of distribution… uh, to actual procurement where you're spending money. In other words, you've got more skin in the game now because you have an opportunity cost. You're spending money on this disease and not on another disease, so you're accountable to make sure that you're making good decisions. And then, or you certainly need to apply these principles.

00:31:20.030 --> 00:31:20.440
ZSOFIA KESZTHELYI
Uh-huh right right, um… So if you think about… Um, no I'm sorry…. I think we kind of discussed this in in detail, but can you think of any other challenges in other than money? Um, that you would expect regarding the sustainability of access to pharmaceuticals in these developing countries.

00:31:47.370 --> 00:31:56.120
INDUSTRY EXPERT #3
Absolutely. So back to the policy makers and those accountable for making the decisions and mapping

the journey for their country. Uh, you know, let's be honest in many of these countries, the political systems are also very fragile. Um, so is there democracy? Is there accountability? Transparency? Are… is there a good system of ethics in place? And I don't mean Western ethics being applied to a country. I mean for that country, you know according to their values. And you know that is linked to accountability and visibility, transparency. This may not be a given, and so you can take some of these countries where donations have been made and basically let's say there is a risk that they could be used inappropriately. You know on the international market they could be resold out of the country, or they could just be wasted because no one really knows what to do with them. And they just… or they're not stored correctly and then they can't be used because they haven't been refrigerated. Um, or they there is no distribution system to make sure that the drugs… so often you really need to have a reliable and informed, educated system in these countries to make sure that things get done…the right way.

00:33:17.250 --> 00:33:31.770
ZSOFIA KESZTHELYI
Now we did talk about local governments´ roles in this and we talked about the global roles and responsibilities. But do you think there is anything bottom up that can be done? So can the patients the locals do something to move it forward?

00:33:35.320 --> 00:33:43.110
INDUSTRY EXPERT #3
Now so much can be done… because at a local grassroots level… I mean life with the disease is about more than the pathophysiology. It's about the pain or the distress that you experience physically with the disease. There's often a psychological and social ramifications, and context of these diseases, the ones that we at [xxx] work with, that's certainly true. And so at a local level, you know dealing with that experience of living with the disease in the community socially, psychologically. Also, in terms of mobility, just getting your life moving, being able to shop, being able to move from A to B, transportation, all of these things. This can only really be addressed locally.

00:34:32.870 --> 00:34:33.900
ZSOFIA KESZTHELYI
Mm-hmm yeah, that's a… that's very true. I'm just… the only thing that I'm thinking about is, um, let's say a community doesn't really have good education. They don't really know about the disease. Um, just from the top of my head, I just see my child. He has pain, but I have no idea what he's suffering from or what I should do to them. Um, what is it that I can possibly do in my country that would make the government or any of the global organizations realize that I need help?

00:35:15.740 --> 00:35:45.620
INDUSTRY EXPERT #3
So I think we must be a little bit careful coming from Europe or North America in that we sort of expect the village members to embrace our education and what we see as the right approach. I mean, back to traditional medicine, back to prophylactic techniques of sickle cell disease, of making sure the kid doesn't go and jump in the river, right? I mean, some of these very fundamental things are very important. And very useful and make a big difference, um. So I think that, while it's very tempting, and I think you were, maybe alluding to this is to help local communities raise their voice. Uh, you know, be a champion for their needs. Um, advocate. We should make sure that whatever is in place is done in their way, not in our way, um, so I was describing earlier in Africa these faith-based sort of community care providers… that works for them. It doesn't bother them that it's linked to a church. In fact, it's probably quite irrelevant for them, um, but it's the way they work. It's the way they operate. It's part of

their culture, and it's well established, it's well understood and their whole modus operandi is working in this sort of context. So I think that yes, locally, raising attention to ourselves is important. Making sure that the Ministry of Health policymakers understand me when it goes to a higher administration level. The voice will be amplified through the health care professionals, through the doctors looking after these patients because they can articulate you know what is this situation? How big a healthcare priority is this versus all of the other diseases you're being asked to think about and spend money on and what are solutions that make sense. Um, so the health care providers on the ground on the on the front line are usually called upon to step up and be those advocates, those voices for the communities.

00:37:50.890 --> 00:38:13.300
ZSOFIA KESZTHELYI
Yeah… in your years of experience, have you encountered any solution that you thought "OK, this will have success" or that you have actually seen being successful in providing access to pharmaceuticals, especially in developing countries. But maybe you've heard of some other initiatives.

00:38:15.370 --> 00:38:20.670
INDUSTRY EXPERT #3
So I think the… in the area of haemophilia it works quite well. Uhm... And the reason is that you… first of all… these are diseases which are genetic, so they're very rarely visited upon a family for the first time. For a first generation, yes, there are spontaneous genetic mutations, 30%, but if you have a child with haemophilia, odds are your uncle had haemophilia too, so that's the first piece of good news in that you understand what's going on and you understand what needs to be done, what you need in terms of treatment. So that's one thing that characterizes haemophilia. So people know what is needed. They know coagulation factor concentrates are needed and just the very fact that the patients and their families know, "aha, this is the medication I need", that's a big step forward. And then if they were living in an underdeveloped country where it's not free of charge or not easily available, the next good thing about haemophilia is that there are expert centres which look after these patients. So maybe they have to make that long journey to the capital city. Maybe they're lucky and there is a treatment centre close by. They go there and this is the brilliance of haemophilia, is that the treater, even if they're living in a remote part of a country which is like struggling right? Maybe Bolivia, maybe Azerbaijan… they know that there is a worldwide organization. They know how to access that organization, whose headquarters are in Montreal in Canada, and they know that they can approach them for humanitarian aid. And they know that there's a whole ecosystem set up to decide, "OK, your needs are, you know, on a scale of country 1 to country 300, you're probably here. This is how much we can assign to you. And this is how we're going to advise you how to use this treatment in the best possible way from a medical and economic point of view". Allocation of scarce resources. So I think to answer your question, haemophilia is a good model where it works quite well.

00:40:39.570 --> 00:40:44.300
ZSOFIA KESZTHELYI
And who is part of this program are or who started to set this up?

00:40:44.760 --> 00:40:48.550
INDUSTRY EXPERT #3
So the organization in Montreal is called the World Federation of Haemophilia. And they have a humanitarian aid policy. But they're also anxious for the reasons I described earlier to make sure that countries don't get stuck in this donation rut, that they actually have a plan to procure, because they

know that it's in the best interest of their patients in these countries when government start to pay attention to haemophilia and start to allocate budget and resources to haemophilia.

00:41:16.120 --> 00:41:22.710
ZSOFIA KESZTHELYI
So do they also do something in terms of education or moving this in a sustainable way?

00:41:21.610 --> 00:41:22.230
INDUSTRY EXPERT #3
Absolutely.

00:41:26.030 --> 00:41:30.940
ZSOFIA KESZTHELYI
That sounds good, so why don't we just all copy this for all the other diseases?

00:41:31.650 --> 00:41:44.660
INDUSTRY EXPERT #3
I think it's a… it's a good idea. I mean I… you know it's not perfect, but I think it's very good and I trust it and I know that the community out there has a lot of trust in it. Uhm… If anything, you could say it's sometimes good for there to be more than just one organization, so one organization if it isn't that, even if it is an NGO, is not dominant or in a monopoly position, you know competition or choice, let's put it that way, is always a good thing. It keeps us all awake and helps us to improve. So yeah, I think I think it is a good model.

00:42:13.440 --> 00:42:18.490
ZSOFIA KESZTHELYI
And are they sustainable financially or do they just work on donations?

00:42:19.600 --> 00:42:31.830
INDUSTRY EXPERT #3
It is fairly sustainable financially. Um, so they received… this WFH receives donations from companies like [xxx]. They also received funding from companies like [xxx]. But they also need a business model like they need revenue and then they need to allocate their expenditures in an accountable way. They are the most sustainable that I've seen.

00:42:46.290 --> 00:42:51.100
ZSOFIA KESZTHELYI
I will look into them and see what's what they do in detail.

00:42:52.370 --> 00:42:59.180
INDUSTRY EXPERT #3
I can give you a contact name if you wish, at the WFH who runs the humanitarian aid program.

00:43:00.210 --> 00:43:03.110
ZSOFIA KESZTHELYI
Thank you I. I would very much appreciate that.

00:43:03.580 --> 00:43:08.010
INDUSTRY EXPERT #3
I'll contact him first and seek his permission to be contacted by you.

00:43:06.990 --> 00:43:07.430
ZSOFIA KESZTHELYI
Thank you. Um and thank you so much for all your ideas and knowledge in the past 45 minutes. Is there anything else that you feel like you would like to add?

00:43:22.750 --> 00:43:24.650
INDUSTRY EXPERT #3
No thanks, it's a really good... really good session. I enjoyed it. Thank you for your great questions.

00:43:41.610 --> 00:43:43.960
ZSOFIA KESZTHELYI
Um, and then that was it. Thank you again.

00:43:46.070 --> 00:43:48.610
INDUSTRY EXPERT #3
Thanks Zsofia, thank you very much. Have a nice weekend.

00:43:48.850 --> 00:43:50.450
ZSOFIA KESZTHELYI
You too, bye bye.

Interview title	Interview with Pediatric nurse
Date, time	13 December 2021
Location	online

00:01:41.760 --> 00:01:51.910
ZSOFIA KESZTHELYI
So just as a brief introduction, could you introduce what you do in just one or two sentences?

00:01:52.510 --> 00:01:53.810
PEDIATRIC NURSE
Like what I do now?

00:01:54.700 --> 00:01:56.310
ZSOFIA KESZTHELYI
Yes, as a profession, yeah.

00:01:54.780 --> 00:02:17.240
PEDIATRIC NURSE
Or yes, yes, I'm a paediatric nurse right now. I work in the paediatric ICU in the Netherlands. I work there now for a year and within a month my… I will start my education to become ICU nurse because now I'm only a paediatric nurse.

00:02:18.040 --> 00:02:19.930
ZSOFIA KESZTHELYI
OK, very interesting.
And was this also your area when you worked in Africa?

00:02:25.950 --> 00:02:41.310
PEDIATRIC NURSE
Uh, I did there everything… like there was a small ward for children, there was a ward for women and there was a ward for men and that was it. And it was a really-really small hospital, so we did just everything.

00:02:29.370 --> 00:02:29.780
ZSOFIA KESZTHELYI
Right, and how did you end up in that hospital?

00:02:42.610 --> 00:02:42.940
PEDIATRIC NURSE
Yeah. Umm…like I wanted to do volunteering job, umm but then the issue was like, uh, you have to pay a lot of money to organizations who provide you that. And I was like, no, I don't want that. But then there was a, uh organization who was non-profit. Uh, so I went there and they had different, uh countries and different hospitals where you can choose from, and this was one hospital that I really liked, it was in a really rural area and you also lived with and Malawian family. So you were really…uh like in the community and that was what I liked. And I also paid the Malawian family rent so they also benefited a little bit from me. And it was not like there are many volunteers, but every family had a chance to host someone so it's not that like one family got the money and nobody else so that was also what I liked about it. Yeah, that was how I came here.

00:04:05.900 --> 00:04:07.730
ZSOFIA KESZTHELYI
Yeah, this sounds amazing actually.

00:04:08.440 --> 00:04:09.040
PEDIATRIC NURSE
Yeah.

00:04:08.640 --> 00:04:17.910
ZSOFIA KESZTHELYI
Alright, so when you hear this phrase “access to pharmaceuticals”, what is the first thing that pops into your mind?

00:04:15.410 --> 00:04:15.860
PEDIATRIC NURSE
Uh-huh… “out of stock”. Uh, yeah, like every day there was something else out of stock and it was not like that every day that there were supplies, so you have to wait till there was a lorry to come up and who will give you some new medication. And you also didn't know if there was the medication that you needed. You know they gave you something and you hope that there was enough and the right things. So that was pretty difficult for… to work and for the people there who lived there and who work there.

Uh, and it was a hospital from the church, so the the…Uh, the nurses there they had to try through church and the government to get the supplies that they wanted... that they needed. And most of the times it was really hard to get it. Like corruption and everything.

00:05:33.790 --> 00:05:37.610
ZSOFIA KESZTHELYI
Also within the church, so did you find that?

00:05:37.300 --> 00:05:41.650
PEDIATRIC NURSE
I didn't find it… like there was… but... It´s hard I think. Like I was there for 2 and a half months and I don't know if there was [corruption] in the church but it could be you know. The church is there like everything. People are like OK the church can help us and there's I think nobody who uh…control them. They can do a lot because people rely on them.

00:06:15.240 --> 00:06:29.090
ZSOFIA KESZTHELYI
And you mentioned that this was a church hospital, but they still got supplies from the government as well? So was there some kind of an interaction? Or was it both the government and the church providing supplies?

00:06:21.980 --> 00:06:23.150
PEDIATRIC NURSE
Yes, yes. Uh, I think the government supplied… they gave the supplies, but also the staff. Like the people who work there is also because the government says you have to work there. Uh, and the church is more like they manage the place, like the head nurse was a nun of the church and she was like, OK, I will take care of everything and she tried her best to take care of everything, but it was really hard because of money… there was also no money. And if something broke down they couldn't make it because they didn't have the right tools to make it or whatever. And so she really tried her best, but it's was really hard because most of the time there was something that they… that she couldn't do anything about it.

00:07:39.010 --> 00:07:55.200
ZSOFIA KESZTHELYI
Right, right. And did you find that these people, the doctors and nurses, got used to these situations? Could they do something about it? Like were there some workaround situations when these kind of supply issues happened?

00:07:46.320 --> 00:07:46.700
PEDIATRIC NURSE
Yes. Sometimes they were like "OK, if this antibiotic is out of stock, then we take another antibiotic. There´s a wide range of antibiotics, so it was not really that…Like people can also be helped with that antibiotic, but…it's not…it's not… for the works of the antibiotic so it's not good to switch every time so that that they did. Or with IV fluids we only had the big bags like for 500 milliliters and they… like the empty ones, they saved it for later. So if there was a baby or something who needed a small amount they took out of the new bag the mililiters that they needed, they put it in the old bag and then they gave it to the to the child and I was like Oh my God…How are they not getting infected by that because the bag was hanging in the sun for days and now you're gonna reuse it…

Yes, they did that kind of things and so like things that I wouldn't do here in the Netherlands, but there that was the only option because if you didn't, somebody else wouldn't get his IV fluids and maybe died, or something else. So I can imagine that they do it…umm because you don't have another option. But also there are a lot of and burning wounds with children who were falling in hot water or in fire and they needed the change of the bandages and it was of course really painful and sometimes we had ketamine to sedate them a little bit, but the most times it was out of stock and then they only had paracetamol and diclofenac to uh, to get rid a little bit of the pain, but it was really painful for the children.
So that kind of things. Yeah, you get creative in some kind of way. And you get used to it even I did get used to it on some kind of level so I can imagine if you work there always and you grew up there and you don't know the other stories, you do that kind of stuff. But they… like they don't have any chance to change it I think. Because the government is… it's a really poor country and the government is… I don't think it's… they have access to the government to say this has to change or something. I think, uh… it wouldn't be effective to do that.

00:10:59.900 --> 00:11:20.450
ZSOFIA KESZTHELYI
Can you explain this IV fluid situation to me? Because I'm not a doctor or a nurse so I don't have a healthcare background, so I'm assuming that they changed the needle and the line that comes from the IV fluid bag, but still in the fluid there is a risk of infection if you use that again?

00:11:21.290 --> 00:11:24.090
PEDIATRIC NURSE
Yes, and what they did is like you have the bag and some of the bags for empty and they saved it for later. So they took out the IV line and they saved it for later, but they were hanging to dry in the sun. So for bacteria it's the ideal environment to grow. And when there was a baby or something as small children and they need only a little bit of fluid, not like the whole big bag… So what they did, they took out, let's say 100 milliliters out of a new bag. And they put it in an old bag and then they put on a new IV line to the child.

00:12:09.220 --> 00:12:09.670
ZSOFIA KESZTHELYI
Alright. Umm can I ask you whether your practices have changed in any way during those 2 and a half months? So when you came back, did you do anything differently because of your experiences in Africa?

00:12:23.330 --> 00:12:24.360
PEDIATRIC NURSE
Uh…not that I really changed something, but I think about the waste that we make a lot. Like not that I'm going to save the IV fluid bags, but sometimes we throw so much stuff away and it's incredible how much waste we make. And so I try to be effective in the ways I use my products, that's something I changed. And also it's not really that I changed, but I was like "OK, that was something that I didn't experience before". Like when people are… like the patients or their family are like… umm… with the food. Let's say they don't like the food and they are going to complain with me about food and I am like "Oh my God in Africa you wouldn't have food if your family is not providing you something now the hospital is giving you food and you are you are complaining about it?" so that that things are like… most of the times I was really patient with that kind of things, but now I'm sometimes like "uhh don't

complain about that". Like that kind of things. And you are really aware of what you have in the Netherlands or in in other developed countries.
Especially with children…umm children do have a lot of pneumonia. So in Africa there were a lot and they die, a lot of them. And in the Netherlands you can save them really easily most of the times and then I think like how… It's so unfair… like that we have all the supplies and they don't. And even with now with the COVID vaccines. Uh, all developing countries were saying we are going to give them the vaccines and the Netherlands said for every vaccine we have here we take one to the developing countries and… and they didn't. Or really-really low. Like 27 millions were here and they would give them 27 million also then. But then they day only gave uh, like 100 thousands… uh were given two third world countries and I'm like "how can you do something like that?"

00:15:26.350 --> 00:15:30.950
ZSOFIA KESZTHELYI
And do you know why? Do you know why they didn't keep their word?

00:15:26.420 --> 00:15:27.130
PEDIATRIC NURSE
Uh. I think they don't say why, but I think, uh, because of we needed them for the third vaccination or the fourth or the fifth… I don't know… I think they think about themselves, but in the end it's… it's also better for us I think when the third world countries are also better vaccinated and for the people there. So I think it's really stupid to do it, and also because you see a lot of things that China gets a lot of attention let's say in Africa because they give a lot to Africa… like the government building in Malawi. It's the most beautiful building I've seen. They said it's because China built it and then I'm like…Why is China building that for Malawi? They need something from them. And you see that a lot in Africa, like also in Tanzania you saw that. Umm and now it's China also saying you can get the recipe of the of the vaccination to make it, uh, in Africa or somewhere else to get people vaccinated, and that is I think the way China gets a lot of power in third world countries and I don't think that's a good thing.

00:16:58.960 --> 00:17:05.760
ZSOFIA KESZTHELYI
Yeah, and what do you think is it is that China needs from these countries? Is it just a market or…?

00:16:59.510 --> 00:16:59.910
PEDIATRIC NURSE
Yeah. Markets also, but also in Africa there is also a lot of umm… how do you call it in English? The things you found in a ground to make something like oil, uh…

00:17:30.320 --> 00:17:31.250
ZSOFIA KESZTHELYI
Yeah yeah, yeah.

00:17:31.500 --> 00:17:32.580
PEDIATRIC NURSE
Do you know what I mean?

00:17:36.900 --> 00:17:41.720
ZSOFIA KESZTHELYI
Yeah, I know what you mean.

00:17:41.380 --> 00:17:58.460
PEDIATRIC NURSE
Yeah, and that kind of things China likes to have that because they can grow and they can make money out of it. And I think in the end, uh, China will make money out of it and Africa not so much money. And also the nature will be really affected by that. But it's also like… we are not also… like we are also doing that kind of things, but I think China is getting bigger and bigger and bigger and I don't think that's a good idea.

00:18:20.150 --> 00:18:37.920
ZSOFIA KESZTHELYI
Right now, let's go back to patients and access to pharmaceuticals. So when you think about patients or anywhere in the world, it doesn't necessarily have to be the developing countries, what do you think their most important need is in terms of accessing pharmaceuticals?

00:18:23.450 --> 00:18:23.920
PEDIATRIC NURSE
Uh-huh like what kind of pharmaceuticals or?

00:18:42.700 --> 00:18:44.540
ZSOFIA KESZTHELYI
No, it's like what is the most important aspect of their access? Umm, for example, no… I don't want to say examples because I don't want to influence your answer.

00:18:58.850 --> 00:19:10.680
PEDIATRIC NURSE
Umm I think it's the way the government works, but also the infrastructure, like I lived in a rural area and I had to… it takes 3 hours by bus to get there on a sandy road like… and it's really hard to go to the to the big city. Uh, and that's also. I think the reason that there are less supplies there because it's really hard to get there and to go back. And sometimes it's even the roads… even closed in raining season. Uh, most of the times the road is really bad, so that kind of things. And also I think the money, the lack of money to buy pharmaceuticals somewhere and to get it.

00:19:59.930 --> 00:20:09.990
ZSOFIA KESZTHELYI
OK, and now the next question is will be quite general so there is no specific treatment area or disease in mind when I ask these questions. Umm so you have already started to touch upon some of the issues that you've seen in developing countries. Is there anything else based on your experience? Any other differences of how access to pharmaceuticals or pharma supply chains are different in developing countries compared to the developed world?

00:20:36.770 --> 00:20:37.660
PEDIATRIC NURSE
Can you say it again?

00:20:38.190 --> 00:20:47.860
ZSOFIA KESZTHELYI
Yes, so how is access to pharmaceuticals or a pharma supply chain different in developing countries compared to the developed world? What are the differences of pharmaceutical access?

00:20:59.340 --> 00:21:05.050
PEDIATRIC NURSE
And like the way the hospital gets it or the patients get it?

00:21:07.640 --> 00:21:08.270
ZSOFIA KESZTHELYI
Either.

00:21:08.600 --> 00:21:11.260
PEDIATRIC NURSE
Either OK, uhm. I think for us as patients, I think it's really easy for us to go to the pharmacy or go to the doctor and get what you want. In developing countries it depends on where you live. If you live in a big city, it's more easy to get it. Unless you have money, of course, because most of the times in developing countries as I have seen money is also a big problem. They can´t buy the pharmacy they needed. And also we are able to make medication by our own and we don't rely on… we rely on other countries, but it's more easy to make it together and to cooperate. In Africa or other different countries, it's more hard to do that because they don't have the access to do that kind of things or people who are able to make medication… or less, let's say.

00:22:44.390 --> 00:22:55.730
ZSOFIA KESZTHELYI
You asked back whether it was about the hospital. So how do you think the hospitals get the pharma products differently in developing countries?

00:22:56.810 --> 00:23:16.170
PEDIATRIC NURSE
Umm in developing countries is also reliable on the relationship you have with the people who have the medication. Let's say the governments or something. It's really on the… on the relationships you have I think. I also experienced something like that because I had to have a and registration to work there as a nurse. And but they didn't tell me before I went to Malawi, so I didn't have the right papers with me to show them. And uh, and then the nun of the church was saying, OK, I go there with you to Lilongwe… that's the big city in Malawi umm… to go to the government and just I will talk to them and then everything will be alright. Umm, but then I had also to pay money to them to the governments to get their registration because I didn't have my all of my paperwork. And… but in the end, she really helped me because she had a good relationship with that one of the government. And I think that's the same thing how it goes with the medication because the government is giving them to the hospitals. And I think when you have a better relationship with them, it's more easy to get this stuff.

00:24:36.760 --> 00:24:37.120
ZSOFIA KESZTHELYI
Yeah. Makes sense. You mentioned that for example, in Europe we cooperate more easily among the countries. Did you see any cooperation in Africa or did you hear about anything that they would cooperate to… I don't know... Get more access to pharmaceuticals?

00:24:59.430 --> 00:25:05.090
PEDIATRIC NURSE
No, I didn't hear that, but I didn't ask them either I think so I don't know.

00:25:07.020 --> 00:25:26.030
ZSOFIA KESZTHELYI
Uhm, OK great. Then the next question. Do you think there are differences in access to pharmaceuticals among the different diseases? Or are these like general issues among all the countries and all the disease areas? For example, I'm thinking about communicable and non-communicable diseases. Is there a difference to access to these kind of specific pharmaceuticals? Is some maybe one more accessible than the other types?

00:25:56.100 --> 00:26:00.680
PEDIATRIC NURSE
Yeah, yeah, definitely. I think the anti-malaria medication. It was almost… it was there. Let's say maybe sometimes not, but not… not as much as like painkillers. It was really hard to get them. And also like medication for heart diseases it was also really hard to get them. Most of the time it was not there and even in the big cities it was not there. We sent patients to the big cities to get their treatment there for their hearts, because we also didn't have an EKG or something like that. So we were like you have to go there, but they went back and even more sick because they didn't get the medication that they needed and it was a lot of the times. And, uh, antibiotics… sometimes they were out of stock. But then they used something else. And they also didn't have the right range of antibiotics. They only had a few.
I think painkillers, uh, it was hard, and like, uh, for heart diseases it was hard to get. Anything else…Uh, like albendazole. Do you know that?

00:27:34.280 --> 00:27:35.620
ZSOFIA KESZTHELYI
No. What is that for?

00:27:35.010 --> 00:27:38.160
PEDIATRIC NURSE
It's used for, umm…like parasites in your, uh uh, in your bowel, let's say… uh, it was fairly common within children because they eat a lot of sand and then you get them, so albendazole, it was always there. Or, uh, that kind of things it was always there. But like the more like morphine, ketamine, it was never there. And also the article that I sent you. Also the anesthesia is also hard to get it, but in the hospital where I work there are no operations so I… uh, we didn't have that problem, but I knew that there was in the in the bigger hospitals that there was that problem.

00:28:39.810 --> 00:28:44.610
ZSOFIA KESZTHELYI
And do you know why these medications were harder to get and some others were easier?

00:28:51.040 --> 00:28:55.240
PEDIATRIC NURSE
Uhm no, I don't know for sure. No no.

00:28:56.270 --> 00:29:07.760
ZSOFIA KESZTHELYI
You also mentioned that there were several children who got burns from falling into fires or hot water. How did that happen?

00:29:04.660 --> 00:29:06.700
PEDIATRIC NURSE
Yeah yeah. That´s because they, uh, Malawian people… most of them, especially the poor ones, are cooking on fire, just on the grounds. And the children are playing around that. So sometimes they fell and they fell in the fire. Or they cooked water for food or to wash or whatever. And when the children are playing there and nobody is looking, they can fell into the water. Yeah, then yeah it's really nasty.

00:29:51.380 --> 00:30:04.030
ZSOFIA KESZTHELYI
Alright umm, so who are the stakeholders within providing access to pharmaceuticals in these countries? Who do you think are the most important players in the supply chain?

00:30:12.080 --> 00:30:15.380
PEDIATRIC NURSE
Yeah, I think still the government is the most. Uh, uh, because they decide where their medication is going, where people are going to work they decide on that, that's really strange. And they say just like you have to go to work there and you go to work there, you can't change where you are going. Or you can´t choose where you're going to work, at least when you work for the government. Like a private one, you can choose, of course, but and same I think it's the same with the medication. And it's not like there isn't somebody else from the government… like there's not like that the hospitals can choose where they buy their medication or something.

00:31:10.600 --> 00:31:19.250
ZSOFIA KESZTHELYI
And do you know why the government has so much power over their workers? So why it can tell them which hospital to work in?

00:31:20.230 --> 00:31:22.950
PEDIATRIC NURSE
Uh, I think it's because, uh like, uh, nobody wants to work in rural areas. Everybody wants to work in the bigger hospitals and I think when they say you can choose where you going to work, the rule areas won't have any nurses or doctors or physician assistants, and so I think that's why they really control it to get the staff where it's needed.

00:31:54.590 --> 00:31:57.130
ZSOFIA KESZTHELYI
Did you hear any feedback on this from the colleagues that you worked there with?

00:32:02.010 --> 00:32:02.640
PEDIATRIC NURSE
Yes. And most of them they did not like it where they worked because yeah, it's a rural area you can´t go anywhere really easily umm and also because of the working conditions. Like it was a really bad hospital because you can´t do anything you could give them some medication, you give them some

bandage but most of the time you had to say you have to go to the bigger city to help… to let you help there. But they really hated that. And also because they are like far away most of the times far away from their family and it's not really easy to go there and it also costs a lot of money for them to travel. Yeah, so most of the times they hated it, but on the other hand they were also saying like yeah it's life this so that's how it is. And maybe in some years I can… because they also change. So within a few years they have to say like… umm the government says like you have to go there, you have to go there so they hope also that there's an uh… other chance to work in a big hospital.

00:33:21.710 --> 00:33:45.130
ZSOFIA KESZTHELYI
And from I don't know a rationality perspective did it make sense? So as you were saying, if this didn't happen then rural areas wouldn't even have this many staff in the hospitals. So do you think this is a way to go to treat this issue?

00:33:45.980 --> 00:33:50.120
PEDIATRIC NURSE
No, I don't think so. It's a short term solution I think. Uh, because most of them, most of the nurses they were trying really hard to do their best. Then some of them you were really seeing like they hate it here so much and also within the patient care, they were not like really good with the patients. Like sometimes when it was really quiet in the hospital and there was one child with a burning wound and we had to change the bandages. And I was like "shall we go to change the bandage?" And she was like "no, I don't want to". And then she was just sitting in the sun and doing nothing. And that kind of things I think you would see it more because they really hated to work there, the situations that that they were in. So I also can imagine that sometimes you feel like that because you want to do more, but there is no option for you to do more, and I can imagine that you feel something like "Pfff today? No.". Yeah, but how to make it better like… that people want to work there… Yeah, that's a really hard question.

00:35:12.470 --> 00:35:14.170
ZSOFIA KESZTHELYI
Yeah it is for sure. OK, so you were saying that the government is probably the most important player in the supply chain. So how do you see other stakeholders´ roles and responsibilities in finding the solution to these issues around access? So let's say the pharmaceutical companies, the hospitals themselves, or distributors.

00:35:42.390 --> 00:38:18.320
PEDIATRIC NURSE
Yeah, I think, uh the hospitals I think they have to try to, uh, to go and work around the government, let's say to try to make their own accesses to other countries or other pharmaceutical companies or something like that, and maybe they can say to the governments… say if you do it like this you get more, or just to try the governments to like let's say… that the government will work better umm if you give them some information to do it better also. Umm and I think the hospitals or the pharmacies, I think they could try that too. To go and look in other ways to get their medication or other kind of medical stuff. And umm, and then just go to the to the government and say just do it like this, this and this and then we get a better working system and the pharmaceutical companies… I think more access to cheaper medication. So uh, make it cheaper for third world countries because they can't afford a lot of money and I know that the companies also have to make money, but I think when you.. the developing countries are not able to pay it, so it's unfair to let them pay a lot of money. The patent on

medication… like some of the developing countries are able to make their own medication, but they don't have the recipe for the medication. So let's share it to them, you know, and I know it's not easy because it's also the way the pharmaceuticals make money… but I think they also have a responsibility to vulnerable people to help them.

00:38:48.680 --> 00:39:03.290
ZSOFIA KESZTHELYI
When you think about hospitals and the government, was there or did you see any cooperation between them? So for example, did the hospital say their needs to the government? Was it ever asked for planning purposes?

00:39:04.000 --> 00:39:20.640
PEDIATRIC NURSE
Yes they did a lot. And the nun who was like say let's say the head of the hospital… she was away a lot just to go to people to talk to arrange things to make it better, uh, but it takes a lot of time because she always had to travel to them. It's not like they had a good Wi-Fi and just talk like that, so it took also a lot of time to arrange things.

00:39:42.050 --> 00:39:46.580
ZSOFIA KESZTHELYI
But do you think it worked? So did the government listen to the hospitals?

00:39:47.880 --> 00:39:48.950
PEDIATRIC NURSE
Umm. Sometimes, but most of the times was like yeah… we are we are not able to help you just do it on your own and try to get some money or that kind of things. Yeah yeah, I depended on like if they had something in stock or whatever they could help you but a lot of times the government was saying like yeah we can't help you because we don't have enough.

00:40:22.780 --> 00:40:36.910
ZSOFIA KESZTHELYI
And in terms of… I don't know… planning for next year. Did they get some inputs from the hospitals on how they should arrange their health policies or purchasing policies?

00:40:38.710 --> 00:41:08.400
PEDIATRIC NURSE
I don't think so. It was more like just surviving the day and next week maybe. Planning is not really a thing that I was seeing there. No, it was not like "OK next year we have to try to achieve this or that and this is how we are going to do it" and that was also because I think it's also a cultural thing. I think people there are not planning that far, but I think also because they are struggling in the moment and it is really hard to think "OK, what do I want next year" And that's not something that people were like … They were like OK if we survive this week it will be fine, you know... If you are struggling every day, you don't think about next year.

00:41:47.990 --> 00:41:49.620
ZSOFIA KESZTHELYI
Yeah, that's right. So you mentioned several issues now in terms of finances and infrastructure and

maybe also the planning thing. So what would be your strategy to solve these issues that you have seen there? How would you start?

00:42:10.800 --> 00:42:11.650
PEDIATRIC NURSE
Umm. Ah, that's a really big question. How would I start umm… I think you have to start small, at least because, thinking biggest thing I don't think that's the solution, but uhm... Let's say if the infrastructure, so the roads or something like that is more easy to go there… It's also more easy to get supplies there. I think that would be also a big change. And also because of the people who live there and also the nurses would get their getting more easy access to the big city to travel there. And they may also like it more to work there because it's more easy to travel and to go around. And I think for the government… they need to go and found solutions to get more access to, uh… pharmacy and also some other kind of medical stuff. Uh, I think they have to do it because… they have to do is to talk to other countries, more developed countries and let's say "help me but not like help me, you arrange it and we say thank you", but let's say "How do we arrange it? How do you arrange that? And can we learn something about that?" Yes we can help them of course, but in the end they have to do it on their own. And also I think they have to talk to pharmaceutical companies and I think they have also a responsibility to developing countries to help them to make more access to medication. I think if that's happening then is for the government also more easy to get medication.

00:44:48.500 --> 00:44:55.030
ZSOFIA KESZTHELYI
Yeah, how did you find the knowledge of nurses and doctors in your hospital that you worked in?

00:44:57.340 --> 00:45:05.070
PEDIATRIC NURSE
For the nurses it's a really different way of working in Malawi, because in the evening and in the night there was no doctor, so the nurses also had to prescribe medication and to exam the patient. So they know a lot about medication or at least the medication that are available there. They knew more about it than I did, but in a more social way they have to learn… that's not something they learned there. Uhm, it's like they're really hard for patients in my opinion. They are really hard for patients and also they did a lot about prevention for pregnancy, HIV, and something like that. And I was there once when they talked to people from the village and the villages around it and they are talking in a really bad way, like angry. And that kind of things they have to learn a lot, but I think in a medical way they know a lot. But let's say in social way they can learn a lot, yeah, and we didn't have doctors. We only did have physician assistants. And we had one physician assistant who was a little bit older and he knew a lot. He was somebody who I trusted, like when he was saying, oh maybe it's like that I was like OK, maybe you're right. But there was also a really young one like my age and he didn't have that much experience, but he was there all by himself, like when he was seeing patients. He was sometimes like "Anna, can you come to help me?" and I was like "OK you don't know". And of course, it's also normal that he didn't know because he was just starting his career, but nobody is helping him. And then you're on your own and you don't know so there's no supervision, or at least less supervision. Sometimes there was, but if it was busy then there was no supervision so he had to do it by his own. And yeah, that was really hard for him. Yeah, yeah.

00:48:10.520 --> 00:48:18.700
ZSOFIA KESZTHELYI
It's really tough. Sorry, I can see that we are a couple of minutes overtime. Do you have a couple more minutes to spare?

00:48:17.080 --> 00:48:18.400
PEDIATRIC NURSE
Yes, yeah.

00:48:19.310 --> 00:48:46.670
ZSOFIA KESZTHELYI
Then I just wanted to ask you about... you mentioned how you would find a solution for these issues. So starting small, smaller steps, do you think that this could work as a sustainable solution? So sustainability in a meaning of having environmental, social and also financial aspects considered. So can we achieve sustainability in pharmaceutical access somehow?

00:48:56.820 --> 00:48:59.750
PEDIATRIC NURSE
Yes, I think it's possible, but it relies on so many uh aspects umm so it's really hard, I think to get it. It's not something you get in two years and then it will be fine and every country is also different, so I think, uh, when you achieve somewhere a solution, it's not saying that in other countries that that will work too. Uhm, but I think it's possible, but they need help to get sustainability. I think they can't do it by their own. I think also because of money issues and that kind of things.

00:49:52.420 --> 00:49:52.810
ZSOFIA KESZTHELYI
Right. Have you seen any solution ever, not necessarily in Malawi, that you think worked well in helping the developing countries in getting access to pharmaceuticals?

00:50:17.550 --> 00:50:20.020
PEDIATRIC NURSE
No, no for pharmaceuticals no.

00:50:20.240 --> 00:50:22.650
ZSOFIA KESZTHELYI
OK, and in any other areas?

00:50:33.190 --> 00:50:51.330
PEDIATRIC NURSE
Yeah, my boyfriend, he worked a in Tanzania. He's a doctor and he was also working in a rural area but less rural than I was working and they also had the theatre room and everything so they did operations. And there was a village near to them, they also had a hospital. And there was an anaesthesiologist and she was providing education for people in the theatre room. Uh, uhm when people were operated they could do the operation, but afterwards just checking the patients, it was really bad. So some of the patients died because they didn't have the right medical care after the operation, so she, she educated those people to get better care after the operation, like they checked the blood pressure better, the temperature etc. And that's how they managed to get better healthcare there. And now she's also trying to do this in other hospitals, and I think that's a good solution to get better health care there. And it

costs money to educate those people, but when some when some of them are educated, other people can learn from them. So it's really sustainable I think in that way, because they can teach each other.

00:52:37.150 --> 00:52:38.180
ZSOFIA KESZTHELYI
And was this her idea or did she do it in her own free time? Or was it an organized thing somehow?

00:52:45.270 --> 00:53:01.780
PEDIATRIC NURSE
I'm not sure, but I think it was her idea. She was also working there so she was seeing the problem, but I think she worked there also with a school there to get them educated.

00:53:02.130 --> 00:53:17.670
Zsofia Keszthelyi
Very nice and then last question from my side, how did you see a contraception in Malawi? So birth control pills or anything? Was it allowed for women to take them, did they have access to it?

00:53:20.700 --> 00:53:25.760
Pediatric nurse
I don't think the control pills… they were not there, but condoms and everything, they were really promoted. Even though it was a Catholic hospital but they promoted the condoms to use and they also provided education about it. And also when there were children from sometimes from 14 or something. And who were pregnant, they got really angry at them. It's not the right way to prevent it, but you see in Malawi, like when you are a little bit educated, they are…really like "how can you get pregnant at 14 and how can you do something like that?" But most times if you are 14 years old or 16 years old, those are people who were really, really poor and didn't go to school or also the parents were not educated. So I can imagine how that goes. So they did about education, they also provided condoms. Yeah, that was something and also with the HIV thing. They also educated about that and also because a lot of people with HIV were bullied in the villages, so they also had some program for that and it was and American volunteer who was doing that for one year. And she managed to get some women in the village who had HIV who are now giving education to people about HIV and also about bullying and everything that they don't have to do that. And yeah, you saw changing it, so that was good.

00:55:31.560 --> 00:55:38.430
Zsofia Keszthelyi
That's nice, that's nice, and in terms of contraception, is it culturally accepted? I've heard a couple of examples where for example, fathers didn't allow the mother to use any contraception because they thought it was not culturally embedded in what they believed in.

00:55:59.080 --> 00:56:09.610
Pediatric nurse
I think, uh, I'm not sure, but I think in in the in the families who are not educated, who are not going to school, who don't have the money, yes, I think it's there. Uh, but if they had a little bit of education, they have different thoughts because of the programs that are there. But the people who are having less access to those programs and everything, they still have that kind of ideas. Yes. And they also think like when we have children, they can take care of us when we are older, so we do have a lot of… we need a lot of children so they can make money for us when we are old and not able to work anymore. And so that's also one kind of problem.

00:53:02.130 --> 00:53:17.670
Zsofia Keszthelyi
Interesting, yeah. Very nice. Alright, do you have any questions at this point?

00:57:08.480 --> 00:57:09.210
Pediatric nurse
No.

00:57:09.540 --> 00:57:14.330
Zsofia Keszthelyi
OK, then thank you very much. This was all then.

Interview title	Interview with Industry expert #2
Date, time	15 December 2021
Location	online

00:02:05.810 --> 00:02:08.370
Zsofia Keszthelyi
Do you have any questions before we begin?

00:02:09.140 --> 00:02:10.570
INDUSTRY EXPERT #2
No, very clear, thanks Zsofia.

00:02:10.900 --> 00:02:19.970
ZSOFIA KESZTHELYI
OK, excellent then please introduce yourself and what you do in just like one or two sentences very briefly.

00:02:21.490 --> 00:02:35.740
INDUSTRY EXPERT #2
So I have been working for [xxx] for 15 years, in commercial, in either a marketing or a sales role, global or affiliate with rare diseases. My core function is really marketing, not access, and I have a scientific background, so a PhD in molecular biology and I transitioned and did an MBA before joining industry.

00:02:52.100 --> 00:02:52.730
ZSOFIA KESZTHELYI
Thank you. When you hear this phrase “access to pharmaceuticals”, what is the first thing that pops into your mind?

00:03:03.630 --> 00:03:04.240
INDUSTRY EXPERT #2
Cost.

00:03:04.460 --> 00:03:05.640
ZSOFIA KESZTHELYI
Cost, OK, and why so?

00:03:08.640 --> 00:03:11.210
INDUSTRY EXPERT #2
Probably because where I grew up everything was out of pocket and therefore if you needed an expensive medication, it came down very much to the cost of that medication rather than the health system in that country because there wasn't one, so it was really "can I personally afford that drug". Uhm, so that would be the biggest limit on access. Also I guess there… so I grew up in Africa and you just didn't have those medications so you would have to import them. And again that was a costly process which we as a family could afford, but for many of our household members, we would have to facilitate that for them.

00:04:00.650 --> 00:04:03.510
ZSOFIA KESZTHELYI
Right, right, May I ask which country this was?

00:04:04.070 --> 00:04:05.040
INDUSTRY EXPERT #2
Sierra Leone

00:04:05.560 --> 00:04:07.390
ZSOFIA KESZTHELYI
OK, very interesting. And so when you think about patients anywhere in the world, it doesn't have to be developing countries, what do you think their most important need is in terms of accessing pharmaceutical products? What is the first thing that they would say?

00:04:25.220 --> 00:04:26.970
INDUSTRY EXPERT #2
Most important need? Infrastructure. I mean so if we look globally, I think that infrastructure… and by infrastructure I mean the access to a competent physician, access to a competent diagnosis, the whole patient journey has to be in place to get appropriate access. I think access to the wrong medication or an easy medication or a quick fix is often there, but if we're talking about access to the correct medication or the correct treatment, requires infrastructure to be in place to allow that to happen. And infrastructure needs funding. Uhm and infrastructure needs a broad umbrella so that all the people within a country can be supported by that infrastructure.

00:05:37.660 --> 00:05:49.750
ZSOFIA KESZTHELYI
Excellent, so I think you've already kind of lead up to the following topic and this question will be a general question, so no specific disease area or treatment in mind. So based on your experience, how is access to pharmaceuticals or a pharma supply chain different in developing countries compared to the developed world?

00:06:03.610 --> 00:06:04.170
INDUSTRY EXPERT #2
I mean… If we simply look at access to innovative drugs, there is a time lag and a filter. I can put it

like that. What's been launched in the developed world, we take Japan. EU top five and US.. it takes time and may not ever happen to launch in South America, India, China or Eastern Europe. So therefore there's a a different innovation quotient in each country. So I think that's one of them, and for many reasons… It could be the launch sequence. It's the regulatory process of that country, it's the willingness to pay of the country, it's the access system, whether it's a tender, there are a 100 different reasons and you know that varies globally. So that's one part, the other one is the health care system. Where in certain countries… as from my accent I am English… You would assume there is a broad access in the countries such as the UK, where you've got an NHS system, but clearly if you have private insurance you have a better option list versus Switzerland, where we all have to pay for health insurance. And I would say we all have the same access to a medication. So I think that the health care system has a huge role to play. Let me think what else… I think those are the two main ones that would come into my mind would be this whole innovation quotient and their health care system and now I can't remember your question specifically, so I can't remember if I've answered it.

00:08:06.340 --> 00:08:17.380
ZSOFIA KESZTHELYI
OK, so the question was how is access to pharmaceuticals different and developing countries? So you mentioned two of these underlying causes.

00:08:17.800 --> 00:08:30.980
INDUSTRY EXPERT #2
Yeah, and if we go back to truly developing countries, there is no healthcare system to some extent, so then it depends on infrastructure built up by non-for-profits, by foundations. And then there's this differential access to treatment and access to care becomes extremely important. **Information is critical**, even in developed markets, so you will find some vulnerable populations in every country who don't have access to information, whether that's a linguistic issue, a technical issue, or an infrastructure issue. And if you don't have access to information, it doesn't matter how good the health care system is, you're still never going to get access to treatment or care. We can do this linguistics as one point as we see more and more transient or mobile populations coming into countries and not every country will have translated the healthcare system into [?] or put it on a piece of paper that's delivered to the relevant social centre of a transient community. So I think information sharing and access to information is critical, and I think COVID has been a highlight of that where if you see transient or immigrant populations not getting vaccinated, is it because they haven't realized they can for free because the information never reached them? Or is it because they don't want to get vaccinated? I suspect you know they listen to local news or read it and don't realize what's going on in the country they live in. And you can see immediately this big divide that we're living with today. And it's not about the health care system or anything except information flow.

00:10:18.390 --> 00:10:29.840
ZSOFIA KESZTHELYI
Right, you mentioned that there is no proper health care system in the developing countries. How do you think it's not properly set up? Or why do you think it's so?

00:10:30.960 --> 00:10:33.920
INDUSTRY EXPERT #2
Well, “no” is probably a bit too general. If I think about the countries I've been exposed to, which would be whether it's India or Asia or Africa. Clearly there are regions of those countries or continents which are well serviced and those are the highly populated. Nigeria has the highest number of

millionaires in the world within its population. But I suspect that you know in rural…in Port Harcourt, there isn't a great health care system for the gardeners, the drivers, or the cleaning ladies who service and work for these millionaires. So again, the infrastructure, where there is enough sharing of the economic facilities, so I want to say the funding that is equally shared throughout the population is very difficult where you have areas of very urbanized rich population and then a rural population who may be transient moving into the city for work, but are based rurally as in India, as in many countries. And therefore, until you've built up that whole system of care, centralized and sustainable, then I think there's going to be a challenge with this "good" health care system. You can't even get good water. We don't know how you're going to get good drugs.

00:12:21.460 --> 00:12:22.320
ZSOFIA KESZTHELYI
Right, right. Going back to the access to pharmaceuticals, do you think there are differences in access among the different disease areas, or are these general issues in developing countries?

00:12:38.190 --> 00:12:51.120
INDUSTRY EXPERT #2
I think there's a broad suite to deliver malarial tablets across Africa. I do not think they're all gonna get the top notch oncology products, so I think there's clearly a disparity. You have to start at the most prevalent broad base disease. I read an article the other day that said that pharmaceutical companies were just developing drugs for non-communicable diseases and ignoring the whole transmittable disease population. Whereas in fact there are extremely good treatments already, for most transmittable diseases, and the challenge isn't developing that medication, the challenge is delivery and pipeline and infrastructure of those medications. Otherwise, we'd all be suffering from tuberculosis, maybe not malaria. Switzerland had some malaria but I don't think malaria is really high on the list, right? So, yes, it's clearly a divide, but it has to start with the diseases that are impacting the most of the population. We had the huge success story before your time of HIV. HIV was supposed to eradicate half of Africa. But medication got out there. The processes worked, it went grassroots, started, became sustainable, and now HIV information and medication is broadband and it hasn't killed off half of Africa or half of India or half of Asia. So the solutions can be there but there has to be a call to action. Otherwise the problem is too big and it isn't the priority for those countries. So you know the sort of "do-gooders" can swoop in and drop a load of drugs on a small population who´s suffering in I don't know… a corner of Nigeria. But that's not sustainable. It's not going to help in 10 years´ time.

00:14:47.250 --> 00:14:48.490
ZSOFIA KESZTHELYI
Right, right? Uhm, are you familiar with the sickle cell disease or do you have any experience working with it?

00:14:54.840 --> 00:15:07.540
INDUSTRY EXPERT #2
Yep, so I have some experience not only from my experience growing up in Sierra Leone which is a sickle cell disease country. My parents met in Lagos, so again, my entire sort of heritage came through Africa. And I currently work with a project looking at developing a new therapy area within [xxx] for sickle cell disease so relatively familiar as a layperson.

00:15:21.200 --> 00:15:28.990
ZSOFIA KESZTHELYI
Right, do you know if there are any specifics of the access to treatment for sickle cell disease?

00:15:32.170 --> 00:15:32.700
INDUSTRY EXPERT #2
I think the word "no" [??] is leading… Access to medication for sickle cell disease is complicated because of its countries of origin. Let's call them that… which is Brazil, sub-Saharan Africa, India. Let's just keep those on hold for a second and focus on where we have immigrant populations who brought the disease into either Europe or Africa. And as the population are non-Caucasian and one of the key treatments is strong painkillers, opioids, there is a perceived difficulty in access to medication if someone goes into an emergency room. As they are not believed to be a sickle cell patient but an addict or somebody trying to get drugs for non-personal use. So that's the emergency issue. So this community perceives (probably with grounding) that they are ostracized or they don't get the health care they deserve. I do believe in sickle cell centres, which tend to be centres of excellence. Now we're talking developed world. They get good care. That is not many currently available medications for sickle cell disease that are effective. And part of that is if we now go back to the origin countries. Distribution of the standard of care which is hydroxyurea, so distribution isn't that easy, it's not paid for. This information on how often to take it, what it does, what are the side effects, plus the fact that it can have impacts on fertility and your next generation. All of this has to be explained. You can't just kind of sprinkle the drugs around the villages and say take a couple each week. So that infrastructure again isn't there. The patient communities in the origin countries, they haven't built a strong network. I think it's coming and I was very pleased yesterday to hear that the Novo Nordisk Haemophilia Foundation has partnered with the Pierre Fabre Foundation in France and they focus on exactly this: building up the patient organisations for sickle cell disease. So I think this partnership is very powerful. So access to drugs for sickle cell across these countries is again multi-dimensional. So I do think there are issues. I think the newer drugs have a higher budget impact and therefore there is some question as to whether or not the paying agencies (depending what country you're in) are going to give access to all. We've already seen that novel therapies, curatives therapies that were brought to market in Europe had a too high price tag to be accepted in the European markets. Now, whether that's because they didn't find the right model or it was too new or whatever, there will be a hurdle. Sickle cell disease does have one huge advantage that it is a prime candidate for curative gene therapy. Which would be marvellous, but how to get curative gene therapy to the majority of the population, which is the origin countries is a huge question.

00:19:59.690 --> 00:20:20.400
ZSOFIA KESZTHELYI
Alright, thank you, this was very broad and very exciting to hear your thoughts on this. Uh, do you know why the patients that you mentioned so who are not in developing countries, do you know why there is this perception that they would use the drugs or misuse the drugs if they are in an emergency situation?

00:20:00.680 --> 00:20:01.180
INDUSTRY EXPERT #2
Well, I think if that if you're non-Caucasian and come into an emergency room demanding an opioid with no proof, no external evidence of pain, there's a bias… A lot of these people live in areas which are of the lower socio-economic level, where there are lots of abusers, addicts. And emergency room staff aren't aware of the ins and outs of sickle cell disease, so it is a bias, it is a bias of someone coming

in and demanding medication because they're in pain with no evidence. I think it's historical, yeah, many reasons I think… But you know, these are the stories we hear from both physicians, so key physicians, not the emergency room physicians and the patients themselves.

00:21:31.770 --> 00:21:49.180
ZSOFIA KESZTHELYI
OK, so you mentioned several issues now that we are faced with in developing countries. So who do you think are the main stakeholders within providing access to pharmaceuticals in these countries? Or who are the most important players in the supply chain?

00:21:55.800 --> 00:22:01.290
INDUSTRY EXPERT #2
I'm writing the word providing access right? Because now you want me to be specific. So at some level the pharmaceutical companies need to be able to put the supply chain in place so that medication available reaches the hospitals and that sounds easy, but sometimes it's not easy. The current standard of care medication is a chemotherapy agent. Therefore it has a high grading, it's gonna be slightly more difficult to import etc. The paperwork has to be there and understood by everybody, and that sounds trivial, but trust me, many, many shipments of many things get stopped at various ports around the world, so that supply chain has to be in there. So that requires that there is at least affiliates or third party representatives in these countries to handle that. And we could say this is the role of the companies, but it's also the role of the regulators and the role of the health authorities. To one approve those drugs. So make them approved in developing countries so that the paperwork can come in place and so that there is at least some sort of payment system - and it doesn't matter how expensive these drugs are - in place for it to make sense. Now we could also say the third party coming in here are the philanthropic or the non-for-profit organizations that support health care globally. Whether that's WHO or the Bill Gates Foundation, where they've been pushing massive healthcare projects through the system, including, you know, malaria care. And I keep saying there is a huge parallel with malaria vaccination and whether or not sickle cell can kind of follow that path. And the hospitals have to have doctors who can and are trained on the treatment of sickle cell disease. How to diagnose it, how to treat it. And on top of that, there needs to be a local distribution process so that medication can reach the populations where it has to go to. A lot of this these drugs are stable at high temperatures, so that's not a major issue. And there are lot of innovative distribution networks out there, but I still believe you know there has to be this baseline health care in place. Now we know it works. We've built it up for a lot of haemophilia across the world. But we've been working on it as an industry and a very, very well organized patient organization globally for 30 years and I think sickle cells behind. So there also has to be the patient pool which is starting… There's no easy answer for providing access. The Community needs to work together. And sometimes you have to start small and build those up. So I have again mentioned the PFF Foundation... Super happy that maybe we can activate the patients to be able to show us how to help rather than us Swiss pharmaceutical companies swooping in, “knowing” how to help. Populations in Sub-Saharan Africa…we probably don't know how to do it yet. You know the will can be there, but you know it's yeah no, not there yet…so we're learning. Novartis has made big steps forward to provide compassionate use medication in a number of countries. But it's a limited supply and limited countries… great first step… and how different companies how can we synergise? So rather than go to the same countries but say OK, you know what can we do in other areas. Until [we] have an approved medication we`ll start by supporting the patients and looking at what we could do for access to care rather than access to treatment.

00:26:29.500 --> 00:26:46.250
ZSOFIA KESZTHELYI
Right, so you started your answer with saying that the pharmaceutical companies need to make sure that they have a supply chain in place and those… so do you think that they are the main responsibles for this?

00:26:29.860 --> 00:26:31.140
INDUSTRY EXPERT #2
Yes, I mean, it's all a supply chain, we own the supply chain, we're responsible for the supply chain. That's it. Until it reaches our warehouses and we sell it to hospitals or pharmacies, that's our responsibility. Getting it from factory to pharmacy. We should be good at that. That's what we do, and I think that is in place. I don't really doubt that. But I think the next step, which is from pharmacy to patient… who's responsible for that? Maybe it is a joint effort. But we are not allowed to meet the patients, touch the patients, see the patients in most countries. So therefore then it has to start being a collaboration or a hands off support process. I mean pharma doesn't get to see patients.

00:27:43.620 --> 00:27:50.020
ZSOFIA KESZTHELYI
Right when you say collaboration, who do you mean? Who should the pharmaceuticals collaborate with?

00:27:43.920 --> 00:27:44.230
INDUSTRY EXPERT #2
Well, it can be the hospitals, it can be (if it's a tender country) how the tender´s set up, it can be the pharmacists themselves. Is it electronic tracking? Can we give medical educational grants to help learn how this happens? Is it about registries being in place, so the information about the patients are logged for you to know who's on medication, who isn't. There's a 100 ways where medical information can be shared or patient support programs can be put in place following the compliance of the country within the regulations of that country. Now I'm being my industry self.
There are pros and cons to us being the second most regulated industry in the world. Yeah, there are pros and cons. There are certain things we can't do legally. I was once told that I shouldn't interact with people with the disease (I was managing a Salesforce) so I shouldn't interact with people with the diseases that I treated. Well, unfortunately, one of those diseases is menopause and I'm a [ ] year old woman which basically meant I couldn't go out with any of my friends. At some point common sense has to take over from the regulations, but there are very strong and very appropriate regulations in place and that means we have to work a lot on these collaborations and how we can support, not directly act. And every country has a different set of regulations and a different set of challenges, and that's where foundations can help or we give grants to local foundations, but it can't always be us swooping in and going “Hey, you know we're gonna start playing in every area of the supply chain”. One, it's not appropriate. Two, we don't know how. And three, it's not allowed. We can't actually take the drug and deliver it to patients´ house because that patient has to be anonymized. Pharma companies should not ever know who… an identifiable sequence of data for the patients on their drugs. That's data protection… so we can only go so far. We can talk to the doctors and the doctors have to then facilitate the rest of it, or the pharmacists. So therefore it does have to be a hand-over, sort of a relay race in place. Uhm yeah, it's tricky.

00:30:39.460 --> 00:30:39.750
ZSOFIA KESZTHELYI
Yeah. It is… and going back to the original question, how do you see the roles and the responsibilities of the governments or health ministries in developing countries?

00:30:55.230 --> 00:31:15.560
INDUSTRY EXPERT #2
I mean, it's really difficult. I think there's a big push at the moment if we stay with sickle cell disease… to raise awareness on the burden of the disease, on the regulations, on the budget allocation for care and support for rare genetic diseases. And that is the health authorities... Now again, it's very difficult to be generic here because every country has a different infrastructure. But whether it's the government or the health authorities or the hospitals - less. They have to take a role in raising awareness, raising the call for action, changing the treatment protocol. And those have to be approved. So if the drugs are going to be used, if the budget is going to be there, it all has to go up the line. It's like any huge organization. The decision is from the top so that hospitals can be as willing to prescribe and treat… and the pharmaceutical companies can try… but if the sickle cell disease drug application keeps getting pushed further and further down the list of priorities… the drug never gets approved. That's just hypothetical, it's not happening anywhere that I know of. So then of course there is a responsibility. We're stuck, we can't get the drug approved. Everything else is in place. Each of those Dominos has to be in place for things to run smoothly. Or understanding why a second treatment option is needed... You know many health authorities say there's one out there already. They have to be educated and informed as to why that isn't sufficient, why they need a new medication or an add-on medication to support the people suffering from sickle cell disease. Now that's not credible just coming from the pharma industry, it has to be a sort of approach from all the stakeholders in the community from patients´ organisations, raising awareness from key opinion leaders, raising awareness from the health authorities, understanding that need and of course we can support with material, with information, with unrestricted educational grants. There's a key position and role for each of these stakeholders, and it's weighted differently in each of the countries.

00:33:41.590 --> 00:33:51.520
ZSOFIA KESZTHELYI
You've mentioned several issues now up to this point, so I would just like to know what would be your strategy to solve these issues. How would you start?

00:33:53.990 --> 00:33:56.160
INDUSTRY EXPERT #2
You have to start in the country. Start small. The pull has to be there for you to action, from the patients… you have to raise awareness. This is this is what worked with AIDS, right? Raising awareness. Stopping the taboo. Often these diseases are taboo, you don't mention that your child has sickle cell disease, because then they'll have no friends because they're going to die by the time they're 15, so why bother… So stopping the taboo, understanding it, bringing the community together. As soon as the community comes together then the ideas come, then the infrastructure and then you can push up. If diagnosis isn't there, there's no point in having treatment. I mean, there's just no point because we don't know who to treat. Training specialized doctors to understand and be passionate about the disease. Everything, every mission needs a champion and if you haven't got champions on the patient and the physician side, we can push as much as we can from the delivery and the willingness, but if there's no opening and no understanding as to why we're pushing, they're just looking at going “I have no clue what you're talking about, [xxx]. Sickle cell disease is not a problem in this country. We don't

know what it is. We have no patients". Of course they have no patients if they don't have diagnosis in place. Of course there's no unmet need if they haven't identified the unmet need. So in developing countries we have to start by really building that awareness, identifying the unmet need. What evidence is missing? What evidence generation do we need? And I really believe that's where the story starts. And it doesn't help you know… it's like telling my daughter that she needs to clean her teeth… she's not gonna do it until she's had her first painful filling. And then she might realize that if she doesn't clean her teeth, it's gonna happen, right? Maybe I'm very old fashioned, I always end up reflecting back on my childhood in these countries where we don't understand, 99% of us and… you are from Hungary… 99% of Europe doesn't understand how Romania and Hungary work, right? Once you're out of Budapest and the bright lights. It's not just you know, we don't transport suburban Denmark into Hungary. And we can't transport suburban Zurich into Sub-Saharan Africa. I mean, if we sent a Dane, a very passionate Dane to Hungary to try and figure out how to start a clinic…They´d fail. Even if they spoke Hungarian, they would fail. Mentality is totally different. The upbringing, the infrastructure, the needs, the pathways… you have to look at the history of the country. And what's made the population evolve, the way the population has evolved is sure as hell not the same in Denmark as Hungary, right?

00:37:41.960 --> 00:37:42.550
ZSOFIA KESZTHELYI
For sure.

00:37:44.530 --> 00:37:49.420
INDUSTRY EXPERT #2
You know, I'm sorry to use Hungary, but I think we were both kind of Hungarians. It's allowed, right?

00:37:50.780 --> 00:37:57.510
ZSOFIA KESZTHELYI
That's for sure. Yeah alright, so starting small, starting local. That's really nice. We can hear a lot about the triple bottom line of companies. As you know, so they include the environmental, the social and financial sustainability. So do you think that your solution that you just mentioned could be sustainable considering all of these three aspects?

00:38:17.020 --> 00:38:18.300
INDUSTRY EXPERT #2
I think it's the only way. So let's start with the social. You have to start… and that's why we have our foundation. That's why we partner with so many of the organisations. We're known for Changing Diabetes in Children, Cities Changing Diabetes, driving changes… our new logo. We don't change anymore. We drive change. Our aim is to provide sustainable access to treatment and care, and therefore I think you have to start small. But there's a business involved. You know you have to have a business in order to be able to support the foundations, everything else that goes with building from the bottom up. That doesn't make us evil. That just makes us a business. But I believe in very much with [xxx], we have a very strong ethic. If we even look at the structure of our shareholders… you know the majority shareholder is a research foundation. So there's always going to be a turnover of X percentage of our profit, of our top line goes back into research outside of [xxx], and inside [xxx] we do the same. So I think at that point, investing in research and the [xxx] Foundation, so the Fonden, also supports many-many projects. We just signed an agreement with India, it was in the press a few months ago, to really reach research and disease understanding in these countries. So there I think we're very strong. And it that sits under also the economic, so sets the sustainability. You know companies are not going to do very well if they give everything away. I mean ultimately, that's not sustainable. So we're a

business, fundamentally we´re a business. We have legacy products which do drive business. But if we keep investing in innovation, which is what the patients need and deserve then of course there has to be, you know, a rollover on the P&L. And I think with the environmental sustainability… you could look at it many ways and I don't think that's got much to do with access, nor specifically developing countries. I think that should be just an ethic because it's largely driven out of production. Those are our biggest sort of production sourcing and I think many companies are… socially and environmentally companies are going in this direction and [xxx] is one of them. I don't think it comes down to having to, you know, plant trees. We're going to make a bigger difference by changing our energy sources to be honest and materials that we use.

00:41:16.850 --> 00:41:22.590
ZSOFIA KESZTHELYI
When you say that we're a business, so we need to make money to bring money back to the foundation... Are you suggesting that the business should come from the developed countries or is it developing markets that we are exploring?

00:41:32.670 --> 00:41:33.490
INDUSTRY EXPERT #2
It's one business. I don't think anyone comes to the end and divides up what's being sold where and says what we can develop where… it's one business.

00:41:43.970 --> 00:41:49.440
ZSOFIA KESZTHELYI
I kind of meant, uh, differentiated pricing or tiered pricing.

00:41:49.740 --> 00:41:51.950
INDUSTRY EXPERT #2
But we have that anyway, and that's defined by the infrastructure of the country as well. Let's take Switzerland. [we] don't determine the price of a drug in Switzerland. The pricing authority does and they look at all the different countries and what the price of that drug is there, they look at the options and they come back to [xxx] and say here's your price. And every two years or every three years, they review the price of every single medication. Then we get a new price… and it's never higher. And if you look at the UK, haemophilia drugs are on a tender. So we can offer a price right? But that price is going to be different to Germany… So the pricing system is already massively tiered and in the US there´s a completely different infrastructure behind that price and how that works with the healthcare system. So price… it's not like we walk in and go “here, this is gonna cost X”. That may have historically been the case, but it's no way the case now, right? So there's already differentiated pricing across the world. And part of that is because of how the healthcare systems are designed and what that list price versus actual price has to support locally. There's many elements to pricing. You need a pricing expert on that one though.

00:43:49.410 --> 00:44:01.320
ZSOFIA KESZTHELYI
Right, I just have one very final question. So uhm, have you may be encountered a solution that you think is sustainable either in sickle cell disease or in other treatment areas?

00:44:06.360 --> 00:44:09.670
INDUSTRY EXPERT #2

I've mentioned a few though, haven't I? And I come back to these. If I look at GAVI, so the Global Access to Vaccines Initiative, where they work with the public private partnership all the way through the development of a drug and they work very strongly with WHO. They've got a model in place that works. But it requires all the partners to be heavily engaged. But I say it works, but they have to go country by country to figure out how it works. It's not like they say, here's the solution to vaccines, off you go. So I think there are more models in place. I don't think there can be one model. They can't be, and you know I come back to the success stories that 20 years ago we never thought possible. "Oh my God, HIV drugs are going to be too expensive. It's never gonna be accessible". Now you can get HIV drugs globally. You can get oncology treatment globally. You can have chemotherapy in different countries. It may not be the most modern, you may have to drive 10 hours to get it. So there are desperately great success stories out there, but there's not one… there isn't one size that fits all. So it is about being adaptable. It has to be locally suited and fit for purpose. Uhm, we can't swoop in and sort of solve the world's problems with one solution. We need to learn from what we see and sometimes big pharma… we're not very good at learning from outside. We just need to be better at it. So I definitely think it's doable. Do I know how? No. But if I did know how, I'd probably be out of a job. So maybe I should just keep thinking about it, right?

00:46:23.090 --> 00:46:30.040
ZSOFIA KESZTHELYI
Thank you so much. This was actually the end of our interview. Unless you have any questions.

00:46:31.020 --> 00:46:36.270
INDUSTRY EXPERT #2
No, that's fine. I hope I gave you what you needed.

00:46:35.440 --> 00:46:39.180
ZSOFIA KESZTHELYI
Yes, it's it was excellent hearing your thoughts. It's really great. Thank you so much.

00:50:40.050 --> 00:50:41.890
INDUSTRY EXPERT #2
No worries, Zsofia, ciao.

00:50:42.200 --> 00:50:42.780
ZSOFIA KESZTHELYI
Bye bye.

Interview title	Interview with Industry expert #1
Date, time	15 December 2021
Location	online

00:02:30.920 --> 00:02:34.270
ZSOFIA KESZTHELYI
Great. Do you have any questions before we begin?

00:02:34.420 --> 00:02:36.150
INDUSTRY EXPERT #1
No, let's just get started.

00:02:36.700 --> 00:02:43.620
ZSOFIA KESZTHELYI
Right then first thing first, could you please introduce what you do in one or two sentences?

00:02:44.530 --> 00:02:45.180
INDUSTRY EXPERT #1
Yes. I work with the access to our portfolio of products, so both pipeline and branded products.

00:03:09.620 --> 00:03:10.010
ZSOFIA KESZTHELYI
Right, so when you hear this phrase “access to pharmaceuticals”, what is the first thing that pops into your mind?

00:03:19.260 --> 00:03:44.980
INDUSTRY EXPERT #1
It's about the potential barriers for patients to get access to treatment, and that can be from a financial perspective, it can be from a more healthcare organization perspective. But overall, patients and how they have access and if not then the barriers that lies between access and the treatment.

00:03:46.420 --> 00:03:57.270
ZSOFIA KESZTHELYI
And if you think about patients anywhere in the world, so this doesn't have to be developing countries, what do you think their most important need is in terms of accessing pharmaceutical products? What is the first thing that they would say?

00:04:02.040 --> 00:04:29.020
INDUSTRY EXPERT #1
I think the important thing is to get the right product, so make sure that the patient has access to the product that they will benefit the most from. And I believe that would be on most patients minds that that that would be the priority. And then you can say, well it might be that they are in a situation where they where they live in a country where there is a big co-pay or they don't have an insurance, so they it's out of pocket everything. Or it's a more tax financed system where they have coverage and I think that plays into the considerations, how much they need to also think about the financial side of things when they think about the product that they need.

00:05:09.540 --> 00:05:16.350
ZSOFIA KESZTHELYI
OK, so the next question will be general in a sense that they don't have a specific treatment area in mind. Based on your experience, how is access to pharmaceuticals or a pharma supply chain different in the developing countries compared to the developed world?

00:05:30.500 --> 00:05:38.200
INDUSTRY EXPERT #1
Well, health care structure is different, so that plays a big role and in that sense that if basic health care is not in place, then the biggest priority is not other type of diseases, it's really basic hygiene, healthcare setup that makes sure that the most basic and simple things can be treated. And I think when you put that aside and that's a given, then you can start to focus on also the access to treatment in general. And

in developed countries, obviously the health care structure is in place, so they go directly into prioritization among a big amount of different diseases. And some are more politically steered on what disease areas to prioritize, but overall it's of course about how big of an unmet need is there to also guide that prioritization. And that's what I see from a Western countries for example. When the less developed countries, even when they have basic health care, they still struggle with a lot of other factors as well. And that means that again, health care is a priority to some degree, but there are also other aspects that plays into the government or decision making. And that's where you could say the limitations are in place because it's more on them, the patients themselves to try to find a way to get treatment and more advanced treatments you wouldn't see in the same way. Because it's again about how much is put aside from a governmental perspective to cover that treatment and how much would the patients be able to cover themselves. So, I think that's to me, the biggest difference.

00:08:03.470 --> 00:08:08.000
ZSOFIA KESZTHELYI
So if I understand you correctly, you believe that it's mostly a financial issue that is faced when accessing pharmaceuticals.

00:08:17.090 --> 00:08:17.840
INDUSTRY EXPERT #1
Yes. I think financial is definitely one of the aspects, but it's financial in the way that the payment channel is organized. So is it a tax finance system, is it insurance paid, is it out of pocket? These kind of ways of financing the treatment plays a big role from a patient perspective, but also from a societal perspective, because if you have this as a starting point, then of course there is also some prioritization involved in those aspects and again that's very much unmet need that drives that prioritization. And it's also the wealth in society and in less developed countries where there's less of funds to be allocated in general to healthcare. Then it's also where they need to look at "OK, what type of treatment can they then offer?" And it might not be the most innovative products they will get at first, they will get it over time, but as a start they might be in a situation where they still will try to get the treatment to the patient, but it's less innovative treatment so it's financial aspects and innovation.

00:10:15.770 --> 00:10:17.120
ZSOFIA KESZTHELYI
Do you see any aspects of what is a challenge in developing countries in terms of accessing pharmaceuticals? Anything else that you can think of?

00:10:30.850 --> 00:10:33.980
INDUSTRY EXPERT #1
No, I think it's again healthcare structure.

00:10:34.340 --> 00:10:34.750
ZSOFIA KESZTHELYI
OK. Do you think that there are differences in access among the different disease areas, or are these just general for all disease areas?

00:10:49.360 --> 00:11:02.580
INDUSTRY EXPERT #1
I think definitely there are differences. It's back to how costly it is compared to how big is the patient population. So it's back to understanding the budget impact from a payer perspective and also

combined with of course the unmet need. How big is the unmet need? How do you make the biggest impact from an improved health perspective by also providing access? So I think these two elements will be the key balancing points from a payer perspective, a politician perspective.

00:11:36.530 --> 00:11:52.050
ZSOFIA KESZTHELYI
OK, now I would like to ask you about sickle cell disease. I know that you're familiar with this disease area, so do you see or how would you characterize the access to treatment for sickle cell disease?

00:11:53.420 --> 00:11:54.500
INDUSTRY EXPERT #1
Well there has been quite some development to also broaden access to treatment for the patients with sickle cell, but there is no doubt that the prevalence of this disease is also in countries where in general they are challenged with health care structure. And in that sense they're still or patients are still challenged in those countries to get the access. And that's of course a bigger problem in the sense that even though companies would like to help, it might not be feasible to provide that treatment because of infrastructure. So you could say in those situations access to care in general is where we can all help but to treatment itself is more of a challenge.

00:13:12.160 --> 00:13:17.020
ZSOFIA KESZTHELYI
When you say infrastructure, are you referring to the healthcare system, as you mentioned before?

00:13:17.570 --> 00:13:47.720
INDUSTRY EXPERT #1
Yes, it's the healthcare system, are there clinics, are there doctors and nurses to help? Also can the patient get to the clinic, that's another part of infrastructure. So they might live far away or not have the resources to get to the clinic, to pay for the bus to get to the clinic, so there might be a lot of different circumstances in patients´ life that also plays a role, but for sure the healthcare itself is a big one there as well.

00:14:04.200 --> 00:14:05.630
ZSOFIA KESZTHELYI
Thank you. Then who do you think are the stakeholders or the most important players in this supply chain of providing access to pharmaceuticals?

00:14:17.100 --> 00:14:21.230
INDUSTRY EXPERT #1
So access to pharmaceuticals in general.

00:14:20.640 --> 00:14:24.680
ZSOFIA KESZTHELYI
In developing countries, so let's focus on developing countries now.

00:14:26.910 --> 00:14:44.260
INDUSTRY EXPERT #1
I think that governments are for sure playing a big role and understanding the needs from a patient perspective and the need for treatment to also really want to prioritize Then it's also organisations,

patient organizations and NGOs as well to help try also to give perspective and make sure that the disease is understood but also try to have a conversation about what does it take to get the treatment and make it available. There are different stakeholders there or you could say players that can help and also provide perspective. And then of course there's the pharma industry as well that can also be part in trying to create more awareness around the disease, around what matters with regards to treatment and also try to help find other ways to then make treatment available or to give access to care so it starts from different levels. I believe some of the less developed countries are "more developed" if you will than others and that of course also plays a role in once again, back to what we talked about before is basic healthcare in place, is infrastructure in place? Then even though they might not have a lot of resources, there is still opportunity to try to help. Where if these basic elements are not in place then it's really difficult and there we more or less start from scratch.

00:16:37.300 --> 00:16:46.150
ZSOFIA KESZTHELYI
Thank you for also mentioning the roles and what the different players need to do. How do you see the responsibilities of the different stakeholders?

00:16:48.310 --> 00:16:50.380
INDUSTRY EXPERT #1
Yeah, that's a good question. I think everybody has some responsibility here and you can say how the different stakeholders are involved also depends a lot on the market or the country I should say. I don't think there is a "one size fits all" plan here that can help in the same way or drive the same way. There might be certain programs or approaches that work for more countries than others, but in general, I think this is very much individual, country-specific things that matter and will play a role also in how we then can help. I think the government itself has the biggest role to make the decision whether or not this should be prioritized. If they can agree on that then of course it's back to how much they can do themselves. Or can they then reach out and have support from others? And in that sense next steps would then be to have health care organizations, also companies to try to find the right approach for that country or region to help. And I think that's again where if we can find a way to create an approach that benefits more then it's of course… that would be a good thing because it also takes time and resources to find a way for country by country. That's also not the most efficient way to do it, so it's about trying to find a way that makes the biggest impact. And here healthcare organizations and pharma companies of course play also a big role, but it starts with the government.

00:19:06.510 --> 00:19:18.220
ZSOFIA KESZTHELYI
Now that you mentioned several issues that we are facing, what would be your strategy to solve the issues? Or how would you start solving these issues?

00:19:19.300 --> 00:19:32.060
INDUSTRY EXPERT #1
I think it's important to understand the patients and what kind of situations they are in and what they face because we might have an idea, but we are not having all the insights from living with the disease in a specific country that might not be that developed. So I think it starts with the patients and the patient journey and understanding that and understanding what are the barriers for treatment. And based on that, then finding solutions or creating solutions that will hopefully have a good and broad impact also. So trying to reach as many as possible with these kind of initiatives that then would be identified.

00:20:20.740 --> 00:20:26.550
ZSOFIA KESZTHELYI
OK, so patients first and would you then go directly to the patients, or would you maybe go through some organizations? Or how do you imagine getting the patient voice heard?

00:20:39.980 --> 00:20:53.650
INDUSTRY EXPERT #1
I think it would be both. I think we definitely would need the patient voice to put ?? to the insights we would generate. But health care organizations have done a lot of great work in the past and are continuing to do that so it would be a shame not to also use that insight and knowledge to get a step ahead in how we can best approach it. But I would say that they probably also have been involving a lot of patients during their work and also seeing by themselves when they've been engaging to find ways to also help countries with their health care problems. So I think it's to receive more insights and knowledge around… and listening in to a patient because there's always a filter, and I think that's very useful to have, but I think overall having the healthcare organizations´ learnings would give a head start.

00:22:01.380 --> 00:22:05.210
ZSOFIA KESZTHELYI
Do you have the experience or maybe the impression that patients and people in general are knowledgeable about different diseases and how they can maybe advocate for themselves?

00:22:21.260 --> 00:22:22.910
INDUSTRY EXPERT #1
That's a very good question. I don't know really, I have to say. My thought would be that not all would have that insight. They might have family members who have suffered from the same disease and therefore also know more about it, but they might not know exactly what would be the best treatment or best way to approach it. So I think there is still also educational work to do to really make sure that they get more insights also into their own disease.

00:23:05.130 --> 00:23:31.560
ZSOFIA KESZTHELYI
I've also heard from some other experts that they find developing countries are very dependent on trust, so patients… and I think this is not just in developing countries but also everywhere else in the world… so the trust is the basic thing that you need to have for patients to be able to maybe accept your treatment options. How do you see this happening or how would you go around building this trust?

00:23:32.670 --> 00:23:33.210
INDUSTRY EXPERT #1
Well, I haven't worked so much directly with the patients, so in that sense I don't have any experience from that side, but on top of my head I think company reputation. Walking the talk for them to see that this is meant to be helpful and trying to really make a difference. I think it's important. And then of course again in countries where they might not know a doctor or have a closer relation to anybody from a healthcare perspective, I think that's where it's really difficult, because that's where they will trust and authority, which would be the doctor. But otherwise I would think trying to have them more involved in and getting to know the treaters, getting to know the health care organizations, associates that can also provide insights to the treatment and maybe also speaking to other patients who could be a bit of

an ambassador in sharing learnings and sharing insights because I think that could probably be a way where they think, “OK, they have had the same experience as I so they will be more insightful to the disease and hopefully also by that more trustworthy”. But to be honest I have absolutely no experience with that.

00:25:49.490 --> 00:25:51.690
ZSOFIA KESZTHELYI
No, that was a great answer. We can hear a lot about the triple bottom line of companies nowadays, so this includes the environmental, the social and the financial sustainability of a company´s operation. Do you think that the solution that you mentioned a couple of answers ago would be sustainable considering these three aspects?

00:26:20.940 --> 00:26:50.370
INDUSTRY EXPERT #1
That's again where we need to figure out the right approach. Because you're absolutely right, these three elements need to be taken into account and in that sense, I believe we can find a way to also make it sustainable, make a sustainable business that can support and help those patients who otherwise would not have access to treatment. I think what we need to realize is that we can't help everybody and we can't help them at once. But we can try to make a big impact and try to find a good solution that can hopefully help many to better lives and to also better treatments.

00:27:15.620 --> 00:27:16.070
ZSOFIA KESZTHELYI
OK great. And have you seen or encountered a solution that you think works really well, either an organization or program that you've seen in any market?

00:27:34.580 --> 00:28:03.880
INDUSTRY EXPERT #1
I've seen some programs that have been rolled out where there's been focus on affordability. So from that perspective, making sure that those patients would get access to treatment. And I've seen or heard about programs where it's been more building not so much around the financial piece but more around the support, so access to care around the treatment so that those patients who are suffering from the disease would still be also supported with the elements from a social perspective, from a financial as well, but more also from a societal perspective on making sure that they are still able to get to work, that they receive the medication that they need (so also the treatment is brought to them). It could be that it's about other aspects of health that need also to be in place. Exercise, for example to help build the better health and also hereby improve the general condition of the patient. So there are different ways of patient support programs that can be structured to accommodate patients in their daily lives, as well as of course the overall treatment. The drug is playing a big role, but there are other elements that also have big influence on the final outcome**.**

00:29:47.820 --> 00:30:08.590
ZSOFIA KESZTHELYI
From what you're saying, it seems to me that these programs are targeting one or another aspect of the same area, but there is no comprehensive program or approach that would kind of serve as an umbrella and include all of these together. Or is this misunderstood from my side?

00:30:08.890 --> 00:30:19.440
INDUSTRY EXPERT #1
No, I think to some extent you are right. I think it's both actually, it depends a bit again on the country and how the program is structured. So I've heard about some programs that actually try to have this umbrella approach. So really taking the holistic perspective of the patient into account and trying to support from different angles. And then there's others who are more focused on one element. So it varies a bit what is the approach. I would think that a more holistic approach would be the most beneficial for securing the long term outcomes at least, where you could say one focused on elements might more be beneficial to overcome one of the key barriers that is being tried to overcome as a starting point, being more of a short term or start up part. So I think yeah, the more holistic is doable, but for that the more you understand the patient and the journey, the better you can also support them in the longer term.

00:31:36.000 --> 00:31:49.770
ZSOFIA KESZTHELYI
Going back to sustainability, what do you think is a challenge in reaching the sustainability in developing countries of accessing pharmaceuticals I mean? So what are the challenges there?

00:31:54.080 --> 00:32:21.910
INDUSTRY EXPERT #1
Well, the challenges are again that they don't necessarily have the basics in place so that we can really make this work because there is too many other disturbing elements that need to be handled before you could say we can provide the treatment. So it's again about trying to balance elements of what's happening otherwise also and then trying also to provide the treatment. The challenges from a sustainability point of view is also about how do we make this a sustainable business? Because if we are not able to handle a sustainable business then it will be a short term focus where we provide something to those countries or those patients. Because if we are not also balancing the financial piece, then we will not have something to invest and also drive forward for new innovation and hereby also creating new opportunities for those patients longer term. So it's really about finding a way that is sustainable for both parties.

00:33:45.630 --> 00:33:51.530
ZSOFIA KESZTHELYI
Some researchers say that differential pricing could be a solution for this. Do you think it would solve this issue?

00:33:56.740 --> 00:34:08.190
INDUSTRY EXPERT #1
I think in some countries, no matter what price you put in, that would not be a feasible to handle for the patients. And I think also again, even if it's yeah, low, very low priced, it might not be that the product gets to the patient. So these two elements… again back to infrastructure, basic health care in place and governments also understanding or realizing this as a priority that needs to be in place. And when that's being set, then of course the price also plays a role. And in that sense that's where it's back to affordability programs and finding ways to then making sure that those patients they can afford to also pay.

00:35:02.760 --> 00:35:17.090
ZSOFIA KESZTHELYI

And I've read somewhere that it's a suggestion to lengthen the intellectual property rights so that pharmaceutical companies would have a longer patent. And then the excess benefit, the profit that they received from these lengthened patents could be turned back into affordability programs, or any kind of developing country projects that would help these countries. How do you view this option?

00:35:40.920 --> 00:35:46.870
INDUSTRY EXPERT #1
I think that´s an interesting thought, because again, when a company has a product going off patent, it´s an immediate impact on the profits, at least for some areas. And I think that's where you could say when you have products where you are having production set up for it and you have the knowledge also from working with that specific disease area and that specific product for long time it would benefit the patients if we could transfer that knowledge also into more focus on programmes instead of being challenged by potential competition due to loss of exclusivity, so I would think it would be a way to also try to move things towards less developed countries, specially also with production in mind. As I mentioned before, over time, the cost of production of course decrease also, and that means that it would also help with providing a more sustainable approach towards the less developed countries.

00:37:25.080 --> 00:37:42.090
ZSOFIA KESZTHELYI
Right, and do you think maybe building production facilities in these less developed countries would be an option? So maybe teaching them how the compound works and how it needs to be produced, and then they could produce it for themselves.

00:37:42.800 --> 00:38:01.210
INDUSTRY EXPERT #1
Yeah, we've seen some examples on that in the past, and I think that's again, instead of giving the man a fish, you let the man learn how to fish. And I very much like that approach. I think that's where it's again creating an opportunity for the country to take ownership. First of all it creates more than only product, it creates also working places and jobs in that country. So there's more to bring to society by doing so, so it has a lot of positive elements. And the ownership itself, I think, is important. Again, back to the government recognizing that and wanting to prioritize that kind of disease is a key element to start with. So yeah, I think that could definitely in some situations be a solution.

00:38:55.800 --> 00:39:01.850
ZSOFIA KESZTHELYI
When you say in some situations, do you have a specific idea in mind when it would and when it would not work at all?

00:39:02.290 --> 00:39:31.450
INDUSTRY EXPERT #1
I think it's again I know I sound like a uh, repetition here but it I think it's about the decision to want to prioritize that from a government perspective. If society, politicians are not deciding that this has to be a priority, then nothing will drive that forward. Then there will be healthcare organizations, companies trying to help with donations maybe, but it will not be successful if it's lacking in ownership of trying to make things change.

00:39:44.350 --> 00:39:45.080
ZSOFIA KESZTHELYI

Excellent. OK, this was actually the end of my questions. So do you have anything else you feel like you would like to share?

00:39:54.730 --> 00:40:02.300
INDUSTRY EXPERT #1
I think we came around a lot of aspects and I think it was interesting questions to consider, I think it's covering what I also had in mind. It's showing that it's an emerging topic more and more and I think it's a really good thing that we keep talking about it because I think it's a lot of learnings still to come and we might have an idea of how we think things are. But again, back to patients and understanding what they face is really the important thing here I believe.

00:40:46.250 --> 00:40:46.710
ZSOFIA KESZTHELYI
Yes. Great, alright then thank you so much for this interview and for all your insights and examples, it was really exciting for me to listen to you. Thank you so much bye bye.

00:41:37.420 --> 00:41:37.930
INDUSTRY EXPERT #1
Bye.

Interview title	Interview with an Expert in access to care
Date, time	21 December 2021
Location	online

00:02:24.910 --> 00:02:30.640
ZSOFIA KESZTHELYI
OK, excellent. Could you introduce what you do in just one or two sentences?

00:02:32.340 --> 00:02:48.490
EXPERT IN ACCESS TO CARE
Yes, in our foundation, what we do is support programs around the world to improve access to care for people living with bleeding disorders in low and middle income countries. And we do this within 3 focus areas, so this is everything that has to do with diagnosis and registry and also with capacity building and then also with awareness and advocacy. And the projects that we support are usually one to three years of duration and what we encourage our partners locally in each of the countries is to involve any other stakeholders around them. Or we also can bring in from our vast international network, experts depending on the needs that our partners would have depending on the objectives of the projects.

00:03:30.810 --> 00:03:38.280
ZSOFIA KESZTHELYI
Could you please elaborate on these three arms that you just mentioned after the foundations work? So what does this entail?

00:03:39.180 --> 00:04:05.290
EXPERT IN ACCESS TO CARE
Yes, so what it entails is, first of all we believe that the diagnosis for a person living with a disease like haemophilia or other bleeding disorders is really crucial. It's really the start starting point of the

journey, because when you have a diagnosis, you know why it is that you have been suffering until now and then you can get into a system. A system of care, a system of support, a system of treatment and be part of a community, for example with the with a patient organisation. So that's why we invest quite a lot in diagnosis. And then also in registries. And this is important to mention that all the data is owned by our partners locally, we do not have any insights into the data. We fund the registries and we can get experts involved to set it up in the best possible way, but it's important that the local partners have data so that they can both a follow up on the on the patients clinically, but then also have data to show to their health authorities and advocate for better care and treatment. And this then goes into one of the other focus areas, the awareness and advocacy work. So actually, because it's a rare disease, haemophilia, in order to identify people who may have the condition, it's important to raise awareness of the condition. So our partners do a lot of awareness raising, they decide themselves where they want to do it, and who they would like to target. And then also advocating so advocating in front of the hospital directors, the health authorities in the country, and that is super important so that everything that they do, our partners, that this also is really systemically anchored and long term. So there's a long term solution and not just a quick fix. And then the third focus area, that's capacity building. And this is where we see like 2 streams within that. So on the one hand side, the medical capacity building, that's the training of health care workers, health care staff in the hospitals. And for haemophilia, you need and multidisciplinary care team. So that's like a haematologist, and any other doctors and nurses, physiotherapists, psychologists, dentists and so on. They all need to know about haemophilia, be trained so that they can take care of the patients. And then we also support the capacity building of the patients. So the patients as individuals, their family members, to know about the condition and what to do in case of the bleeding, how to prevent bleedings, where to go. And then also the patient organisation that is really the voice of the of the patients to represent the patients in front of the different groups that they interact with.

00:06:58.700 --> 00:07:02.460
ZSOFIA KESZTHELYI
OK sounds amazing, what you do actually. OK, so when you hear this phrase “access to care”, what is the first thing that pops into your mind?

00:07:13.190 --> 00:07:42.980
EXPERT IN ACCESS TO CARE
The first thing that pops into my mind is that the gap is not yet closed and so access to care is given in many countries of the world, but certainly not in most countries of the world and this is irrelevant to which condition we're talking about. I guess there are some conditions that have better access to care also in the low and middle income countries, but probably not as optimal as in some. And I think, we live in two countries, you in Denmark and me in Switzerland where we can say, well, optimal… what is optimal? I think there's always things to be improved of course, but we have access to care both from an accessibility point of view. So you know, also here, of course, if you live in the middle of the mountain, it would still not take you several hours to access care. And then of course also the affordability point of view is extremely important, that care is affordable for most people living let's say in Switzerland or in Denmark. And this is what is not given around the world.

00:08:40.210 --> 00:08:56.670
ZSOFIA KESZTHELYI
You mentioned that of in course low and middle income countries in a lot of places the care is not accessible. Do you think there is a wide range or a wide difference among the low and middle income countries? So is there a difference between Africa and Asia and I don't know, maybe South America even?

00:09:00.500 --> 00:09:13.070
EXPERT IN ACCESS TO CARE
Yes, yes yes. We definitely see a very big difference between the different countries. And when it comes to access to bleeding disorders care and treatment, there are a countries like Mexico where if you live in one of the bigger cities you have pretty good access to care and treatment today. But if you compare Mexico, just the capital cities with let's say Lesotho, there's a huge difference. But then if you go more into the rural areas of a country like Mexico or China, then it also looks very different than in the capital city or in the bigger cities.

00:09:55.840 --> 00:10:04.830
ZSOFIA KESZTHELYI
Is it only in comparison between rural areas and bigger cities or in comparison between for example, rural in Mexico and rural in China?

00:10:07.240 --> 00:10:09.800
EXPERT IN ACCESS TO CARE
That as well and I think for bleeding disorders care… it's specialized care. So of course you would not have it in every single health care point everywhere in the country, but I think if there can be a referral system established so that at least people can be identified also the ones living in the rural areas and then referred to a bigger centre, at least to second level or ideally third level care, that of course would be ideal. And this is definitely the issue still, so we have in countries like in Mexico and China, on the third level care hospitals the access to care is pretty good… not optimal, but pretty good. But then people are still travelling long distances to reach that care.

00:11:16.090 --> 00:11:22.550
ZSOFIA KESZTHELYI
OK, um, when you think about patients anywhere in the world so this doesn't have to be low and middle income countries, what do you think their most important thing is in terms of accessing care? What would be the first thing that they say?

00:11:34.930 --> 00:11:38.380
EXPERT IN ACCESS TO CARE
Well, I think that the first thing is probably the diagnosis, I mean knowing what they have. And if we say that they already know that, then it would be to access the treatment. And then one of the biggest issues is definitely also transportation because of the time that it takes. So if you have haemophilia you may not go to school and not be able to go to work for not only a day but several days, weeks and even months because you have to travel somewhere and you have to be hospitalized until you're back again and you're ready to take up your normal day-to-day and it can take a very long time. And I think we have seen examples and now I take an example from Mexico where in one of the key centres in the northern part of the country in Monterrey, they're taking care of paediatric population with haemophilia and in this centre they have really achieved that people with haemophilia almost don't need to visit the hospital. Because they have their treatment at home, they have been so well educated (both the kids and of course the parents or their caregivers), and also they are just a call away from the healthcare professionals at the centre who can most of the times guide them remotely. So they only really need to visit the centre when they have to come and pick up their medicine once in a while or when there is really something complicated that cannot be solved. And I think this really brings quality of life

because it makes it makes people be able to live their normal lives and be able to contribute to society and be part of society. So that totally breaks the vicious circle that we usually see with haemophilia.

00:14:10.160 --> 00:14:13.930
ZSOFIA KESZTHELYI
What is the vicious circle in your opinion in haemophilia?

00:14:14.840 --> 00:14:33.560
EXPERT IN ACCESS TO CARE
It has to do with the fact that if you don't have access to proper care, to treatment, then you suffer from bleedings and that means you're in pain, you have to stay at home and your family is touched by it. So if you are a child, at least one of your parents cannot maybe go to work, you have to be taken care of. Often that disrupts also families, so we often see mothers taking care of their kids on their own and fathers leaving the family and that leads to a vicious circle of poverty and thereby also less access to care, less access to treatment and so it's important to turn that wheel around. Because people with haemophilia can really live almost normal lives or the lives that they desire if they are taken well care of and treated.

00:15:18.560 --> 00:15:26.150
ZSOFIA KESZTHELYI
And if this model works so well in Monterrey, then why isn't this copied in other parts of the world?

00:15:27.910 --> 00:15:48.500
EXPERT IN ACCESS TO CARE
Yeah, that's a good question… So we are sharing the story from Monterrey with the world. And there are other examples like those. I think what is extremely important is to have a really, really dedicated healthcare professional team. These people, they go way beyond their duty and this is something that we see in many places around the world, when it comes to haemophilia. They know the families, they know the patients, they know their lives and they accompany them throughout their lives so they become somehow like family. And I think it's this extreme dedication and commitment that is there from the healthcare professional team in this specific case of Monterrey… but then of course also the availability of the treatment. So this centre only really was able to create all that infrastructure of care, having the team trained and organize all of that when the state had also started providing treatment. So that patients could also come and get their treatment. There are of course other things that you can do also when you don't have treatments to prevent bleeding… with education to know really what to do so that you prevent the complications at least of treatment or when you have little treatment to treat the bleedings that are really severe. But there are several puzzle pieces that need to come together. And you definitely also need to have some strong leadership. And this is definitely the case in this centre.

00:17:37.440 --> 00:17:57.790
ZSOFIA KESZTHELYI
So now you mentioned a lot of good things and I would like to go back to the issues a little bit. So in the next question please tell me if you don't feel like you have the right experience in terms of the pharma, but I think you do actually so… How do you think the pharma supply chain or the care supply chain is different in developing countries compared to the developed world? So if you think about the different players in the supply chain…

00:18:14.580 --> 00:20:38.480
EXPERT IN ACCESS TO CARE
I do believe that sometimes maybe there's not a clear referral system… and we had this this issue in Kenya, where we have supported the Kenya Haemophilia Association to establish several centres and at that time there were four or five centres across the country. And we involved an expert who supported them in actually creating what would be the ideal referral system so that people don't fall in between the different points of care within the system and so no matter where you live you have a process to be directed to the next level of care and that it doesn't take a lot of time and that it also doesn't cost the people that much, and I think this is something that needs to be optimized definitely. Ideally you would have the care infrastructure everywhere spread around the country, but you also have to be realistic with the resources that these countries have. So how to make it possible that no matter if you live in e.g. Brazil in the middle of the Amazon, you can access care or you can get in contact with, through telemedicine or whatever way, get the care that you need. Uh, so really sort of thinking about these pathways that the patients have to go through. First of all to get diagnosis, and I think this is really one of the biggest issues still in developing countries, in low and middle income countries. Then once you're diagnosed, then everything else is easier to fix. But I think the diagnosis part is definitely one that that needs to be looked into. So how to get to an early diagnosis? Because the earlier you would you diagnose the condition then you can also take care of it, treat it and the outcomes will be better for the rest of the life of the patient.

00:20:40.540 --> 00:20:49.230
ZSOFIA KESZTHELYI
And why do you think there's differences there? So what is the issue behind this problem in the referral system?

00:20:51.680 --> 00:21:00.020
EXPERT IN ACCESS TO CARE
It's probably a lack of resources. There are so many things that the health care system needs to take care of and of course, there are some priorities that you need to decide on. But this is where I think it's important that, for example, there's a strong patient organisation that really advocates for the importance of also offering current treatment to the people that have a rare disease that maybe are not the big numbers or the ones where the government can say we have saved millions of lives or 100 thousands or 10 thousands of lives, but that these people are also part of the health care agenda. I think the issue doesn't come only from the bleeding disorders angle. It's really a bigger systematic issue. And of course on the treatment side, definitely the cost of the treatment is a huge burden. Then there are more specific things like for treatment with haemophilia, it has to be stored at a certain temperature. Or there are some solutions now that don't need that, but then they're too costly to be afforded by these countries. You also need to know how to infuse the treatment, it's not like it is and oral and you can just take a medication and swallow it and then it works. So there's still several barriers both in the in the referral system, and also in the access to knowledge and well trained health care professionals and that they can be trained in their countries and don't need to rely on training from abroad. And then of course also the treatment itself. I get very excited when I hear that there may be an oral solution eventually for people with haemophilia, that would make a huge difference. And of course what I hope is that it is at an affordable price. So that also low and middle income countries can afford it.

00:23:38.350 --> 00:23:44.760
ZSOFIA KESZTHELYI

I remember that the first time we spoke, you mentioned that you also work with sickle cell disease a little bit. How would you characterize the access to treatment for sickle cell disease?

00:23:56.760 --> 00:24:05.790
EXPERT IN ACCESS TO CARE
Yeah, I think I definitely don't know as much as with bleeding disorders. But I think that it's very similar in the sense that diagnosis is not yet where it should be and there is a lot of movement to do new-born screening, which is crucial because as with haemophilia, the earlier you diagnose it, the better. And so that is definitely their issue number one. And then of course, once people are diagnosed that they get treated, that they get everything that they need. And this is even more complex than haemophilia because you need different types of treatment. When you are a child you need some sort of treatment, but then when you grow older you need other kind of treatment and it can have an impact on so many different parts of your body that you need an even bigger multidisciplinary care team. You need access to so many different specialists depending on where it affects you at the most, or how many places of your body is affected so I think that's even more complex. And as with haemophilia, it's not that you need to have all these expert healthcare professionals there only to take care of the people with sickle cell disease, but like they have in the centre in Monterey this haematologist, she takes care of all kinds of haematological diseases, not only bleeding disorders. And then she has the orthopaedic surgeon, or the physiotherapist, and the other people that have their work in the hospital so they take care of also all kinds of diseases. But she has been able to get them to be part of the haemophilia clinic, they meet once per week, they look into cases, they work together and they are available, and they've been trained so they know about haemophilia and what to do. And this is what I also think is important for sickle cell disease that you have in the core that are the super experts, but then they can rely on a network of healthcare professionals that can then come in depending on the needs of each individual patient. And I think this is finding the right balance in terms of how much can you use what is already there and how much do you need to add.

00:26:56.200 --> 00:27:00.390
ZSOFIA KESZTHELYI
Do you mean in terms of healthcare professionals or?

00:27:01.280 --> 00:27:20.470
EXPERT IN ACCESS TO CARE
Both in terms of the healthcare professionals so the human resources, but then also the buildings, the clinics and how do you work in the most efficient way with the least resources possible but to reach an optimal care.

00:27:21.080 --> 00:27:21.670
ZSOFIA KESZTHELYI
I see. So we discussed some parts of the supply chain issues. Now I would like to ask you how you see the main players in the supply chain in low and middle income countries. So who are the main or the key suppliers or stakeholders in this chain?

00:27:50.840 --> 00:28:12.080
EXPERT IN ACCESS TO CARE
Um, well, I think the ones who are in the front really taking care of people with haemophilia are the doctors and nurses, and the medical staff, but then they need to have a lot of support and buy-in from their hospital authorities, like the director and there are probably some levels in between depending on

the size of the of the hospital and the hierarchies that they have. So I think this is what we see that the haematologists need to be not just haematologist. They don't need to "just" be able to take care of the patients and be able to offer them the clinical care that they need and the treatment and all of that. But they need to be negotiators. They need to be advocates, they need to be able to deal with all kinds of stakeholders so upwards within their hospitals and then also within the whole healthcare system. And this is then quite complex in most of the cases. So what we and also our partners are doing in some countries is also looking into getting haemophilia and sickle cell under the non-communicable disease programme of a given Minister of Health of a given country. Because the NCD programs are getting more attention and haemophilia and sickle cell disease are NCDs, they're just more of the neglected NCDs. So trying to really find ways in positioning these rare diseases…. I mean, sickle cell is not as rare, depending on where you are… on the right channels. So there are decision makers in these healthcare systems that of course don't know anything or very little about the diseases themselves, so these haematologists together with the patients, the patient advocates, the organizations, they need to educate the people in their system, so really identify (and this is what we also help them with), map out the different stakeholders that have some sort of decision power. It is in terms of distribution of health care workers´ resources, or budgets for treatment and also for the labs. So we support them with the purchasing for example the equipment that they may need, but then how are these labs maintained and the supply of reagents then also and sustained over time. So they need to then also identify who are the decision makers and in those regards to get their approvals and their commitments. And this is, where not everybody has those skills and the experience and expertise that it needs to be able to handle all of that and we do see some across the world that are extremely strong and we make them also share their experiences with others. And of course every country and even sometimes every state within the country functions in a different way, so you need to identify your own way through. But I think it's often also the case in some companies, when you have so many layers of hierarchy like you have somewhere in the bottom a super good idea or super good way of doing things, but until it comes through upwards and then afterwards can get downwards again to other parts of the organization, it takes a lot of time. So this is somehow our complex way of doing things in general in the world, both in companies and in the healthcare systems.

00:32:20.460 --> 00:32:28.510
ZSOFIA KESZTHELYI
And how do you see the pharmaceutical companies´ roles and responsibilities in finding a solution to these issues?

00:32:29.540 --> 00:32:59.830
EXPERT IN ACCESS TO CARE
I've been in contact with different companies also through the work that we do and I've seen a bit different approaches also and I think what I would encourage companies to do is really to tailor their support in whatever way it is (and their work in the end so that they can create a business) to the needs of the health care professionals, to the patients, to the countries´ systems. And that it is more complex than only thinking of the prescriber or the one decision maker here and there. And if supporting e.g. registries or something like that, is not just for the benefit of the company, but it has a lasting value, it has a lasting impact for the people that are using it in the different countries. So that it doesn't only just feed into a clinical trial or whatever that the company needs, but that it provides data to the people in the countries, in the treatment centres, in the places, in hospitals, in healthcare systems so that it really can generate evidence that can be used not only in the interest of the company, but also really in the interest of the local communities.

00:34:21.560 --> 00:34:22.080
ZSOFIA KESZTHELYI
Thank you. You mentioned before that you find it important that the healthcare professionals are trained locally and they don't have to rely on some external countries training them. Why do you think this is important and how would you do this?

00:34:40.510 --> 00:34:55.730
EXPERT IN ACCESS TO CARE
On a regional level this is also what we have been investing a lot in, is creating these hubs like training hubs. So within Latin America there are different centres in different countries that they can offer also training to other countries within the region. I think it's also important of course to see and learn from let's say if you are in Bolivia to get insights into how it looks like in the UK or wherever else, in the USA. But it's I think it's important that they can maybe also get trained by people who have gone through similar circumstances or challenges and can relate much more to the reality that they're going through. And there are countries where you cannot become a haematologist in that country, that specialization is just not offered. I think this is also something that is important because it's not only for bleeding disorders, there are other haematological disorders, diseases that have to be taken care of. So also this is something we we're supporting in Northern Myanmar where now it is possible to get the accreditation of, get all the training and the curriculum and so on, and it has been all established so that haematologists can get trained out of their own system. And it is important because the more you know, the more you are specialized, the better you'll be able to take care of the patients and to prepare the next generation. I mean, there's always the haematologists that have the whole experience and then need to train the students and they are the ones that will take care of the people with haemophilia in the next years.

00:36:50.060 --> 00:36:58.750
ZSOFIA KESZTHELYI
You mentioned several issues that you think are part of the systematic issue, so to say. Um, what would be your strategy to solve these issues?

00:37:05.110 --> 00:37:10.980
EXPERT IN ACCESS TO CARE
Well, I think the strategy that we have in the foundation is that we have a framework that we call the health care system framework which has 8 dimensions e.g., we evaluate health service delivery or how does the health workforce look like, how does the treatment look like, how does the governance look like, how the patient organisation and so on. And then really identifying where are the gaps within each of these streams. But they are all so interconnected so they all have somehow an impact on each other or rely also on each other. And then sort of their buyers really prioritize… and this is our local partners, this is not us doing that but our local partners then saying OK these are all the issues somehow mapped, including all the challenges and which of those are the most urgent ones, which of those should they prioritize and where do they see the biggest opportunities also to change things. And then sort of cluster those and address those. And of course I think not forgetting about how all of this is interconnected. And I think it's really about listening to the people who know the best or who know the most and if they don't know, then try to get people in who know and who can help at least with questions inspiring to get to the solutions. And this is also where one person doesn't fix everything, so you always need a diverse group of people who have different insights who then together can get many pieces of the puzzle together.

00:38:58.820 --> 00:39:08.430
ZSOFIA KESZTHELYI
The last time you mentioned the strategy that you are joining forces with different patient populations. So how does that look like? Can you please elaborate on that?

00:39:09.560 --> 00:39:15.740
EXPERT IN ACCESS TO CARE
Yes, exactly. So as I mentioned before, you cannot look at bleeding disorders in an isolated way within a system. So this is also where we are encouraging our partners, and actually the idea came from some of our partners who asked us if we could support them when they would be joining forces with other groups. And then we tested it, we piloted it and we saw how successful that was. And so I think this is where there's not one solution that fits all as our approaches in general, there's not just you know, you go and do ABC and then you'll be fine. So each and every country or group has to really define what are their key challenges and how can they get… maybe there are other groups that have similar challenges and how can they join forces to address those challenges. And this has been the example of working together with the sickle cell community for example in Kenya and Tanzania and in other African countries. They have very similar challenges, I think I mentioned a bit before, with diagnosis, with raising awareness, with advocacy, and the training of healthcare professionals. Some of the healthcare professionals, they are the same group of people, so they need to be trained on both diseases. Why not do that jointly instead of making these people travel to the capital city twice or more times to get trained for one thing and then for the other thing and then for the third. So trying to see where are these synergies and how can you do 1 + 1 to make three. And I think we are in the early stages and we're doing that both on a local level, our partners are trying to do that, so finding their local partners. And then we also as an organization are opening our ears and eyes and feelers to partner with the right global organizations that can bring more of those synergies with us to our local partners.

00:41:25.310 --> 00:41:35.660
ZSOFIA KESZTHELYI
And do you think this is sustainable from a point of view of social, environmental and also a financial perspective?

00:41:36.910 --> 00:41:57.180
EXPERT IN ACCESS TO CARE
Yes, definitely. I think if everybody just continues working in their own silo, you do waste resources, no matter which kind of resources we're talking about. And definitely for us, for example one partnership that we are now starting with a foundation that is active in the sickle cell space, they have a long experience in sickle cell disease and great expertise there. They have also their financial resources and we have our experience and expertise in haemophilia and our financial resources. And when we put this together, I definitely think that we can do more than what we had planned to do. And we can also just see it just by mapping the regions that each of our programs would be touching upon. By joining forces we will be reaching a bigger part of the geography than if we had done it on our own. And that has definitely also an impact both on the financial and human resources, on the social impact that we are creating, but certainly also on the on the environment. Because when you have to transport people and use plain, car or whatever and do it 10 times and you can do it maybe in 5 times or only twice because you are joining forces, you are not doing everything individually, it does have an impact definitely.

00:43:07.500 --> 00:43:08.290
ZSOFIA KESZTHELYI
Excellent.

00:43:07.730 --> 00:43:26.200
EXPERT IN ACCESS TO CARE
But of course there's also that it comes with a certain complexity as well, and where I think we all need to be open to see what is it that we have in common more than what differentiates us and how this is not just our own work, but how it is all of our work together and that this will be difficult, maybe to attribute it specifically like “this is what we did as one organization”. But “this is what all of us did as several organizations joining forces”.

00:43:49.520 --> 00:43:56.910
ZSOFIA KESZTHELYI
Have you already encountered some difficulties with joining forces? So were there any specific examples of hardships?

00:43:57.590 --> 00:44:01.770
EXPERT IN ACCESS TO CARE
Well, actually, I think we were expecting many more difficulties than we have now had, so it's actually been a very… I think there are more and more organizations thinking that way and well, we've also looked into many, many organizations, and then we have only approached the ones based on some criteria that we had, that we thought would be compatible also with what we're looking for. And it has been amazing to see the openness and just this somehow not selfish approach and I'm really thrilled to see how this is going and of course now we get into more the implementation phase, but I think when you are open to recognize the work of others and to also just not being territorial… I think that is very-very important. That you contribute to a bigger goal.

00:45:15.930 --> 00:45:28.140
ZSOFIA KESZTHELYI
I just have one final question. So what is the first goal of this joining forces in sickle cell disease and haemophilia? What is the first goal that you would like to achieve when you implement?

00:45:29.880 --> 00:45:59.550
EXPERT IN ACCESS TO CARE
The first goal is really to impact more people, doing that in a better way, in a more efficient way, and getting really better care to them by being able to advocate together, by raising awareness together, by training together, by doing things jointly, really reaching many more people than we would on our own.

00:46:00.130 --> 00:46:05.710
ZSOFIA KESZTHELYI
Oh, so this organizational partnership would be about both advocacy and training?

00:46:06.800 --> 00:46:09.720
EXPERT IN ACCESS TO CARE
Yes exactly, oh sorry, I'm just getting a call in here, so...

00:46:14.430 --> 00:46:21.020
ZSOFIA KESZTHELYI
Yeah, I think we are basically done, unless… do you have anything else to add that you would like to mention?

00:46:22.480 --> 00:46:51.810
EXPERT IN ACCESS TO CARE
No I think just that I see this in several sectors, so happenings are not only in the healthcare sector, but also in the educational sector… There's so many initiatives that have been running independently from each other and now are joining, merging. And I think this could be interesting also for the pharmaceutical industry. I mentioned it several, like 10 years ago in a meeting and people were very like "no, not joining forces with the competitor". And I think it depends on what it is for. I would definitely consider in which kind of initiatives it would actually be possible to join forces with a competitor and not seeing the competitor as a competitor in those of course, but as a partner.

00:47:18.810 --> 00:47:19.520
ZSOFIA KESZTHELYI
Why do you think…

00:47:25.510 --> 00:47:32.310
EXPERT IN ACCESS TO CARE
I do think that there's a lot of work that needs to be done, and that every pharmaceutical company does on its own, e.g. to advocate, to raise awareness and so on. But on that level, especially on raising awareness of the different conditions, of the need, for local governments to take care of these patients, why not do that jointly? I think it would have a much bigger impact. And also in advocating it's not that you're advocating for a specific product only, but you're advocating to change the system so that you can get your product in. And in that I think also for the healthcare professionals, the haematologist as an example… they are visited by the sales reps from that company, from that company, there all the time… And somehow, if there's a way to also make it more efficient for the healthcare professionals so that they can in one get a good overview of the different products… I know this is challenging, I mean, I don't say that it, you know, I'm not on that side of the work, but I'm just thinking… If we train on sickle cell and haemophilia even though we don't have really anything to do with sickle cell disease… or it comes to disabilities or orphan diseases or whatever. But we can offer both in one instead of wasting people's time. I think these are things that should be should be considered throughout the value chain also to pharma companies.

00:49:16.030 --> 00:49:22.160
ZSOFIA KESZTHELYI
Excellent thank you this was a very interesting thought. I haven't heard this from anyone so very exciting, yeah.

00:49:26.050 --> 00:49:32.510
EXPERT IN ACCESS TO CARE
Yeah, let's see. Let's see if… I think there are already movements towards that. But maybe somebody can be a bit bolder and I would hope that I could be [company] opening the doors to also others to join.

00:49:44.420 --> 00:49:44.670
ZSOFIA KESZTHELYI
That would be nice. Alright, thank you so much for this interview. I really enjoyed hearing your thoughts and ideas and what you do in the foundation. So many thanks again.

00:49:56.930 --> 00:50:14.410
EXPERT IN ACCESS TO CARE
Thank you also for your questions and let me know if you yes there's any addition that you would need in the next weeks and something you may. Yeah it may be crosses your mind sometime and I'm happy to just have a quick call or an email or something.

00:50:21.180 --> 00:50:22.450
ZSOFIA KESZTHELYI
Alright bye bye.

00:50:21.760 --> 00:50:25.450
EXPERT IN ACCESS TO CARE
You too take care, Zsofia. Bye bye, good luck with everything.

00:50:25.470 --> 00:50:26.360
ZSOFIA KESZTHELYI
Thank you.

00:50:28.080 --> 00:50:28.900
EXPERT IN ACCESS TO CARE
Bye.

Interview title	Interview with Medical doctor #2
Date, time	6 January 2022
Location	online

00:01:37.130 --> 00:01:49.730
Zsofia Keszthelyi
OK sounds good. Very good, then as a starter, could you please introduce yourself and what you do in just a couple of sentences?

00:01:50.930 --> 00:01:59.040
Medical doctor #2
Yeah, so thank you. My name is Doctor [XXX]. I'm a medical doctor and a lecturer based at the [XXX]. I teach hematology and blood transfusion related to the pathology and diseases associated with blood disorders. Other than that I also support private facilities, where I work as a consultant, and support aspects of care and quality in general. And then of course we also run this voluntary program for patients with bleeding disorders, and we do this closely with the rest of the team, including my colleague who is on board with us this evening.

00:02:42.990 --> 00:02:45.590
Zsofia Keszthelyi
What is this program about actually?

00:02:46.550 --> 00:02:55.990
Medical doctor #2
So the Bleeders (?) program is basically a program that looks specifically for patients with bleeding disorders. So if you come to Africa as a continent we have had a lot of challenges in terms of access to care, especially to disadvantaged groups, including hemophilia and other bleeding disorders. So there are very many reasons why this is the case. One is because Africa is full of infectious-related diseases, and so a lot of governments have tended to focus on communicable diseases at the expense of non-communicable diseases. Including others like sickle cell, which I know is of interest to you. So a lot of governments have tended to focus on infectious related disorders and so these non-communicable diseases have been left out. And so bleeders have been left out to the extent that care is absolutely nowhere. So we have patients who have been taken care of but cannot access care. So we have to try and close that gap by being the advocates for care and trying to struggle (?) with them as we move along.

00:04:03.410 --> 00:04:20.360
Zsofia Keszthelyi
Right I think you already started to touch upon the issues, but then my next question to you would be… can you tell me what the issues are in terms of accessing pharmaceuticals or accessing care in your country?

00:04:21.460 --> 00:04:51.570
Medical doctor #2
So let me start by saying that care begins from a diagnostic perspective. So if one has a disease that requires diagnosis at whatever level, access to diagnostics is a big challenge, so we don't have facilities that have capacity to diagnose. So if you're born with that disorder, you can only wait until the disorder starts complicating for you to access care. So we don't have mechanisms to actually identify disorders or even screen for disorders, so that capacity is not there. The second is that care is heavily limited to specific areas, so you might find a whole expansive region with possibly just a single facility providing care and so people have to travel long distances to seek care. And that is the reason why Kenya as our government decided to decentralize care to what we call counties so care has now been brought further down to people. And so every county can discuss their health needs and try to see where else to capacity build as a way of providing care closer to people. The other thing is, even where a disease has been diagnosed, the challenge is that we don't have enough experts to manage those disorders. So you would find that at the lower levels you have a smaller care (?) that cannot be able to manage specific conditions. So care is better at a higher level, which is ready and available so that again complicates the problem. The other issue is that if you looked at the pharmaceutical aspects, where medications have to be provided to manage a disorder. Either the drugs are not available, or if they are available they aren´t reachable because of cost implications or you have a disease that is complicated to the extent that you have to engage large amounts of pharmaceutical products to control and maintain the disease. So it makes care relatively expensive and since we are dealing with relatively poor and disadvantaged citizens, you find that people will just survive for as long as the disease is not killing them, they'll struggle with the complications. So these are some of the things that actually make care a bit inaccessible to the majority of people.

00:07:05.780 --> 00:07:26.430
Zsofia Keszthelyi
Let me just ask a couple of follow up questions about what you said. So you mentioned that there is no

proper diagnosis or a diagnostic procedure. Why is this so? Is this a lack of financials or lack of proper procedures in place? Or why is there no diagnostics or screening?

00:07:27.640 --> 00:07:58.550
Medical doctor #2
So these challenges are multifaceted. If you look at… so first of all for you to diagnose a disease, you need facilities, and the facilities could be physical facilities. And as I say it, you, you would find that an expansive region has one treatment facility, so even availability of our physical infrastructure is not available. The second is the personnel who can actually manage this diagnostics are not available. So you would have to train, you would have to look for the right expertise and it gets more complicated if the region is disadvantaged in terms of safety. If there is no security in an area then experts would hardly go there and so you would find that there are areas where you have congestion in terms of services while other areas are completely deficient because the personnel can actually not access or reach those particular regions. The other one is you might have equipment, but then the other accessories are missing. There is no power to move the machines, you don't have a maintenance contract for those equipment, you don't have reagents reaching those particular areas. And so you might have equipment that are just sitting there doing nothing and you don't even have mechanisms to monitor the performance of those particular equipment. So as I see it, the challenges may be multiple in nature and so part of the things that we attempt to do is to try and plug in and see where we can make some sense. And one of the things that we tried to do as a solution is we try to try to move specimens or move services in a certain direction. So you create a flow so that if a service is required in a specific area, you can take stuff… for example if it is about samples and then you move those specimens to specific areas where testing could be done, then results are relayed back and then just trying to use technology to manage their conditions at whatever level. And technology may include teleconferencing with patients wherever they are, trying to understand what the problems could be and managing them symptomatically, rather than using modern technology or methods of diagnosis. So we actually use symptomatic diagnosis rather than laboratory based on other aspects of diagnosis.

00:10:18.130 --> 00:10:34.460
Zsofia Keszthelyi
I see. Are there for example patient pathways or protocols in place? For example, if a child is born are there specific screenings that need to be done written down in a protocol?

00:10:35.360 --> 00:11:04.840
Medical doctor #2
It's a good question and this is something we were trying to tackle last month, while we were in Tanzania for patients with sickle cell and generally other inherited disorders. So again, you know this is a continent as I did mention, that is not heavily indulged, so even protocols may not necessarily be well made to include accesses in terms of screening for specific pathology. Remember, as I mentioned to you, a lot of governments are struggling and so there is no way you can make a process excessively expensive when you cannot even provide the bare minimums. So a lot of protocols are not necessarily available, and if they are available, it may just be mentioning you know a passing statement that may not necessarily even attract or create attention in a facility. So we don't actually have well prescribed screening programs and by extension, care gets limited to diagnosed patients.

00:11:43.480 --> 00:11:57.450
Zsofia Keszthelyi
You also mentioned that there are not enough experts in the field. Why's that? So is it a lack of education or is being a doctor not prestigious enough for people to go?

00:11:58.920 --> 00:12:21.500
Medical doctor #2
No. So being at doctor is a nice thing. You noticed that I've kept you waiting because we have to multitask. There's so much to be done, you know you are treating and then you're supposed to be attending a meeting and you're supposed to be managing some political issues. So basically being a doctor is quite prestigious. It's a good thing to do. It's a good thing to have, but the challenge is, training at doctor is expensive. So previously we had fewer training institutions, but lately we have in Kenya now several training institutions that are developing doctors and other clinical experts, including sub-specializations and things of that nature. But having said that, it's one thing to train, it's another thing to utilize that person. So you would find that we have a lot of doctors or clinicians who have not been absorbed by the government because the government is broke. It doesn't have money to pay these doctors. So you cannot engage them in areas where there is need. So people tend to travel, move out of the country and that causes brain drain. So people get trained, then instead of being utilized the government is unable to absorb them and so they will move out. And then we have regions where experts are few, quite disadvantaged areas. Especially we are dealing with the people who are nomads. You would hardly get these people going to school and so you may not get enough experts to manage site communities.
00:13:39.660 --> 00:13:48.630
Zsofia Keszthelyi
You mentioned that the government has decentralized the care. Do you think it works better this way that it's decentralized?

00:13:50.080 --> 00:14:19.810
Medical doctor #2
Truly speaking, the answer is yes, we've had enormous change in terms of availability of care, because every region looks at the needs within those particular areas, and you would see the populations demanding care. So if there are no facilities you would see now county governments or regional governments now trying to provide care to its citizens. That level of decentralization has really created change, the regions also are able to hire doctors based on their needs. They can hire experts and specialists based on needs and so care is getting a lot better and getting more improved. Those of us who have also plugged ourselves into processes that are voluntary, advocacy has also gotten better. And governments are now listening. So people are getting to hear about even disorders that initially were never known and so when we work with the different groups, different entities that also helps because then we can create some awareness and people can start availing care to patients in different parts of the country.

00:15:11.020 --> 00:15:35.760
Zsofia Keszthelyi
I've heard from some countries that the government actually decides about which doctor works where. So as a doctor you wouldn't have a say in which facility you would work in, but the government would tell you that you would need to go to this or that hospital. Is it this way in Kenya or are you free to choose wherever you want to work in the country?

00:15:36.620 --> 00:15:45.890
Medical doctor #2
So previously you know there were limited choices a doctor would have because you finish and you are posted to a specific area to then provide your services. And trust me, you would hardly have a choice. But lately that has changed so people have choices and the misfortune is that people tend to choose good areas. I mean, you want to choose an area where comforts are available, life is easy, and that disadvantages a lot of people. So this has greatly change as care got decentralized, people no longer move in different parts of the country. And if you have to move, you being there is timed because if I go to a community that I don't speak their language the moment they get their community member and then I'm as good as meant to be leaving (?). And this causes a bit of a disadvantage, especially to communities that may not be having specialized, trained individuals, but I think overall, I would say that this culture of forcing doctors to work in different places has stopped. It was good because you would hardly choose where to go. You would have to take your services where the government decides, but that of course has stopped since we went into regional types of government.

00:17:09.080 --> 00:17:15.420
Zsofia Keszthelyi
Thank you. Then you said that the drugs are not always available. Can you elaborate on this, so why is this so or what kind of drugs are we speaking about?

00:17:23.820 --> 00:17:31.340
Medical doctor #2
Basically in most developing countries, we have clustered medications. Such that you don't necessarily treat a patient based on their needs, you use clustered groups of drugs. The second thing is there are disorders that require certain types of medications. But you would find that those drugs are not readily available. So even if you prescribed, they are not there. So a lot of diseases, especially non-communicable diseases, may not necessarily be having all the drugs within the reach of the patients. For example, if I just picked sickle cell, hydroxyurea is a key drug that should be readily available. But unfortunately, the drug is not readily available to people, so you can prescribe, but it is not there. The other thing is, if you looked at hemophilia for example and other bleeding disorders, the drugs are not available to patients through the counter. You would have to wait for a donation for you to access treatment. So drugs are actually a luxury for certain diseases either because they're too expensive or the government has just not invested in those drugs. Some other drugs have also not been approved for use in our countries, so even if I drug was to be availed, they are not approved for use in those countries, including in Kenya. There are drugs that have not been approved for use. So even if it is readily available across another country, they may be restricted in our country. So those are the challenges on drugs.

00:19:16.580 --> 00:19:20.750
Zsofia Keszthelyi
Are there also challenges you're facing in terms of infrastructure?

00:19:22.390 --> 00:19:29.300
Medical doctor #2
Infrastructure, I think is a key issue. As I started off, you hardly get adequate infrastructure in many places, and if it is available, it may just be very basic. It may not be able to accommodate the kind of care you would want to provide in an area. So yes, infrastructure is highly prohibitive.

00:19:51.420 --> 00:20:00.710
Zsofia Keszthelyi
Sorry, I actually meant the infrastructure of transportation of drugs.

00:20:01.010 --> 00:20:05.330
Medical doctor #2
No, no I don't think that is a big problem. We have a good network for transportation.

00:20:05.950 --> 00:20:12.660
Zsofia Keszthelyi
OK, excellent. Is this true even for rural areas so rural hospitals?

00:20:13.720 --> 00:20:19.930
Medical doctor #2
Yes, I would say yes, because we have had very good infrastructure from the time we decentralized our governance. A lot of places have actually improved in terms of physical infrastructure. Roads are passable. People can move around, they have different means to move around. So movement is not a big hurdle, it's more on the availability of other modalities of care rather than the transportation as a hindrance.

00:20:44.580 --> 00:20:54.060
Zsofia Keszthelyi
Do you have an overview of how the government is planning the purchase of different drugs?

00:20:55.070 --> 00:21:00.980
Medical doctor #2
So I'll tell you, this is heavily dependent on the level of advocacy. So the government has means of identifying essential drugs and we have an essential drugs list, but the challenge is it may be inconclusive so people have to keep pushing to have different drugs added in that essential drug list because the government purchases based on the essential drugs list. So if we had a way of making sure that all the drugs are listed in in that particular platform, then I think the government could easily prioritize.

00:21:32.080 --> 00:21:46.840
Zsofia Keszthelyi
Mm-hmm, and is the government asking hospitals about their needs? So are you ever asked what is the drug that you need the most or that you would like to have more of?

00:21:47.970 --> 00:22:19.110
Medical doctor #2
So the government tries to pull as much information as possible, but again, remember people prescribe based on what they´re used to, so there´s still a lot of education to be done for drugs that may be new. And if a drug is not readily available, people give what is always available and so you need continuous education and sensitization, especially with the newer products so that then people can get used to those products and the government can start appreciating that these products are also required. And I'll tell you that there are diseases where even older products are not in use because they are not being used by anyone, and even newer products then would even be impossible to have. So yes, we have

information channel to the government on utility of drugs, but whatever is consumed highest is pegged on peoples practices rather than what may be newer science or newer products for use.

00:22:47.920 --> 00:23:17.940
Zsofia Keszthelyi
Uhm, so you already mentioned sickle cell disease and that would be one of my areas of interest. So you mentioned hydroxyurea that is normally prescribed. So can you tell me how is the treatment or care for sickle cell disease? Maybe like a patient pathway or how does it look like once you find that you have this disease?

00:23:20.010 --> 00:23:23.420
Medical doctor #2
So first of all, for you to be diagnosed takes forever. Because sickle cell presents with sudden symptoms that initially people would think you have malaria. You know yellowness of eyes in Africa is associated with parasites, malaria being one of them. So initially people start managing your for malaria. They'll start treating you for all sorts of things, and then they would pile you up with drugs that would literally poison you, especially drugs to replace iron. They would think you don't have enough iron because you have anemia. So basically you'll be mismanaged quite a bit lower downstream our treatment processes. So by the time you get diagnosed, you've actually literally been mismanaged. But once diagnosed, then people would tend to be very basic in terms of care. One is you know, enhance fluid intake, rehydration. And pain management, and they would also give you some antibiotics to try and take care of infections. Sometimes we start patients on hydroxyurea, but it is not always available. So at a bare minimum you start removing the challenges associated with the disease by protecting the patient a little bit. But then we also never give our patients drugs to remove excessive iron. Because the challenge with sickle cell is the breakdown of cells and that accumulates a lot of iron, so we hardly give these patients drugs for iron and the reason is we don't have capacity to look for amounts of iron in the body. You know the diagnostic components. Remember what I talked about, so even monitoring is a key problem and because the tests are expensive and not readily available, people would hardly help patients to remove the excess iron. Now, for patients that can afford, obviously you know you want to manage them appropriately. Prepare them for bone marrow transplants and even those transplants are done outside the country. Now lately we have newer methodologies, one including removing abnormal cells using what we call red cell exchange, but again, that is not usually there.

00:25:45.240 --> 00:25:48.830
Zsofia Keszthelyi
But is this not available in the country? Is this what you're saying?

00:25:49.320 --> 00:25:56.610
Medical doctor #2
So bone marrow transplants are not available. Red cell exchange is available in the bigger cities, but again, it's not always the norm.

00:25:57.880 --> 00:25:59.960
Zsofia Keszthelyi
Is this because it's just so expensive?

00:25:58.090 --> 00:25:58.350
Medical doctor #2
One is because the government has not given priority to it and the patients cannot afford it. Red cell exchange is about $1000, so that is not cheap at all.

00:26:10.220 --> 00:26:17.300
Zsofia Keszthelyi
Yeah yeah, but is the other treatment cheaper, so the drugs, are they cheaper?

00:26:18.430 --> 00:26:37.520
Medical doctor #2
Even the others are not any cheaper. Trust me, a lot of families are distorted, disintegrated, men have left families because of the challenges of costs. It's very expensive and they have to keep getting admitted all the time because of complications. So care is very expensive to these families.

00:26:38.550 --> 00:26:44.700
Zsofia Keszthelyi
And is this drug, hydroxyurea working well for all the patients?

00:26:45.910 --> 00:27:09.520
Medical doctor #2
I think for majority of the patients that we've ever prescribed, yes it works. The challenge is availability and continuity of the drugs, availability to different facilities, smaller facilities. I know that the company that does hydroxyurea is trying to bring it in to our industry to support the utility of hydroxyurea for patients in the country. But again, you know these are things to begin.

00:27:10.050 --> 00:27:13.020
Zsofia Keszthelyi
Sorry I couldn't catch… what are they trying to bring in?

00:27:13.360 --> 00:27:22.580
Medical doctor #2
They're trying to bring in the drug, but at the same time try to bring a register so that then you can be able to pull data for patients on hydroxyurea.

00:27:22.980 --> 00:27:27.610
Zsofia Keszthelyi
Uh-huh and do you find this a good thing to have a register?

00:27:28.140 --> 00:27:43.560
Medical doctor #2
Of course it's a good thing, but then it should not just be targeted to a specific drug, it should be a register that looks at other bits of data, so that then people can use data that is pulled as this drug is used.

00:27:44.610 --> 00:27:53.370
Zsofia Keszthelyi
Now that you are mentioning this, uhm, you also said that you are using some kind of technology, for example through phone conversations. Uhm, what is the technological level in the hospitals currently?

00:28:00.650 --> 00:28:07.050
Medical doctor #2
It is dependent on an individual. So a lot of us can do teleconferencing, we can train online, so a lot of Kenyans are actually now more familiar with the newer methodologies of communication. There are smartphones, people have computers. A lot of regions now can access computers, and people can actually talk and consult online, so even telemedicine is now setting in. Of course it may not be well established, but at least people are moving in those directions.

00:28:45.380 --> 00:28:59.840
Zsofia Keszthelyi
That's amazing. And so do I take this well that it's even available in the rural areas, so families from rural areas can they also join via Internet or phone?

00:28:59.240 --> 00:29:12.030
Medical doctor #2
Yes yes yes. Even rural homes can actually join via Internet. People can communicate from anywhere truly. People have smartphones even in the smallest of villages. So yes, you can communicate.

00:29:12.780 --> 00:29:24.480
Zsofia Keszthelyi
Great. Is there any other technology that is used in healthcare? I mean registries or any technological tools in the hospitals maybe?

00:29:26.080 --> 00:29:40.560
Medical doctor #2
Yeah, so one of the things that a lot of facilities have tended to do is to go soft. People are no longer writing on paper, so a lot of things are now going soft and that makes it easier for people to access information. People are also accessing information online. You know you can seek information even before you get care so you can Google and get information even before, so that that has also helped quite a bit. People are now more informed and I guess people also are demanding to be given reports from the clinicians and people are now starting to converse. You know it's not like before where doctors were assumed semi-Gods, so people are getting to know their rights.

00:30:17.580 --> 00:30:19.120
Zsofia Keszthelyi
That's really great. Uhm, right. So I think we discussed a lot of issues now and I would like to hear your thoughts about potential solutions. So what you find that these access problems could be solved? How do you think it should be solved?

00:30:39.560 --> 00:31:09.690
Medical doctor #2
So as I said, I think I've been talking while giving you some solutions in between for diagnostics. So different groups are trying to work with the different governments or regional governments to try and

support them. You know, bringing care closer to the people. So a few of us are accessing some of these regional governments, talking to them, discussing with them how to bring in care, but beyond that we try to encompass sustainability. Remember, you can bring in something new, but if there is no will to sustain then it is of no value. So these are discussions that we've been trying to do. The other one is, uh, advocacy using media, policymakers, we also go to community leaders, just trying to engage different community leaders, we also talk to religious leaders just to try and see whether we can make an impact. For scenarios where we think people have misunderstood diseases, we also try to educate and we use different mechanisms to do that. Sometimes we when we go to radio stations or TV stations, we talk about these diseases just to sensitize the general public. The other one is we petition governments. We actually go to parliaments and petition parliaments and say this disease requires attention, this disease needs funds to be allocated so we champion for budgets to be allocated to this disease. Those are some of the things… and then of course working with the different groups, different international groupings and supporters, funders. Just like we are working with the Novo Nordisk Haemophilia Foundation to support hemophilia and sickle cell. So yes, we use different groups and methods to avail care.

00:32:35.490 --> 00:32:43.500
Zsofia Keszthelyi
When you're saying sustainability, what do you mean? How is this solution sustainable?

00:32:44.190 --> 00:33:12.700
Medical doctor #2
So let's take for example, you brought in diagnostics. I can give you a machine, but the machine requires reagents, the machine requires personnel. So the facility has to commit to give personnel to be trained. The facility has to commit to buy reagents for sustainability in terms of testing, and then the doctors have to be educated to use the facility that has been availed. So you would teach them an order for tests, because now the tests are readily available rather than using a clinical acumen to treat a patient, so that is what I meant by sustainability.

00:33:16.490 --> 00:33:24.020
Zsofia Keszthelyi
OK, OK, and you also mentioned talking to religious leaders. Why is that beneficial?

00:33:24.810 --> 00:33:52.690
Medical doctor #2
Because they are influential. You must look for an entry point… you want to get someone who, when they talk, the community listens. So we use different avenues including religious leaders and people visit religious institutions on a regular basis, and so if you have a religious group supporting you to convey and communicate to their communities, the better for you.

00:33:54.590 --> 00:33:55.190
Zsofia Keszthelyi
I see. Can you speak about what you do with the Novo Nordisk Haemophilia Foundation? So how does this grouping between hemophilia and sickle cell disease work?

00:34:06.530 --> 00:34:30.310
Medical doctor #2
So what we did was for Novo Nordisk Haemophilia Foundation and Novo Nordisk Foundation in general… One of the things we decided to do was to try and merge the two diseases under the same

roof. Remember these are two inherited disorders. One is a bleeder, the other one is a clotter. Now when you want to develop capacity for a clinician, if you just went with one disease, hemophilia is not always the common problem. But a doctor´s time can be better spent with a sickler because there are more sicklers in the country. So when you capacity build a clinician to manage a sickler and you capacity build them to also manage a hemophilic, you use that clinician better. The second thing is you can also use other specialists. For example, the labs can be developed to manage both disease entities and so there´s better utility of services and the personnel within a facility. You would hardly get a clinic closed because it's only for hemophilia. When you know that you have sicklers in that clinic and the clinic is busy then you almost guarantee a hemophilic service because the clinician is there. So the whole intention was to try and use a common disease to support a less common disease.

00:35:32.950 --> 00:35:44.180
Zsofia Keszthelyi
Makes sense, yeah, have you may be partnered with other countries to maybe negotiate with pharmaceutical companies or anything like that?

00:35:44.940 --> 00:35:58.900
Medical doctor #2
So I'm not very good in negotiating with pharmaceuticals, but we negotiate with them to discuss aspects of care. Of course if they are willing to provide the medicines, that would be nice. I have attempted to negotiate with our few, but a lot of times we don't make much progress because either the government has to allocate some funds or things of that kind. We've also recommended to some to donate through different bodies like World Federation of Hemophilia. There we have local company representatives that can also bring in the drugs, but when you do that then you want to negotiate with the government to waive taxes. When these drugs are given by the pharmaceutical companies. Question is for how long can this pharmaceutical companies give you the product? So you must start engaging the government for sustainability purposes.

00:36:44.380 --> 00:36:52.950
Zsofia Keszthelyi
Do you think that drug donations would solve a lot of issues in terms of accessing care?

00:36:53.590 --> 00:36:59.900
Medical doctor #2
I don't think that is a good solution, it's a very short term, quite myopic approach to care, because unless you have a sustained process, donations may not be the way to go. I would only say donations are to stimulate and make people realize that there are products that can be used. So this is just to sensitize people about the availability of medications. But it should not be the norm that donation should be the ultimate process to availability of pharmaceuticals.

00:37:29.080 --> 00:37:37.770
Zsofia Keszthelyi
What would you think about a solution of maybe let's say Kenya producing their own generic drugs with the help of other pharmaceutical companies, maybe?

00:37:43.890 --> 00:37:51.670
Medical doctor #2
Truly speaking, I think that would be the ultimate… that would be a nice thing to have. If we ever get

there, that would be great. If we have mechanisms to just manage and manipulate drugs that´s even better for us.

00:37:59.580 --> 00:38:05.190
Zsofia Keszthelyi
And what do you think this would require? So what are the steps to get to this point?

00:38:06.430 --> 00:38:29.050
Medical doctor #2
So the market is available, it is just the companies to be guaranteed that they can come into such a country and invest and still get returns for their investments and be secured or be guaranteed of safety and security because that is what always causes a problem. So if those guarantees are made then you know people come and invest.

00:38:29.860 --> 00:38:40.790
Zsofia Keszthelyi
So do you think that was or that is the reason that the safety and security is not there? That's the reason that companies haven't come to these countries yet?

00:38:41.970 --> 00:38:55.970
Medical doctor #2
I think the problems are bigger than what I'm saying, because there's the politics, there are interests, there are people who do wish this continent never grew, so they would rather keep donating and you know… just misusing this continent as much as they can. Not because… you see if Kenya wants to be safe, a lot of countries can push Kenya to have safety. And when those countries, the bigger brothers… if the bigger brothers, say Kenya, you must be safe, we will always be safe. And people can be boxed into some level of safety. But you see, it is the same people who create insecurity. You know the continent is full of resources that people would want to rip, so they'll create as much insecurity while they're taking whatever they want to take in the background. So I think this is a bigger problem than what I'm actually saying, and of course, you know there must be some good political will for people to come and invest, including creating good investment environments. People are going to Rwanda… what is special in Rwanda is just because the political environment is good for investors and the process of initiating a business and the bureaucracies have been limited. So all these are things that politically speaking can be amended to suit progress and development, especially within the pharmaceutical world.

00:40:15.770 --> 00:40:26.700
Zsofia Keszthelyi
If I may ask a more sensitive question because I've heard it from some of the respondents so far. So what is the corruption situation in your country?

00:40:27.790 --> 00:40:55.720
Medical doctor #2
So we are getting better because people now can speak, people are vocal. If you came to me with corrupt intentions, I can take you to court. So our corruption index is getting lower, it's getting better. So corruption is not always the norm. People want to be given a service. Of course we are not saying it´s completely eliminated, but it is much reduced so it's much, much better.

00:40:56.390 --> 00:41:10.740
Zsofia Keszthelyi
That's really good to hear. And then as we spoke about technologies, do you have any other ideas how technology could be used to improve the care in the country?

00:41:11.870 --> 00:41:41.340
Medical doctor #2
Yes, so telemedicine is for me going to be a key solution to a lot of problems if we all engaged wherever you are just like we're having a conversation with you. If you are a doctor, they give you a case. You should be able to help me manage that case. So I think care is going to improve even as we move along and with these new modalities of managing patients I think things are going to improve. We have E-pharmacy. You don't have to keep moving around, you can just order drugs, prescribe, send to pharmacies and someone delivers the drugs to your house. You know we have methods of paying, so there are many new technologies that are actually going to change care overall. People are now getting monitors, you know, taken to their houses. So basically there's so much change that can make care much more friendly and accessible to a bigger population regardless of where people are. So my assumption is that these new methods of care will actually improve the quality of care that we give to our patients.

00:42:23.530 --> 00:42:27.390
Zsofia Keszthelyi
Is it because you can reach more patients or?

00:42:26.840 --> 00:42:57.240
Medical doctor #2
One is you can reach more patients, you can serve more patients, you have a much more balanced program. So if I know that I have 20 patients to see, I would schedule my time appropriately, compared to a scenario where people are just popping in, popping out and there's no order. And you can also determine the amount of need if you have data. So this also helps us to pull data and understand better how people are taking care of themselves wherever they are.

00:42:58.130 --> 00:43:03.590
Zsofia Keszthelyi
Have these technological solutions been accelerated by COVID-19?

00:43:04.320 --> 00:43:22.620
Medical doctor #2
Certainly, yes, COVID has made a lot of changes and we pray that… we don't want COVID to continue, but at least it has been a lot of changes in a lot of places and I think we can only hope for the best. Let this be a learning curve for all of us. So then then we can all support each other wherever we are.

00:43:23.320 --> 00:43:34.640
Zsofia Keszthelyi
Great. How was COVID-19 for you in your country? How was this perceived or what were the challenges there?

00:43:36.200 --> 00:44:06.130
Medical doctor #2
It came with a lot of scare before, but as usual, people care less about COVID compared to their stomachs. You know, yeah, why would you care about COVID when there's no food? So even when all these public regulations and restrictions were being put in place, people didn't care so much. People still needed to move because you would rather die from COVID than die from hunger. So for us, a lot of restrictions just never made logical sense, and so people are still moving around regardless. Right now nobody really cares whether you are in a mask or not. It's done more for the regulator rather than for the person. And this was just adding more costs to the individuals, but we thank God that COVID came. Some people may have lost lives, but not as much as we may have seen in other continents. But of course COVID killed quite a number of people.

00:44:36.800 --> 00:45:00.910
Zsofia Keszthelyi
I really haven't heard anything about African countries in terms of COVID, I think all the news that I've read was about the US and Europe and maybe Asia, but not Africa at all, so I really don't know anything, but was it also that like when you went into the hospital, did you see people with COVID everywhere and the masks and you stayed home and…?

00:45:00.770 --> 00:45:30.970
Medical doctor #2
So, so I'll tell you, the problem with us is when you got diagnosed with COVID, people are being taken to restricted centers so you know it became a stigmatized disease. And for us when you want to kill a disease quickly, you stigmatize it because they're not willing to come out to say “yes, I have COVID”, so we were not thinking outside the box on other methods of managing the disease. We were reacting by arresting people, taking them to seclusion sites, and so it became messy and the government could not manage obviously. They are thinking that by putting these people in isolated areas, they are controlling the disease. But that really never helped. The second thing is even from a diagnostic perspective, we didn´t have reagents, we didn't have equipment, we didn't have technology or personnel who could manage these tests. And so a few of us had to plunge ourselves into these process, try to understand what was going on, try to match what the others were doing, where we had regions you know, tried to see how to get specimens, and so even when the disease was getting stigmatized that few of us decided to just plunge ourselves into understanding the disease and supporting our people wherever we could.

00:46:21.440 --> 00:46:29.860
Zsofia Keszthelyi
So did this hinder other curative therapies so other diseases… were they neglected because of COVID?

00:46:30.960 --> 00:46:56.740
Medical doctor #2
I mean, so that may not have been the case, but at least COVID overwhelmed the treatment facilities and so you would get people who are sick, but there's no space in the hospital. If someone needed oxygen there, you know, oxygen was nowhere. And suddenly people just realized that our facilities could be overrun by this disease. And you know, people just opted to either die at home or just keep quiet and die wherever you can die.

00:46:58.350 --> 00:47:01.350
Zsofia Keszthelyi
And how are you with the vaccination right now?

00:47:01.690 --> 00:47:07.130
Medical doctor #2
We are now at 10% of the general population.

00:47:06.600 --> 00:47:07.740
Zsofia Keszthelyi
Of the first dose?

00:47:08.610 --> 00:47:25.930
Medical doctor #2
No, full for vaccination. In fact, people are now starting their booster doses, I´ve had my booster myself. So yeah, we are now at booster doses. 10% of the population has been vaccinated and we hope we continue vaccinating more until there we have everyone vaccinated.

00:47:16.410 --> 00:47:16.840
Zsofia Keszthelyi
Nice. And do you receive donations of vaccinations, do you know?

00:47:33.520 --> 00:47:46.390
Medical doctor #2
So, so that may be a tough question for me, because we only hear that vaccinations have arrived, whether they are nations, whether they are bought, we don't know. Nobody talks about it. So you know, those are political issues. Nobody wants to tell you that they never spent money and that it was a free donation.

00:47:52.890 --> 00:48:10.360
Zsofia Keszthelyi
For sure, yeah, it's just I've heard of some countries in Europe, for example, that they wanted to donate a lot, but then I've heard that they somehow resigned from donations and it was just all a mess. I just wasn't sure. That's really interesting to see or hear your perspectives, because as I said, I haven't heard anything about Africa in general. Do you have anything else to add or any other solutions that you would like to mention? Any other topics?

00:48:35.140 --> 00:48:43.700
Medical doctor #2
I guess for now, I'll leave it at that and so that then I can attend to one or two other issues having to be completed and the day is coming to an end. But otherwise I'm grateful that we've had this conversation finally, I'm sorry that it took quite a while. I think my small brain could not remember so much, so bear with me. But overall, I think it has been good having this conversation with you.

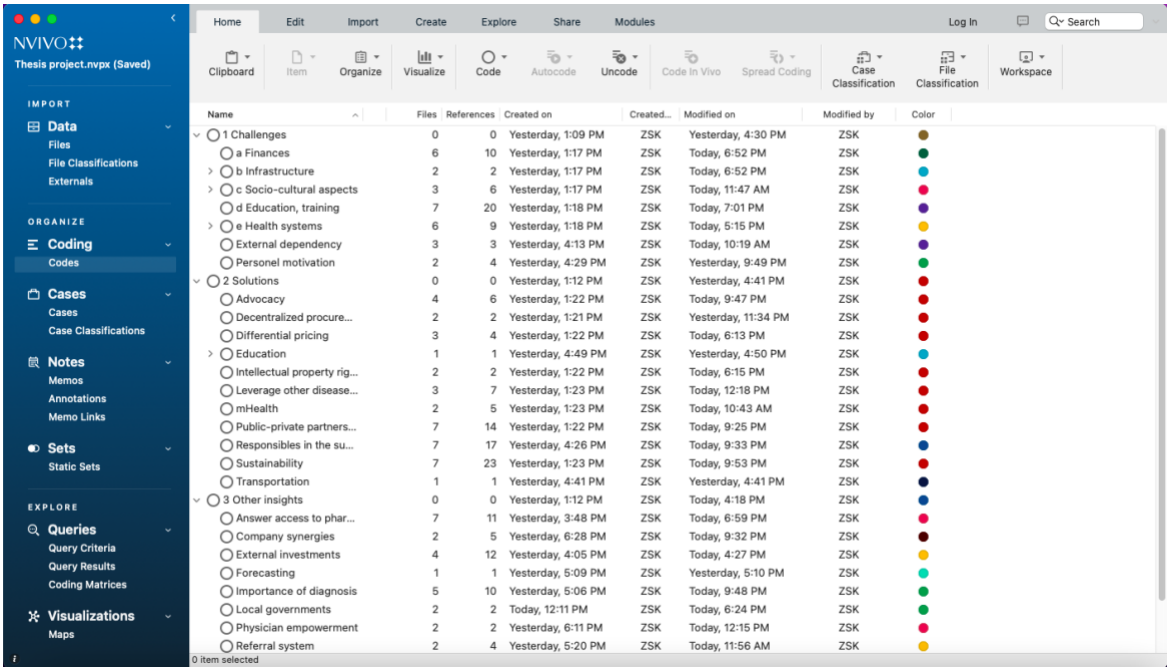
00:48:49.630 --> 00:48:50.740
Zsofia Keszthelyi
No, no problem. Yeah, it was very beneficial for me. I really enjoyed this conversation so much so really I'm very thankful for both of you to join and to agree to this interview. It was really fantastic and

you've helped a lot for my thesis. So thank you very much and I don't want to take more of your time so please go back to your work and thank you so much.

00:49:24.580 --> 00:49:26.620
Medical doctor #2
Thank you too and have a good evening.

00:49:27.050 --> 00:49:28.140
Zsofia Keszthelyi
You too bye bye.

Appendix E - NVivo coding



8 REFERENCES

Agarwal S., Perry H.B., Long L.-A., Labrique A.B. (2015). Evidence on feasibility and effective use of mHealth strategies by frontline health workers in developing countries: systematic review. *Trop Med Int Health*, vol. 20, pp. 1003–1014. doi:10.1111/tmi.12525

Ajepe, B. (2015). The opportunities and challenges for pharmaceutical supply chain in Nigeria/Africa. *Clinical Pharmacology & Biopharmaceutics*. https://www.omicsonline.org/proceedings/the-opportunities-and-challenges-for-pharmaceutical-supply-chain-in-nigeriaafrica-37433.html

Amankwa, B. & Bhatnagar, H. (2018). *Paving the Way for Access to Medicines in Ghana*. https://www.gh.undp.org/content/ghana/en/home/blog/2018/ghananationalmedicinepolicy.html

Andreassen, T. (2015). Patent funded access to medicines. *Developing World Bioethics*, vol. 15, pp. 152–161. doi:10.1111/dewb.12058

Asamoah, D., Abor, P., & Opare, M. (2011). An examination of pharmaceutical supply chain for artemisinin-based combination therapies in Ghana. *Management Research Review*, 34(7), pp. 790-809. DOI 10.1108/01409171111146689

Bals, L., & Tate, W. L. (2018). Sustainable Supply Chain Design in Social Businesses: Advancing the Theory of Supply Chain. *Journal of Business Logistics*, 39 (1), pp. 57-79. https://doi.org/10.1111/jbl.12172

Banton, C. (2020, October 26). *Third World.* https://www.investopedia.com/terms/t/third-world.asp

Bendul, J. C., Rosca, E., & Pivovarova, D. (2017). Sustainable supply chain models for base of the pyramid. Journal of Cleaner Production, vol. 162, pp. S107-S120. http://dx.doi.org/10.1016/j.jclepro.2016.11.001

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp. 77-101. doi: 10.1191/1478088706qp063oa

Breen, L. (2008). A preliminary examination of risk in the pharmaceutical supply chain (PSC) in the national health service (NHS), UK, *Journal of Service Science and Management*, vol. 1, pp. 193-9.

Bryman, A. & Bell, E. (2003). *Business Research Methods*. Oxford University Press

Cardoso, S.R., Barbosa-Póvoa, A.P., Relvas, S., & Novais, A.Q., (2015). Resilience metrics in the assessment of complex supply-chains performance operating under demand uncertainty. *Omega*, 56, pp. 53–73.

Chundru, S. (2015). Sustainable Development for the Healthcare Industry: Vantage Point from Emerging Economies. In P.A. Morgon (Ed.). *Sustainable Development for the Healthcare Industry* (pp. 85-98). Switzerland: Springer International Publishing

clinicaltrials.gov. (2020, January 31). *Study to Assess Safety and Impact of SelG1 With or Without Hydroxyurea Therapy in Sickle Cell Disease Patients With Pain Crises (SUSTAIN).* https://clinicaltrials.gov/ct2/show/study/NCT01895361

clinicaltrials.gov. (2022, January 11.). *Study of Two Doses of Crizanlizumab Versus Placebo in Adolescent and Adult Sickle Cell Disease Patients (STAND).* https://clinicaltrials.gov/ct2/show/NCT03814746?cond=Sickle+Cell+Disease&cntry=GH&draw=2&rank=6

Craighead, W.E. & Nemeroff, C.B. (Eds.). (2004). *The concise corsini encyclopedia of psychology and behavioral science*. John Wiley & Sons, Incorporated.

Dieleman, J.L., Schneider, M.T., Haakenstad, A., Singh, L., Sadat, N., Birger, M., Reynolds, A., Templin, T., Hamavid, H., Chapin, A., & Murray, C.J.L. (2016). Development assistance for health: past trends, associations, and the future of international financial flows for health. *The Lancet*, 387(10037), pp. 2536-2544. DOI: https://doi.org/10.1016/S0140-6736(16)30168-4

Ding, H., Liu, Q., & Zheng, L., (2016). Assessing the economic performance of an environmental sustainable supply chain in reducing environmental externalities. *European Journal of Operational Research*, 255, pp. 463–480.

ECA – Economic Commission for Africa. (2021). *Building competitive and resilient pharmaceutical value chains through the African Continental Free Trade Area*. Addis Ababa, Ethiopia: ECA Printing and Publishing Unit

Gunasundari, E. (2018). Best Practices in the Pharmaceutical Supply Chain Management. In H. Nozari & A. Szmelter (eds.) *Global Supply Chains in the Pharmaceutical Industry* (pp. 228–247). IGI Global. https://doi.org/10.4018/978-1-5225-5921-4.ch010

Hawley, J. (2020, August 8). *How Pharmaceutical Companies Price Their Drugs.* https://www.investopedia.com/articles/investing/020316/how-pharmaceutical-companies-price-their-drugs.asp

Hua, G., Cheng, T. C. E., & Wang, S. (2011). Managing carbon footprints in inventory management. *International Journal of Production Economics*, 132(2), 178–185. https://doi.org/10.1016/j.ijpe.2011.03.024

Khokhar, T. & Serajuddin, U. (2015, November 16). *Should we continue to use the term "developing world"?*. https://blogs.worldbank.org/opendata/should-we-continue-use-term-developing-world

Kvale, S. (2007a). Planning an interview study. In S. Kvale, *Qualitative Research kit: Doing interviews* (pp. 34-50). SAGE Publications

Kvale, S. (2007b). Conducting an interview. In S. Kvale, *Qualitative Research kit: Doing interviews* (pp. 52-66). SAGE Publications

Laokri, S. (2017). Collaborative Approaches and Policy Opportunities for Accelerated Progress toward Effective Disease Prevention, Care, and Control: Using the Case of Poverty Diseases to Explore Universal Access to Affordable Health Care. *Frontiers in Medicine,* 4(130). doi: 10.3389/fmed.2017.00130

Lee, J-Y & Hunt, P. (2012). Human Rights Responsibilities of Pharmaceutical Companies in Relation to Access to Medicines. *Journal of Law, Medicine & Ethics*, 40(2), pp. 220-233. DOI: https://doi.org/10.1111/j.1748-720X.2012.00660.x

LLC, The Health Strategies Consultancy. (2005). *Follow the Pill: Understanding the US Commercial Pharmacy Supply Chain*, Kaiser Family Foundation, Menlo Park, CA.

https://www.kff.org/wp-content/uploads/2013/01/follow-the-pill-understanding-the-u-s-commercial-pharmaceutical-supply-chain-report.pdf

London, T. & Hart, S.L. (2011). In T., London, S.L., Hart (Eds.), *Next Generation Business Strategies for the Base of the Pyramid: New Approaches for Building Mutual Value,* first ed. Pearson Education Inc, Upper Saddle River, NJ.

Mustaffa, N.H. & Potter, A. (2009) Healthcare supply chain management in Malaysia: A case study. Supply Chain Management. *An International Journal,* 14(3), pp. 234-243.

Novartis. (n.d.a) *Sickle Cell Disease*. https://www.novartis.com/diseases/sickle-cell-disease

Novartis. (n.d.b) *Expanding the Novartis Africa Sickle Cell Disease program.* https://www.reporting.novartis.com/novartis-in-society/strategic-areas/addressing-global-health-challenges/expanding-the-novartis-africa-sickle-cell-disease-program.html

PATH. (2015). *Diabetes Supplies: Are they there when needed?.* Seattle, WA, USA. https://path.azureedge.net/media/documents/NCD_nes_long_rpt.pdf

Porter, M. E. (1996). What is strategy?. *Harvard Business Review,* 74(6), pp. 61–78.

Porter, M. E. (2008). Value-Based Health Care Delivery. *Annals of Surgery,* 248(4), pp. 144-150.

Porter, M. E. (2010). What Is Value in Health Care?. *The New England Journal of Medicine,* 363(26), pp. 2477-2481.

Robinson, J.C., Ex, P., & Panteli, D. (2020, January 23). *Drug Price Moderation in Germany: Lessons for U.S. Reform Efforts.* https://www.commonwealthfund.org/publications/issue-briefs/2020/jan/drug-price-moderation-germany-lessons-us-reform-efforts

Sabherwal, R. & King, W. R. (1991). Towards a theory of strategic use of information resources: An inductive approach. *Information & Management*, 20(3), pp. 191–212.

Saunders, M., Lewis, P., & Thornhill, A. (2009). *Research methods for business students.* (5th ed.). Pearson Education Ltd.

Saunders, M., Lewis, P., & Thornhill, A. (2012). *Research methods for business students.* (6th ed.). Pearson Education Ltd.

Shah, N. (2004). Pharmaceutical supply chains: key issues and strategies for optimization. *Computers and Chemical Engineering*, 28, pp. 929–941.

Silverman, D. (2014). Research Ethics. In D. Silverman, *Interpreting Qualitative Data* (pp. 139-161). SAGE Publications

Silvestre, B. (2015). A had nut to crack! Implementing supply chain sustainability in an emerging economy. *Journal of Cleaner Production*, 96, pp. 171-181.

Soiferman, L. K. (2010). *Compare and Contrast Inductive and Deductive Research Approaches.* Online submission. Retrieved from https://files.eric.ed.gov/fulltext/ED542066.pdf

Stauffer, D. (2003, April 28). *Supply Chain Risk: Deal With It.* Harvard Business School. https://hbswk.hbs.edu/item/supply-chain-risk-deal-with-it

Steele, P., Subramanian, L., & Tolani, F. (2019). Interventions to Improve Access to Medicine in Developing Countries: Mapping WHO's Building Blocks and Supply Chain Functions. *Acta Scientific Pharmaceutical Sciences*, 3(7), pp. 111-120.

Stevens, H. & Huys, I. (2017). Innovative Approaches to Increase Access to Medicines in Developing Countries. *Frontiers in Medicine*, 4(218), pp. 1-6. doi: 10.3389/fmed.2017.00218

UN – United Nations. (n.d.). *Take Action for the Sustainable Development Goals.* https://www.un.org/sustainabledevelopment/sustainable-development-goals/

UN – United Nations. (2021). *The least developed countries in the post-COVID world: Learning from 50 years of experience*. New York, NY USA: United Nations Publications. https://unctad.org/system/files/official-document/ldc2021_en.pdf

UNDP. (2020). *COVID-19 and Human Development – Exploring Global Preparedness and Vulnerability.* https://datastudio.google.com/reporting/abd4128c-7d8d-4411-b49a-ac04ab074e69/page/QYXLB

Van Aken, J. E., Berends, H., & Van der Bij, H. (2012). *Problem solving in organizations: A methodological handbook for business and management students* (2nd ed.). Cambridge University Press

WHO – World Health Organization. (2006a). *Sickle-cell anaemia – Report by the Secretariat.* https://apps.who.int/iris/bitstream/handle/10665/20890/A59_9-en.pdf?sequence=1&isAllowed=y

WHO – World Health Organization. (2006b). *Management of birth defects and haemoglobin disorders: report of a joint WHO-March of Dimes Meeting*. https://apps.who.int/iris/bitstream/handle/10665/43587/9789241594929_eng.pdf

WHO – World Health Organization. (2018, July 17). *Be smart, Know about Sickle Cell Disease!*. https://www.afro.who.int/news/be-smart-know-about-sickle-cell-disease

Williams, O.D., Ooms, G., & Hill, P.S. (2015). Cautionary notes on a global tiered pricing framework for medicines. *American Journal of Public Health*, vol. 105, pp. 1290–1293. doi:10.2105/AJPH.2015.302554

WTO. (2017). *Understanding the WTO-Intellectual Property: Protection and Enforcement*. https://www.wto.org/english/thewto_e/whatis_e/tif_e/agrm7_e.htm

Zahiri, B., Zhuang, J., & Mohammadi, M. (2017). Toward an integrated sustainable-resilient supply chain: A pharmaceutical case study. *Transportation Research Part E*, 103, pp. 109–142.

Zhalechian, M., Tavakkoli-Moghaddam, R., Zahiri, B., & Mohammadi, M., (2016). Sustainable design of a closed-loop location-routing-inventory supply chain network under mixed uncertainty. *Transportation Research Part E: Logistics and Transportation Review*, 89, pp. 182–214.

Zhang, N.S., He, W., & Tan, P.S. (2008). Understanding local pharmaceutical supply chain visibility, *SIMTech Technical Reports*, 9(4), pp. 234-239.