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Faculty of Life Sciences
Masters Degree Public Health

Master Thesis

“Necessity, Concepts and Feasibility of Culturally
Tailored Diabetes Education for Migrants in the
Netherlands and the United Kingdom: A Qualitative
Study on Experts' Views”

Date of Submission:

December 19th, 2014

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Acknowledgments

All my thanks go to the people who believed in me and supported me throughout the process of writing my master thesis.

My family had been my biggest supporters, my life partner Ole and our daughter Iyla, my parents and siblings. Thanks for taking care of Iyla and your emotional support.

I would like to thank my two supervisors Prof. Dr. Färber and Prof. ret. Deneke, for your encouragement and your support. I am grateful for the regular communication, your understanding as well as your valuable input, peer reviews and suggestions on several chapters.

This master thesis arose from the SITD (“Entwicklung und Evaluation einer Schulung zur Förderung der Selbstmanagementkompetenz von illiteraten türkischstämmigen Diabetes Patienten“) project that was undertaken by the Centre for Psychosocial Medicine in cooperation with the department for General Medicine at the University Medical Centre Hamburg - Eppendorf (UKE) I would like to thank the SITD staff C. Mews, J. Wrede-Sach, B. Gül as well as Prof. Dr. med. M. Scherer and Dr. rer. hum. biol. N. Pohontsch for their support, the interesting discussions and the possibility for cooperation.

Aileen Sobeng Ashe, I thank you for your encouragement to move on when I doubted as well as for your help with the validation of my empirical data.

I further thank my readers, dear colleagues, friends and family who assisted me during the last year: Justine Tanoey, Ilana Cooper, Marianna Donlin, Ben Thomas, Paula Bialski and Lorna McHardy.

Special thanks to my entire interview partners who offered their time and expertise. Your willingness made this thesis possible.

Further, I thank all the experts who helped me with the recruitment of diabetes interventions, send me research papers, and contributed with their knowledge and cooperativeness.

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Abstract

Purpose: The aim of this study was to investigate experts' perspectives concerning necessity, concepts and feasibility of culturally tailored diabetes education for ethnic minority groups in the Netherlands and the United Kingdom.

Background: Prevalence rates of Type 2 Diabetes Mellitus (T2DM) are high, especially among under-served population groups including ethnic minority groups (EMGs). There has been increasing recognition that T2DM education programmes are critical to good diabetes self-management. Although studies have shown that disadvantaged population groups are less able to benefit from standard interventions, only a few culturally tailored diabetes interventions exist in the European region.

Methods: A comparative qualitative case study was carried out, that combines expert interviews and document analysis. Six semi-structured guideline-based interviews were conducted in the Netherlands and the United Kingdom. The generated data was analysed in the framework of qualitative content analysis.

Results: Four interventions in two countries were included. Findings showed that country-specific systems and decisions on a structural level have a strong impact on availability and implementation of culturally tailored diabetes education programmes.

In both countries challenges for implementation included cooperation with stakeholders, communication, organisational aspects, attendance, human resources, and financing. Building the intervention around empowerment, to focus on culturally sensitive communication, to train health professionals and to actively involve the target group was found to be conducive for successful implementation.

Conclusion: This study identified inter-country differences. Findings indicated consistent variables that are relevant to culturally sensitive education, although target groups differed. Overall, this study argues in favour of cultural tailoring, but highlights the risk of ethnicizing people during this process.

Keywords: Culturally tailored, diabetes education, ethnic minority groups, disadvantaged groups

Abbreviations and Acronyms

AWBZ	Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten)
BME	Black and ethnic minorities
BMI	Body Mass Index
CCAT	Cultural-Competent Assessment Tool
CQC	Care Quality Commission
DEP	Diabetes education programme
DSM	Diabetes self-management
EMGs	Ethnic minority groups
ENAR	European Network Against Racism
EU	European Union
EuroStat	European Statistics
GP	General Practitioner
HAW	University of Applied Sciences (Hochschule für angewandte Wissenschaften)
HCS	Health care system
HL	Health Literacy
HLC	Health Locus of Control
IDF	International Diabetes Federation
IDI	International Development Inventory
MAKSS	Multicultural Awareness/Knowledge/Skill Survey
MPH	Master of Public Health
NCD	Non-Communicable-Disease
NHS	National Health Service
NIC	National Insurance Contribution
NICE	National Institute for Health and Care Excellence
NL	The Netherlands
OECD	Organisation for Economic Co-operation and Development
PCT	Private Care Trust
PMI	Private Medical Insurance
PPI	Patient and Public Involvement
QCA	Qualitative Content Analysis
QRM	Qualitative Research Method

RTC	Randomised Controlled Trial
SA	South Asian
SES	Socio-economic Status
SITD	Entwicklung und Evaluation einer Schulung zur Förderung der Selbstmanagementkompetenz von illiteraten türkischstämmigen Diabetes Patienten
SDH	Social Determinants of Health
SHI	Social Health Insurance
T1DM	Diabetes mellitus Type 1
T2DM	Diabetes mellitus Type 2
UK	United Kingdom
UKE	University Medical Centre Hamburg-Eppendorf
UN	United Nation
US	United States
VHI	Voluntary Health Insurance
WHO	World Health Organisation

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Chapter 1: INTRODUCTION TO THE STUDY

1.1 Introduction

Diabetes is a serious and growing public health concern in Europe. In 2011, approximately 35 million people (aged 20-39 years) were estimated to have diabetes within the European Union (EU) (OECD, 2012, p.13). This number is expected to increase in the coming years. The International Diabetes Federation (IDF) predicted diabetes prevalence to rise to 43 million in 2030 (IDF, 2011a; OECD, 2012, p13).

There are two types of diabetes mellitus: type 1 (T1DM) affecting children and young adults who are genetically predisposed, and Type 2 (T2DM), affecting adults with “*well-defined biological and behavioural risk factors*” (Whiting, Unwin & Roglic, 2010, p.79) such as being overweight and having a sedentary lifestyle. Age and being overweight are two main risk factors for T2DM which are increasing in the EU population. European countries are experiencing a demographic change in age composition characterised by an increase in age and decrease in fertility rates. Hence, a further rise in the prevalence of T2DM in EU is expected (OECD, 2012).

Further, the present-day EU population is comprised of multiple ethnicities with diverse cultures and religions. Recent studies indicate that certain population characteristics such as specific population sub-groups like Ethnic Minority Groups (EMGs) and those with lower socio-economic status (SES) may aggravate the incidence of T2DM as they have a higher likelihood to acquire diabetes (Kofahl, Mnich, & Kalvelage, 2011, p.9; OECD, 2012, p.17; Oldroyd et al., 2005, p.487; Vissenberg et al., 2012, p.2).

SE factors that embrace levels of education, income, living conditions, occupation and access to information and care are unfavourable risks in acquiring T2DM (OECD, 2012, p.17; Vissenberg et al., 2012, p.2). To what extent SES, and aspects of lifestyle such as being overweight and physical inactivity contribute to higher prevalence rates among EMGs is still unclear. Apart from the extent of contribution both demographic variables and issues around ethnicity are compounded in immigrant populations leading to disadvantaged positions in society. As a result EMGs are among the most vulnerable members in the EU with respect to T2DM and its care.

According to Ujcic-Voortman’s findings (2009, p.511) on diabetes prevalence and risk factors among EMGs in the Netherlands (NL), T2DM prevalence rates are higher in Turkish and Moroccan immigrants than in the native white Dutch population. It is stated that the high numbers result only partly from lifestyle risk factors and disparities in demographics. Studies in the United Kingdom (UK) also confirm that T2DM prevalence is higher in EMGs including the South Asian (SA) population and underlying reasons are intertwined (Gholapa et al., 2011, p.45; Hawthorne et al.,

2008, p.3). Likewise, the NL and Germany detected significantly higher T2DM prevalence rates among Turkish immigrants (Kofahl et al., 2009, p.24). Interesting was the comparison to Turkey. Kofahl's study (2012, p.229) shows that prevalence rates in Turkey do not differ from other industrial countries, which supports the assumption that T2DM acquisition increases by SE factors in countries of immigration.

Although the risk factors of increased T2DM prevalence in EMGs remains partly unclear, there is transnational consistency that diabetic patients with a low SES including EMGs face various health burdens. They are disproportionately affected by T2DM, acquire the condition at a younger age, have an increased risk of late diagnosis, receive poorer treatment, and thus, present higher numbers of diabetes-related complications, increased mortality rates and are less able to self-manage the complex task of diabetes care (Hawthorne et al., 2008, p.3; Kunst, Stronks & Agyemang, 2011, p.106; OECD, 2012; Oldroyd et al., 2005, p.487; Vissenberg et al., 2012, p.2).

Diabetes Self-Management Skills (DSM) are crucial elements of diabetes care (Whiting, Unwin & Roglic, 2010, p.82). The multifactorial nature of DSM presupposes several abilities in order to control the chronic condition. A good understanding of the disease, treatment, behaviours and actions that influence the condition, and possible complications are preconditions for adequate diabetes management (OECD, 2012, p. 21). It should not be underestimated that these chronic condition put an enormous demand on diabetic patients every day, as well as on the health care system (HCS). In short, the diabetes epidemic affects the EU at every level including individuals, families, carers, employees and the economy because of its chronic nature. Thus, from an economic and individual perspective, good diabetes education is considered a cornerstone for self-management and the management of diabetes (OECD, 2012, p.21; Onwudiwe et al., 2011, p.30).

EMGs with a high-risk profile for T2DM are often the ones that present low self-management skills and benefit relatively little from Diabetes Education Programmes (DEPs) leading to health disparities (Hawthorne & Tomlinson, 1999 cited in Baradaran et al., 2006, p.2; Kofahl, 2011, p.9; Onwudiwe et al., 2011, p.30-31).

Several barriers to DSM for low SE groups and EMGs have been identified. These include low diabetes-related knowledge, lack of self-efficacy, low health literacy (HL), low level of empowerment, and the absence of diabetes-related social support (Onwudiwe et al., 2011 p.30; Rechel et al., 2011, p.4, Vissenberg et al., 2012, p.2).

Acknowledging both, that is the need of diabetes education and the societal and individual health burden of poorly or untreated T2DM among EMGs and the resulting health inequities, confirms the importance of culturally appropriate DEPs.

International literature (Greenhalgh et al., 1998 & Davies, 2006 cited in Stone et al., 2008 p.2; Rechel et al., 2011 p.6) and diabetes guidelines (NICE Guidelines: The management of T2DM, 2008) also recommend the provision of culturally sensitive DEP for EMGs.

The study in hand investigates diabetes interventions for the two largest EMGs in two European countries: the Turkish and Moroccan population in the NL and the SA population in the UK.

1.2 Motivation of Study

The motivation of this study stems from personal interest and experience working with vulnerable groups in community and health settings.

During the Master of Public Health (MPH) course I deepened my knowledge about several public health interventions and became acquainted with the Social Determinants of Health (SDH). The presence of health disparities between EMGs and the native white population became apparent during my international work experience in clinical settings. In light of this, I decided to investigate European countries and their approach to T2DM education for EMGs.

During the initial stages of my research, the gap between recognition of the requirement for cultural sensitive diabetes education and the availability of interventions became apparent. This was confirmed by the SITD (“Entwicklung und Evaluation einer Schulung zur Förderung der Selbstmanagementkompetenz von illiteraten türkischstämmigen Diabetes Patienten“) research project at the Centre for Psychosocial Medicine and the department for General Medicine at the University Medical Centre Hamburg-Eppendorf (UKE). The research project “Diabetes einfach schulen – Forschungsprojekt SITD” aims for the development, testing and evaluation of training material that is culturally sensitive, considers HL levels, and is tailored to target groups’ needs. The adapted material, as well as background information, will be available on a website to support health educators during delivery.

In close cooperation with the researchers¹ of the SITD project and the principal investigator² I discovered that interventions at a European level would be relevant to my research. Some European member states, including Germany, the NL and the UK have developed DEPs tailored for EMGs but they vary greatly concerning scientific evaluation, intervention approach, and implementation. Grounded on the insight of the SITD project and acknowledging their investigations in the German context, this study is intended to extend the current scientific knowledge by assessing European perspectives.

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² Prof. Dr. med. M. Scherer

This master thesis focuses on the exchange of experts' knowledge concerning necessity, concepts and feasibility of culturally tailored diabetes education for immigrants in the NL and the UK.

1.3 Research Question

This master thesis seeks to address the following research question and sub-questions.

Research question:

Are the existing culturally tailored diabetes education programmes applicable and what are the influencing variables?

Sub-questions:

1. Which attributes characterise diabetes education programmes tailored for ethnic minority groups?
2. What kinds of barriers exist?
3. Which variables have a positive impact on implementation?
4. Do experts' solutions and suggestions in the NL and the UK differ and/or correspond?

1.4 Significance of Study

This study contributes to the research field of cultural sensitive diabetes education for different reasons: First, the combination of literature review, document analysis and qualitative field data allows an overall picture on the provision of DEPs for EMGs, facilitating and inhibiting structures, concepts and realisation of tailoring as well as revealing issues around the target population. Second, the before described triangular perspective on programme design and implementation investigates evidence-based effectiveness as well as experts' experiences and expertise. Third, the European comparison enables inter-programme and inter-country assessment.

The choice of expert interviews is relevant for this study. The qualitative method allows us to go beyond the question whether cultural specific education is required and question why culturally tailored diabetes programmes might be of relevance. In addition, concepts hidden behind the term "culturally sensitive" can be unpacked.

The study compares German³, Dutch and British programmes as comparable DEPs for immigrants exist. Comparing the above offers the opportunity to learn about the relevance of HCSs and policies on DEPs for EMGs.

³ Germany was included during pretesting stage, because the SITD research project investigated already the German context.

1.5 Source of Data

The research combined two sources of empirical data: primary and secondary data.

Primary data included expert interviews and related studies which investigated the included DEPs.

Secondary data included a literature review. Data was collected via an extensive literature and internet search including scientific research and grey literature on availability of DEPs targeting EMGs.

The electronic databases Cochrane Library, PubMed, Medline, and Science Direct were reviewed thoroughly. A systematic search using the terms 'culturally appropriated or cultural sensitive or culturally tailored' in combination with 'diabetes education or diabetes care or diabetes self-management' and 'migrants or immigrants or migrants groups or ethnic minority groups or disadvantaged groups' was conducted. The abstract texts from these results were then examined for relevance to the study.

Further references were obtained from publications and hand searches such as Google Scholar, the WHO, OECD, IDF, euroStat websites, health ministries and from European and international guidelines.

Articles, books and grey literature published in English, German or Dutch were included.

1.6 Outline of the Study

This master thesis is divided in six main chapters. The first chapter gives a general insight into the topic, outlines the relevance of study and states the research question. The second chapter reviews existing literature in the field. It provides fundamental background information and builds the basis for the following chapters. Information is given concerning migration, country specific key data, T2DM, the theoretical framework that underpins the work in hand, factors that impact health of EMGs, aspects around culture and diabetes education. The third chapter describes the investigatory part of the work. This includes research design, data collection, analysis, validation and limitations. Chapter four presents study results, which will be discussed in the fifth chapter. In this chapter a relation between theoretical concepts, scientific knowledge and field data will be established. The last chapter, number six summarises the main issues and suggests recommendations for good practice.

Chapter 2: BACKGROUND OF DIABETES EDUCATION PROGRAMMES FOR ETHNIC MINORITY GROUPS

2.1 Diabetes Mellitus

2.1.1 Etiology and Classification

Diabetes is a heterogeneous group of disorders characterised by abnormal high blood sugar levels and glucose intolerance. The chronic condition results from an inability of the pancreas to produce enough insulin or the insufficiency to use the insulin that has been produced effectively. Both cause a high concentration of glucose in the blood, which is called hyperglycaemia (ICD-9, 2013). Insulin is a hormone responsible for blood sugar regulation. An uncontrolled and increased blood sugar level demonstrates undiagnosed and/or poorly treated diabetes, leading to serious health implications over time (Whiting, Unwin & Roglic, 2010, p.79).

The metabolic disorder diabetes has been classified in four main types: type 1, type 2, gestational and other types. Type 2 is the most common form of diabetes worldwide, 80-95% of the cases are attributed to T2DM (ICD-9, 2013; Whiting, Unwin & Roglic, 2010, p.78).

2.1.2 Type 2 Diabetes Mellitus: Etiology, Symptoms and Treatment

For a long time T2DM has been described as non-insulin-dependent and/or adult-onset diabetes mellitus; however, during the last decades T2DM can be seen to be increasing among children and adolescents. The condition develops from an insulin deficiency (reduced production) that can no longer compensate for the inability to use insulin properly. The severity of both characteristics can individually differ.

A great spectrum of factors contributes to the risk of developing T2DM, such as the genetic predisposition, environmental and behavioural aspects. Especially overweight, obesity (abdominal obesity) and physical inactivity counting as major risk factors (WHO, 2013).

Symptoms comprise of constant thirst and hunger, excessive need to urinate, vision changes, fatigue, and unintended weight loss (ICD-10, 2013). The severity of clinical signs can vary between individuals, implicating the risk that symptoms are mild and the disease is only diagnosed post-onset through the occurrence of complications (Whiting, Unwin & Roglic, 2010, p.78-79).

Common **complications** of T2DM are damage of the eyes/blindness (diabetic retinopathy), kidney failure, and nerve disorders (diabetic neuropathy). Further it can lead to heart disease, stroke, and even limb removal (ICD-10, 2013).

As diabetes is a chronic condition it cannot be cured. Therefore, **treatments** aim, first to stabilise glucose blood levels as normal as possible, and second to prevent secondary diseases and future complications.

According to the “Diabetes National Service Framework” (NHS, 2007) in the UK, good diabetes care covers three main areas: 1) increasing knowledge and establishing a supportive network (structured DEPs, counselling and support by health professionals), 2) lifestyle modifications (facilitating to develop and realise lifestyle changes) and 3) handling of blood glucose levels (if required assistance to take medications properly) (Whiting, Unwin & Roglic, 2010, p.88).

2.2 Migration and Its Influence on Health

Migration is a topic of interest to almost all European member states as associated economical, societal and political challenges had become noticeable during recent years. In 2011 the European Statistics (EuroStat) estimated that more than 30 million immigrants live in the EU and the majority originates from non-EU countries. The largest number of immigrants (566,044) live in the UK, followed by Germany with 489,422 foreign nationals. Migrants from Turkey and Morocco make up the biggest EMGs (non-nationals) living in the EU (RIVM Bilthoven. Nationaal Kompas Volksgezondheid, 2007 cited in Ujcic-Voortman et al., 2009, p.511; Vasileva, 2011, p.3).

Conditions in which people are born, make a living, work and grow old are considered as SDH. Therefore, migration itself counts as an important SDH (Davies et al, 2009 cited in Rechel et al., 2011, p.4; WHO, 2010), which is extremely difficult to compare as it differs widely between individual cases. Aspects including reasons and time of migration, countries of origin and destination, time spent in the country of residence, and the residence status, present a broad array of migration-related factors.

It is crucial to distinguish that migration by itself is not a risk factor, but due to geographical and SE segregation and lacking access to health services, EMGs face health risks like other deprived groups in the country of migration (Bhopal, 2007, p.152; Lampert & Voth, 2009).

The World Health Organisation (WHO) Report on Migration and Health in Europe (Kunst, Stronks & Agyemang, 2011, p.106) stated higher diabetes incidence and prevalence rates among EMGs compared to the native white population. In addition, a number of European studies focused on diabetes mortality in immigrants and the native white population and discovered higher rates among EMGs (Chowdhury & Hitman, 2007, p.279; Kunst, Stronks & Agyemang, 2011, p.106; Oldroyd et al., 2005, p.487; Vandenheede et al., 2012).

Increasing migration and the fact that immigrant populations present particularly high diabetes prevalence rates impose an enormous challenge to local HCSs, which had originally been designed

to meet the needs of the locally born population. It is not migration per se which increases the burden for HCSs, but disadvantaged groups do, especially if these groups present low acculturation levels. The term acculturation implies complex processes of getting acquainted with habits and attitudes of the country of residence and adaptation (Redfield et al., 1936 cited in Delavari et al., 2013, p.2). Familiarity with local health care practices and implicit knowledge is a required prerequisite in order to make use of health care services. Both can only be gained by experiences and hence are often lacking among foreigners and socially excluded groups.

Conflicting are findings shown in Delavari's systematic review (2013) that investigated the link between acculturation and obesity among immigrants in high-income countries (only studies from the United States (US) met inclusion criteria). Male immigrants presented higher rates of weight gain with greater acculturation caused by adaptation to local habits of a more sedentary lifestyle, whereas women presented the opposite, which might be attributed to the ideal of beauty of the host country. Indeed the situation in the US and in European countries might be different; however, what does count is that immigrants are susceptible to the cheap availability of meat, fat and sugar, which are all drivers of obesity.

Although food choices are based on what is obtainable, it is also known that culture (country of origin and country of residence) has a major influence on dietary patterns and therefore national and regional differences exist (Kittler, Sucher & Nelms, 2012, p.12). Strong heterogeneity can be seen in diets and eating cultures across the EU (Kittler, Sucher & Nelms, 2012, p.130-160).

For the next two sub-chapters that provide more detailed country specific information on migration, it is crucial to be aware that comparing statistical data regarding EMGs is complicated, as different definitions are hidden behind these numbers. There is a wide variation concerning first and second-generation immigrants. In addition, the process of acquiring the nationality of host countries differs in terms of time and requirements.

2.2.1 Migration to the United Kingdom

Immigration after World War II was characterised by post-war adjustments, de-colonization, and economic migration. Unlike the NL and most other EU countries, the UK integration policy was largely determined by relations with Commonwealth countries (Bauer, Lofstrom & Zimmermann, 2000, p.5). The British Nationality Act released in 1948 allowed only citizens of Commonwealth states to enter the UK. Caused by the easy access, large immigrants groups from Commonwealth countries and Pakistan immigrated to the UK (Bauer, Lofstrom & Zimmermann, 2000, p.5).

The term SAs encompasses people of Indian, Bangladeshi and Sri Lankan origin (presenting different religion, culture and rates of diabetes).

The mass migration from India to the UK can be subdivided in two major periods. The first migration inflow took place in the early 1950s, mainly from the Punjab region (the province is part of India and Pakistan) and the Sylhet province (which nowadays belongs to Bangladesh). The people who immigrated during that time were mostly Muslims, had only low educational levels, and little linguistic competence in English. The majority of this group ended up as workmen, living in socially deprived neighbourhoods, with little earnings and poor working conditions. Nowadays the descendants of this migrant group still live under similar conditions.

In the mid 1970s political turmoil caused the second migration wave of SAs to the UK. The majority of the second mass migration belonged to Gujaratis presenting high levels of educated individuals and were predominantly Hindus (Hanif & Karamat, 2009, p. 27).

The UK tried to introduce strategies to limit the number of new immigrants but instead migration inflow continued due to family reunification (Bauer, Lofstrom & Zimmermann, 2000, p.5).

Nowadays the SAs count as the biggest EMG living in the UK encompassing more than 4% of the total population (Hanif & Karamat, 2009 cited in Gholap et al., 2011, p.45). Important to notice is the heterogeneity of the SA population in the UK. On the one hand a large percentage can be ascribed to a disadvantaged group with low SES; on the other hand, approximately 30% of doctors employed by the NHS are from SA descent (Hanif & Karamat, 2009, p.28).

2.2.2 Migration to the Netherlands

Comparably to the UK, the NL experienced a great inflow of workers caused by the return migration from their former colonies Indonesia, Suriname and the Antilles.

The Dutch post-war economy grew fast and labour force was lacking. Therefore, the NL, similar to Germany, recruited substantial numbers of the so-called “guest-workers” from Mediterranean countries (among others, Turkey) to compensate economic shortage during the 1950s and the 1960s (Zimmermann, 1995 cited in Bauer, Lofstrom & Zimmermann, 2000, p.4). The programme intended to be a temporary solution, but return migration became difficult and instead, a new wave of migration inflow followed, mainly because of family reunification (Bauer, Lofstrom & Zimmermann, 2000, p.4).

The “guest workers” had to pass a medical examination and a qualifying test and thus entered the NL as “healthy migrants”. However, educational level was not an aspect considered for recruitment. In the host country, the majority had been employed in unfavourable labour positions and under

poor working conditions leading to early retirement (Kofahl, 2011). Zorlu & Hartog's (2001, p.12) study supports these findings by highlighting high unemployment rates, early retirement and usage of disability benefits among Turkish and Moroccan immigrants, bearing in mind that similar results have been observed in low skilled Dutch natives.

Nowadays Turkish immigrants make up the largest community among minority groups in the NL followed by Moroccan communities (Euwals et al., 2007; RIVM Bilthoven. Nationaal Kompas Volksgezondheid, 2007 cited in Ujcic-Vortman et al., 2009, p.511). In 2012, the Turkish population living in the NL made up 2.3% and people with a Moroccan descent accounted for 2.2% of the total population (CBS, 2012).

2.2.3 Integration Policies (UK & the NL)

A broad variety of strategies exist that aim to integrate immigrant populations. Within the European region three different concepts can be recognised: assimilation, multiculturalism and exclusion.

The NL and the UK approached integration by applying a multicultural model. Multiculturalism is based on a communitarian approach encouraging diversity. This model supports EMGs to maintain their cultural identity and it stimulates the coexistence between cultures, religions and values (Regout, 2011, p.7-8).

Regardless of inter-country differences in societal models and migration composition most EU countries have started to progressively deviate from historically rooted integration policies (Regout, 2011, p.9). For instance, the British and Dutch governments are moving from a “supportive-oriented” towards an “incentive-orientated” approach that sees assimilation and adaptation to the host country as compulsory and hands over the responsibility to the immigrant (Euwals et al., 2007, p.13).

A good example of an “incentive-orientated” activity is the introduction of the Dutch “inburgering” programme in 1998. This programme embraces Dutch language training, an introduction to local institutions, values and the national labour market, and counts as a precondition to acquire permanent residence and the Dutch nationality (Euwals et al., 2007, p.13).

Like other European countries, the British government attempts to tailor immigration to the UK by encouraging immigration of migrants who could potentially benefit the national economy and ward off refugees and asylum seekers. Comparable to Dutch policies, nowadays migrants have to pass a language test in order to acquire British citizenship and naturalisation (Nationality, Immigration and Asylum Act 2002, released in 2005) (Regout, 2011, p.15).

Both countries started their immigration policy by promoting multiculturalism but ended up applying more and more models of assimilation (Regout, 2011, p.14-21). It remains doubtful if governments implement methods of cultural integration to fight problems that are actually attributed to failed SE integration and thereby neglecting the cause of abortive integration.

2.3 United Kingdom

2.3.1 Epidemiology Data

In 2011, the IDF has estimated a diabetes prevalence of 6.8% of the total UK population aged 20-79. Further, the adult diabetes prevalence is projected to increase up to 7.5% in 2030. The Health survey for England 2011 stressed the strong link between income and the occurrence of T2DM in the general UK population. Rates were highest in most deprived areas. 11% of men and 5.9% of women in the lowest quintile of household income presented with the chronic condition, whereas in the highest quintile only 4.7% of men and 3.7% of women had diabetes.

In general current data about diabetes prevalence rates in the UK is scarce, especially for immigrant populations. The latest data available originates from the Health Survey for England 2004 that identified a 2.5 to 5 times higher diabetes prevalence rate for immigrants with a SA origin compared to the native population. Of note, data was self-reported and included only doctor-diagnosed diabetes. Gholap's study (2011, p.46) emphasised the fact that large percentages of diabetes cases among SAs remain undiagnosed, which indicates even higher diabetes prevalence rates. According to the Diabetes Organisation UK and Khunti's study (2009, p.12), the T2DM prevalence is even 6 times higher in SAs living in the UK.

Additionally, it had become evident that SA minority groups develop diabetes 5-10 years earlier in comparison to the native white population (Gholap et al., 2011, p.46; Khunti, Kumar & Brodie, 2009, p.12). High rates of obesity and low level of physical activity have been detected to be more prominent among SAs, both characteristics associated with an increased risk of T2DM. Further, premature and high rates of mortality are linked to diabetes among the SA population (Gholap et al., 2011, p.46).

2.3.2 Inequalities

In 1965 the UK released their first anti-discrimination law, which was later extended by more comprehensive "Race Relation Acts". Although from a structural perspective equal rights and opportunities exist in the UK, the European Network Against Racism (ENAR) Shadow Report in

2006 presented contradicting results. Inequalities linger on areas like health, education, housing, justice and employment. For instance, immigrants are still twice as likely to be unemployed, to live in homes below the local standard, and they are more likely to have poorer health outcomes than the native white population. Furthermore, poor performances in the educational system tend to be more frequent in EMGs, which is primarily ascribed to having a low SES instead of ethnicity (Regout, 2011, p.14).

The complexity lies in the fact that it is difficult to distinguish and concluded if inequalities are indeed caused by ethnicity or due to SE disadvantages. Nevertheless, in both conditions access barriers and less supportive structures for T2DM management from their social environment contribute to exclusion (Onwudiwe et al., 2011 p.30; Rechel et al., 2011, p.4, Vissenberg et al., 2012). Huassain-Gamble's study (2006) assessed indicators for little participation of SAs in clinical trials. The results displayed professionals' perspectives that lack of time and resources, perceived cultural and language barriers and little support are the main reasons.

Low literacy is another component that is associated with social inequality. This is grounded on the fact that literacy skills have an enormous effect on a persons' job situation and consequently, decisive for income, housing and the SE position.

The International Adult Literacy Survey carried out by the Organisation for Economic Co-operation and Development (OECD) (cited in Easton, Entwistle & Williams, 2013, p.2) found that in the UK, 23% of the adults scored at the lowest level of the 5-point scale assessing functional literacy. Low literacy is closely intertwined with low level of HL, which means a limited ability to select, comprehend and apply health information and, thus, to make informed choices. The strong correlation between low HL and limited access to health care services as well as poor use of health resources has further implications for health outcomes (Dewalt et al., 2004 cited in Easton, Entwistle & Williams, 2013, p.2).

2.3.3 The British Health Care System

The HCS in the UK is based on the Beveridge system providing care to all residents through the National Health System (NHS) (Gray et al., 2007, p.1317).

Health services are primarily financed from public sources, mainly general taxation and National Insurance Contributions (NICs) and require very little patient cost-sharing and direct payments. Nevertheless some care is funded privately through Private Medical Insurance (PMI) (Boyle, 2011, p.21). The NHS (established in 1948) offers preventive medicine, primary care and hospital services, which are for the main free at the point of care. In the UK the public sector is the main provider of care; however, the role of the private sector has increased in recent years. Out of the

entire population approximately 12% is covered by PMI and, thus, gets faster access to elective care and has the choice of specialists (Boyle, 2011, p.21).

The primary care system includes community health services, NHS Direct, NHS walk-in centres, dentists, opticians and pharmacists, and it has a gatekeeping role in determining access to more specialised health care services. Normally self-employed General Practitioners (GPs) and their practices are the first point of contact between patients and health professionals (Boyle, 2011, p.23). Salaried specialist doctors and other health professionals who mainly work in public hospitals deliver services of NHS-funded secondary care. Aside from the NHS a small private sector exists. It provides acute elective care and is financed through private insurance, direct payments from patients or publicly-funded payments by Private Care Trust (PCTs) and Department of Health.

The last big reform took place in 2000, which included among several other reform measures the development of the National Institute for Health and Care Excellence (NICE) guidelines, the establishment of other service specific guidelines and the introduction of the Care Quality Commission (CQC) to evaluate and control providers quality of services (Boyle, 2011, p.23).

On one hand the population health in the UK has tremendously improved during the last decades, which manifests on indicators such as an increase in life expectancy, declining mortality rates for respiratory, cancers and circulatory diseases, and decreasing infant and perinatal mortality rates. On the other hand, health inequalities across SE groups have been increasing since the 1970s, becoming obvious by comparing life expectancy of low and well-educated groups (a difference of 7.3 years for men and 7.0 years for women) (Boyle, 2011, p.15; Graham & Kelly, 2004, p.1). Among others is the steep increase in adult and child obesity, one of the biggest public health concerns in the UK (Boyle, 2011, p.15-16).

Diabetes care: Regardless of income and/or employment every resident in the UK is entitled to free diabetes treatment (Gray et al., 2007, p.1318). The NHS covers diabetes related hospital stays, equipment such as test stripes, needles, insulin, and patients with chronic conditions are exempted from prescription charges. The NHS covers further costs for secondary diseases attributed to T2DM. From a patient perspective access to diabetes care is not influenced by financial terms, but rather the fact that they are not familiar with what health service offers. This, in turn, might limit the uptake of diabetes education.

Although since 2003 the NICE guidelines recommend that structured diabetes education should be provided to every newly diagnosed diabetic patient (NICE, 2003) the provision of DEPs varies across the UK. This is mainly based on the reason that local governments (authorities) have the competence to make decisions about which services are provided (Boyle, 2011, p.32).

2.4 Netherlands

2.4.1 Epidemiology Data

In the NL an adult diabetes prevalence of 7.3% of the total population has been estimated in 2011. Similar to the UK the number of diabetes cases in the NL is very likely to rise in future. In 2030 diabetes prevalence is predicted to increase up to 8.8% (IDF, 2011a).

A vast body of literature (Kunst, Stronks & Agyemang, 2011, p.106; Uitewaal et al., 2004 cited in Ujcic-Vortman et al., 2009, p.511) stresses the fact that diabetes prevalence is higher in the main EMGs (those from Turkey, Morocco, Surinam and Antilles). The T2DM prevalence rates are two to three times higher in Turkish immigrants than the native Dutch population (Lindert et al., 2004 cited in Kunst, Stronks & Agyemang, 2011, p.106; Uitewaal et al., 2005, p.428; Ujcic-Vortman et al., 2009, p.513). After stratifying for risk factors such as low SES and obesity, the prevalence rate remained higher but was no longer significantly different from the native white population. This supports the assumption that SE disadvantages are at least partly responsible for higher prevalence rates (Ujcic-Vortman et al., 2009, p.514). In contrast, numbers have been assessed for immigrants with a Moroccan descent, and prevalence rates were still significantly higher after accounting for risk factors, leading to the conclusion that higher prevalence rates might also be traced back to other aspects, including endogenous factors.

The influence of these factors (dyslipidaemia, hypertension, HDL cholesterol level) in increasing the risk of T2DM is further confirmed by the strikingly high percentage of overweight and obesity among Turkish and Moroccan immigrants (>70% overweight and 48% of the Dutch population and >33% identified as obese compared to 18% of the Dutch individuals) (Rechel et al., 2011; Ujcic-Vortman et al., 2009, p.514).

2.4.2 Inequalities

In 1983 under the influence of international treaties the NL enacted an anti-discrimination law (Article 1 of the Dutch Constitution) aiming to assure equal treatment for all persons living in the NL (Bleijenbergh, van Engen & Terlouw, 2010, p.183). Comparable to the UK, equality exists on a structural level (before the Dutch law) but literature and statistics reveal contrasting findings.

The WHO stated in their report on Migration and Health in Europe (Kunst, Stronks & Agyemang, 2011, p.107) that Turkish immigrants presented lower SES, higher rates of overweight and obesity and lower levels of physical activity than the native white Dutch population.

In the NL some studies have stressed discriminatory behaviour of employers against EMGs. Skin colour is a known aspect that is associated with discriminatory behaviour (Crenshaw, 1989,

p.43&45; Krieger, 1999, p.295). This applies only partially for the NL. Zorlu & Hartog (2001, p.13) detected stronger prejudices against Turkish and Moroccan immigrants compared to Surinamese and Antilleans. Immigrants from Turkey and Morocco face stronger discrimination, work in less favourable job conditions and have higher unemployment rates. This might be partly explained by the fact that schooling in countries that have been former colonies is rewarded higher. For instance, the education system in Surinam and the Antilles is based on the Dutch system and, therefore, somewhat familiar (Euwals et al., 2007, p.2).

The NL, as well as other European countries, faces issues of inequality when it comes to immigrant populations. This is well demonstrated in unemployment rates that have been about three times higher among EMGs (Joppke, 2007 cited in Regout, 2011, p.19). Groen Links (2006, cited in Bleijenbergh, van Engen & Terlouw, 2010, p.181) presented alarming results in their experimental study. Moroccans who applied for a traineeship had a 30% higher chance to be rejected compared to Dutch applicants even though all references were identical. In conclusion, it can be said that formal equality (before the Dutch law) does not necessarily lead to procedural (negotiation position) and material (equal outcomes) equality (Bleijenbergh, van Engen & Terlouw, 2010, p.183).

Although EMGs face disadvantaged position in the labour market with regard to literacy, the NL scored better than other European countries. The Survey of Adult Skills carried out by the OECD (OECD, 2013) highlighted an above-average proficiency in literacy for adults in the NL. Immigrant populations, whose native language is not Dutch, presented much lower levels of literacy in the Dutch language. Nevertheless, compared to other European countries, their literacy levels remain above average.

2.4.3 The Dutch Health Care System

The Dutch HCS, similar to most central European countries, is based on the Bismark system that is characterised by statutory health insurances (Schäfer et al., 2010, p.13).

One of the biggest health care reforms took place in 2006, which reorganised major structures of the Dutch HCS. Whereas the old model was controlled by the supply-side, the new system is demand-oriented and built on an insurance market that intends to be both patient-focused and competitive (Muiser, 2007, p.4). Automatic coverage is no longer provided but residences of the NL are obliged by law to obtain health insurance (Muiser, 2007, p.10).

The introduction of the new HCS allows managed competition between the three actors; the health care insurers, the patients, and the health care providers, supervised by the government and controlled by independent bodies. Therefore, health insurer and provider have the option to bargain, to a certain degree, with health care provider for instance on price, volume and quality of care. In

short, enrolment is free, risk selection by health insurers is forbidden, and the insurer can act as a private company (Schäfer et al., 2010, p.22). Self-regulation has always been an attribute of the Dutch HCS. Professional associations carry the responsibility for re-registration schemes and quality control for instance through the development and implementation of guidelines.

The Dutch HCS is predominantly financed through social health insurance complemented by small governmental revenue and very little direct payments (Muiser, 2007, p.6). The system consists of three different compartments.

The compulsory Social Health Insurance (SHI) scheme is responsible for medical expenses such as long-term care and the provider for chronic conditions that require continuous care. This compartment is mainly funded through income-dependent contributions and is regulated by the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ). The AWBZ is embedded in a complicated cost-sharing system.

The second compartment includes a SHI system insuring the entire population for “basic health insurance”. This basic health insurance scheme covers curative care and is financed through both, a flat-rate premium (directly paid by the patient to the health insurer of their choice) and an income-dependent contribution (paid by the employer to the Health Insurance Fund).

The third compartment is composed of a complementary Voluntary Health Insurance (VHI) that implies services which are not covered by the other schemes (Muiser, 2007, p.6-8; Schäfer et al., 2010, p.53-54).

In primary care GPs function as key persons because their referral enables access to hospital and specialist care (except emergency care). Dentists, midwives and physiotherapists can be accessed independently. In general, patients have the freedom to choose health providers and health institutions (Schäfer et al., 2010, p.22-23). The Dutch citizens have to deal with only a few out-of-pocket payments for health services compared to other EU countries.

Like, the UK, the Dutch HCS has been accountable for some major improvements in health outcomes, for instance, in terms of life expectancy at the same time the occurrence of chronic conditions increased. The NL faces the challenge of health disparities, which is evident in the higher burden of disease among immigrants compared to the native Dutch population. As has been observed in the UK, the steep rise in obesity is a pressing public health issue in the NL. Self-reported data, revealed 50% of the population as overweight (Schäfer et al., 2010, p.6-9).

However, it has to be emphasised that it might be too early to assess the results of the health care reform of 2006, thus, many population health outcomes still have to be attributed to former strategies.

Diabetes care: The Dutch HCS covers costs of diabetes care including costs related to equipment and treatment. However, the introduction of the new scheme in 2006 allows the provider side (insurer) to attract specific patient groups by offering options to extend the basic package of diabetes care (Muiser, 2007, p.4). This in return affects equity due to financial and acculturated deviations (level of information, gathered experience and familiarity of the local HCS) among population groups.

A brief comparison of the UK and the NLs' health policy relevant to diabetes care is presented in Table 1.

Table 1. Statistical comparison - NL and UK

	United Kingdom	Netherlands
Statistics		
Estimated diabetes prevalence (% of total pop. aged 20-79) in 2011	6.8%	7.3%
Predicted diabetes prevalence (% of total pop. aged 20-79) in 2030	7.5%	8.8%
Estimated no. of diabetic patients in 2011	3,063,910	881,630
Predicted no. of diabetic patients in 2030	3,645,860	1,094,580
Spending on diabetes as a % of total health expenditure in 2011	7.7%	8.5%
National plan	National Service Framework for Diabetes (2001)	Ministry of Health, Welfare and Sport's Diabetes Action Programme
National register	No	No
Existing guidelines	National Institute for Health and Clinical Excellence (NICE), General Medical Service Contract & Quality Outcomes Framework	Dutch College of General Practitioners guidelines & Government guidelines on diabetes and pregnancy & Dutch Institute for Healthcare guidelines

Source: IDF, 2011b, *Diabetes - The Policy Puzzle: Is Europe Making Progress?* p.138 (UK); p.98 (NL)

A summary of the health insurance systems in both countries is presented in Table 2.

Table 2. Health care systems in comparison - NL and UK

	United Kingdom	Netherlands
System	Beveridge	Bismark
Last reform	2000	2006
Insurance scheme	Universal coverage	Compulsory
Financing	Financed through taxation. State dependent	Mainly through income- dependent contributions, partly through AWBZ
Regulation	No possibilities for self- regulation	Partly self-regulated by health provider and insurer
Structure	1. NHS 2. PMI (private insurance)	1. SHI 2. Basic insurance 3. VHI (private insurance)
Out of pocket payments	Hardly any patient cost-sharing and direct payments	In general little patient cost- sharing and direct payments The “basic insurance” is partly financed through out of pocket payments
Freedom to choose health provider health institution	No The local PCS have a gatekeeping function to access further health care services and specialised care	Yes Patients can freely choose health institutions and provider of medical services
Role of GP	First person of contact, who refers patients if needed	Key person, referrals from the GPs provide access to further services
Quality control guideline	Yes	Yes
Coverage of diabetes care	Yes	Yes

Source: Own creation, adapted from WHO - Health care in Transition: Boyle, 2011 (UK) and Schäfer et al., 2010 (NL)

2.5 The Theory of Intersectionality

Crenshaw's theory of intersectionality gained attention through the release of her famous essay "Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics" (1989).

Since then it dominates health care research and practices focusing on feminist health care and power relations. This is not only because she identified the importance of multiple inequalities but also how they overlap and influence each other. The theory traces back to the assumption that every individual holds multiple social identities, for instance gender, race, class, age, ethnicity, or migrant status (Caldwell, Guthrie & Jackson, 2006, p.164).

Rummen's work (2003, cited in van Mens-Verlust & Radtke, 2006, p.4) underlies the fact that a person's affiliation to a social group, for example from the same ethnic background, might shape the sense of personal identity of this person. However, others also identify people by allocating them to a certain group. Both have obvious implications for everyday life. With regard to the identity defined by the ethnic background it is crucial to highlight the unspecific nature of this category. For instance, the term SAs subsume people from various origins; therefore, not only does every individual encompass multiple identities (race, gender, SES etc.), but each category also consists of multiple characteristics (Geiger, 2006, p.271).

The theory of intersectionality will underpin this master thesis. This study's theoretical framework moves beyond the intersection between race and sex, and additionally comprises concepts of diversity and the complex construct of social identity and structures of oppression. These are all crucial elements to understand political decisions, social positions of EMGs, aspects of health inequalities and eventually the need for culturally appropriated DEPs, as well as possible explanations for the scarcity of such health care services.

Unlike other concepts that explain the interaction between advantaged and disadvantaged positions in society, the intersectionality theory assumes that socially constructed categories deviate as interrelating functions. This leads to a complex synergy of oppressions and disadvantages, as well as enabling structures, privileges and advantages (Crenshaw, 1989, p.45; Schulz & Mullings, 2006, p.5). All of these act simultaneously, are inseparable and intertwined.

On a long-term, these synergies result in inequalities and affect SDH (McGibbon & McPeherson, 2011, p.60). For instance, social class related oppression cannot be seen as isolated without considering the impact of ethnic affiliation. This means, the influence on everyday life will always be a combination at least of both categories: class and ethnic affiliation (Makowski, 2012; van Mens-Verhulst & Radtke, 2006, p.2).

At a structural level the issues of inter-culturalisation, acculturation and integration policies dominate public debates. Both the process of making organisations culturally sensitive as well as the process of assimilation by making “cultural groups” adapt to the beliefs and habits of another culture are strongly affected and dependent on political decisions, for instance, by integration and antidiscrimination policies.

On one hand, policies aim for equal access to health and equal provision of care. On the other hand, political decisions are often not intended to reduce the existence of social hierarchies. Instead, laws are enacted to support marginalized groups via a top-down approach retaining power relations and structures of oppression (Crenshaw, 1989, p.45; van Mens-Verhulst & Radtke, 2006, p. 7-8). Structural oppression causes inequities in health outcomes of social issues which include, among others, intersections of classism, racism, and sexism. These structural determinants of health are in their nature complex and changing with the political orientation of the current government (McGibbon & McPherson, 2011, p.61).

Wilkinson (2003, cited in McGibbon & McPherson, 2011, p.63) stresses on obstacles in research and political areas with regard to realisation of intersectionality. She invokes to base programmes on the need of the target group and that persons with intersecting identities should be studied before formulating policies and designing programmes. This is complemented by the emphasis to investigate institutionalised racism and its articulation with class and gender in order to comprehend and counteract disparities in health (Schulz, Freudenberg & Daniels, 2006, p.373). Taking both into consideration would mean that diabetes education is mutually influenced, by variables that are individual/groups specific and structural/institutional.

The intersectional theory raises awareness for the multi-layered construction of health disparities. Its complexity is well visualised by some health paradoxes (Mullings & Wali, 2001; Parra-Medina, 2003 cited in Jackson & Williams 2006, p.131-154).

One health paradox is explained by the assumption that a linear correlation exists between variables (e.g. ethnicity, class) and health outcomes. This means, for example that a middle-class Turkish immigrant is expected to present better health outcomes than their lower class peers. However, health outcomes of a middle-class immigrant can be poorer compared to people from the same ethnic group but belonging to a lower social class, as presented in the study of Jackson (2005, p. 65) for African Americans. Another paradox is the assumption that health benefits from income status do not differ between genders.

The fact that a person holds multiple social identities is the reason for the existence of these health paradoxes.

2.6 The Social Determinants of Health and its Impact on Diabetes Outcomes

This chapter reveals a variety of factors that have an effect on health outcomes of diabetics and with direct attention to immigrants with T2DM. In this context the SDH will be introduced.

“Health and wellbeing are influenced by many factors comprising past and present behaviour, health care provision and ‘wider determinants’ such as social, cultural and environmental factors.”

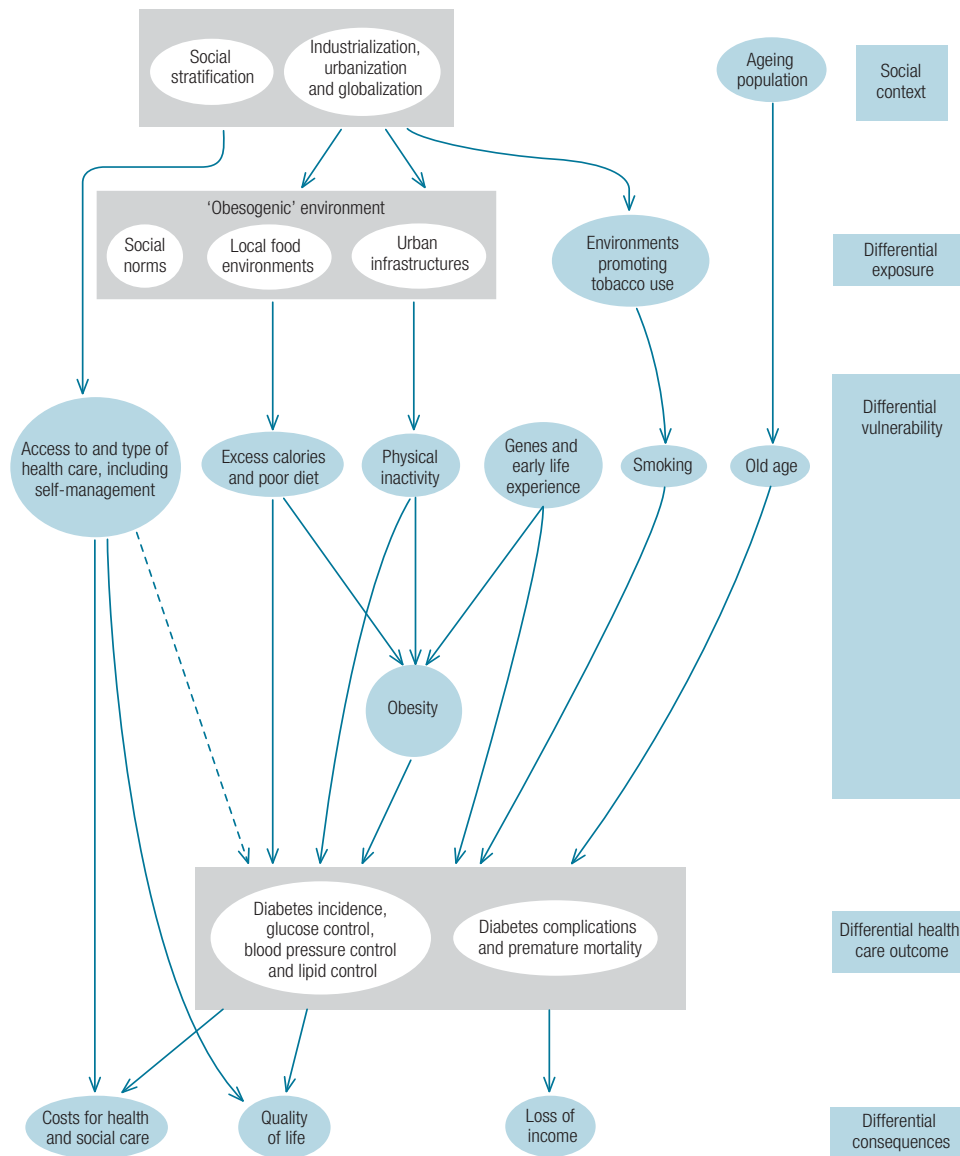
Wanless, 2004 cited in Graham & Kelly, 2004, p.3

As a response to a wider criticism of public health research and policy, the SDH had been introduced in 1970. The critique was again accredited as evidence proved that isolated medical care had a relatively little stake of the major improvements in health achieved through the late 19th and 20th century (Graham & Kelly, 2004, p.3). The SDH can be simply explained by all non-genetic and non-biological factors, for instance income, education, employment, housing, and the environment and their impact on lifestyle and health.

The WHO (Whiting, Unwin & Roglic, 2010) created a hierarchical model (fig. 1) of causation highlighting social determinants and its impact on the course of diabetes. The model demonstrates the association between pathways, the different levels and the increased likelihood of acquiring diabetes and its consequences. It is grounded on five levels, “with socioeconomic context leading to differences in vulnerability to diabetes and health care outcomes, which leads to differences in consequences on quality of life and socioeconomic circumstances” (Whiting, Unwin & Roglic, 2010, p. 85). The following sections 2.6.1-2.6.3 have been based on the SDH and the diabetes-related pathways presented in figure 1.

Figure 1. Model of diabetes-related pathways

FIGURE 5.4 Overview of diabetes-related pathways



Source: Taken from Whiting, Unwin & Roglic 2010 a source from the WHO Report: Equity, social determinant and public health programmes, 2010, Ch.5, p.87.

2.6.1 Socio-economic Status

With regard to factors that impact health outcomes of diabetics, the link between higher diabetes prevalence rates and population groups with a low SES have been widely discussed.

The fact that in middle-, and high-income countries diabetes prevalence tends to be higher in poor and marginalised population groups (Hathrone et al., 2008, p.2; Whiting, Unwin & Roglic, 2010, p.80) confirms health inequity just as the association between SES and poor health (Muff, 2009, p.15). In case SE variables, such as level of education, income, housing and access to information are poor they increase the risk in acquiring T2DM (Krieger, 1997 cited in Espelt et al., 2008, p.1972; OECD, 2012, p.17; Parmakerli, 2011, p.608; Vissenberg, 2012, p.2). These risk factors seem to be more prevalent among groups of lower SES (Whiting, Unwin & Roglic, 2010, p.81-83). Associated with lower SE positions are not only high T2DM prevalence, but also incidence at a younger age, more diabetes-related complications, higher mortality rates, and less ability to manage the complex tasks of self-management (Espelt et al., 2008, p.1972; OECD, 2012; Vissenberg et al., 2012, p.2).

At this point it is not of relevance to clarify if higher T2DM prevalence rates originate from SES and/or ethnicity but it is important to emphasise that most immigrants have lower SE positions; thus, face various health burdens as stated above. They frequently live in socially deprived areas and work in low-paid jobs (Oldroyd, Banerjee & Heald, 2005, p.489; Rechel et al., 2011, p.4-5). To notice heterogeneity and social class variation within EMGs and patient population, is of crucial importance, notwithstanding in the European region, that EMGs can be considered as a vulnerable group.

Class bias can be observed in the provision of health services. Often deprived population groups receive poorer services due to their limited ability of articulation. The aspect of social preconception is compounded in immigrants as further aspects of racism (e.g. health information provided in the language of host country, lack of professional interpreters, and prejudices) and structural aspects (e.g. shortage of resources to meet the needs of immigrants) come into the equation (Nørredam & Krasnik, 2011, p.72-74). For instance, policies of health services are based on the needs of the majority and not on minority populations, furthermore health services are planned and implemented primarily by people belonging to the majority population (Muff, 2009).

Despite demographic variables, lifestyle factors are strongly attributed to a persons' SE position. Overweight and obesity play a major role in terms of diabetes prevention and management. The distribution of obesity is one of the underlying reasons for the distribution of T2DM by SES in higher developed economies. Moreover, physical activity levels seem to be distributed by SES in a similar way as obesity. In other words, a low SES correlates with higher rates of obesity and

physical inactivity. Smoking demonstrates another example of a diabetes-related risk factor, which is more prevalent among population groups with a low SE position (Whiting, Unwin & Roglic, 2010, p.80-81).

People with lower SES tend to make their food choice rather on the criterion of price than on quality, and it is widely recognised that on average “unhealthy” food is cheaper. In addition, a positive association between level of knowledge and quality of nutritional behaviour has been proven to cause class specific eating habits and further, a higher likelihood of eating related diseases among deprived population groups (Muff, 2009 p.114). Not only price and educational level, but also “local food environment” and “urban infrastructure” contribute to eating behaviour pattern.

It can be assumed, that handling an “obesogenic environment” might be more challenging for people with a lower SE background. The diabetes-related pathways (fig.1) as well highlight the relation between low levels of education (“social context”, “social stratification”) and potential consequences such as a reduced uptake of care, the “lack of ability to self-manage the chronic condition” leading to a “poorer control” and even “higher mortality rates”.

2.6.2 Social Environment

The self-management of chronic diseases is embedded and interacts with three major factors: the provider (formal side: health care professionals), the informal social network and the physical environment. All three factors have a potential influence on each other as well as on self-management skills (Gallant, 2003, p.171). The social network of people with a low SES is more likely to encompass primarily people with the same social background. Having friends and/or acquaintances from other SE backgrounds enhances the access to information, introduces resources and attitudes, for example diabetes related information and role models (Vissenberg et al., 2012, p.2).

Diabetes related health outcomes are influenced by different psychosocial mechanisms. Gallant’s review (2003, p.186) on the influence of social support on chronic illness self-management revealed that psychosocial mechanisms have a bidirectional effect, positive as well as negative.

Norms and values of social networks have an impact on behaviour structures of population groups, some of these are peer pressure, customs and behaviours of social comparison. Other ones are social commitment and social support. The former leads to reinforcement of social roles by community participation (Berkman & Glass, 2000 cited in Vissenberg, 2012, p.2). The latter, social support is positively associated with lifestyle changes however patients with a low SES often lack diabetes-related social support (Gallant, 2003, p.187; Riley, 2001; Marlatt & Donovan, 2008 cited in Vissenberg, 2012, p.2).

In EMGs, supportive structures can be either very strong due to group affiliation, or very weak as a result of being alone in a foreign country (social isolation). Vissenberg (2012, p.2) argues that social networks of people from disadvantaged population groups seem to negatively impact diabetes management. A social environment that impedes a healthy lifestyle and DSM through negative role models or peer pressure can lead to adverse effects (Gallant, 2003, p.189-190).

Mulvaney-Day's (2007, p.490) study investigated how family and community support affect the self-rated physical and mental health of Latinos in the US. Outcomes suggest that a good social connection to family and friends can support the experience of health benefits. It stays unclear if findings can be generalised to immigrant groups in the European region.

The hierarchical model of causation (fig. 1) speaks about "social norms", leading to aspects such as "access to health care and self-management", "excess calories intake and poor diet", "physical inactivity", and "smoking". It can be assumed that intra-social network values and habits towards lifestyle issues are relatively homogenous. In short, all aspects mentioned above are likely to be influenced by the social environment.

2.6.3 Religiosity and Health Locus of Control

In 1954, Rotter (Rotter, 1982 cited in Graffeo & Silvestri, 2006, p.593) developed the concept of Health Locus of Control (HLC) based on the Social Learning Theory (Wallston & Wallston, 1978, p.107). The HLC explains the extent of control someone experiences for his or her own health. The concept distinguishes between an internal and external locus of control, the first can be explained as a strong feeling of responsibility towards someone's own condition whereas the latter refers to persons who believe that he or she has very little control over what will happen (fatalistic view) (Graffeo & Silvestri, 2006, p.593). It is generally assumed that the HLC is a significant predictor of adherence to treatment (Wallston & Wallston, 1978, p.112) and improves self-management (Kaplan et al., 1999 cited in Graffero & Silvestri, p.594).

As previously described DSM requires a high amount of self-determination, self-efficacy and responsibility of patients in order to achieve and maintain lifestyle changes over time. Targeting diabetic EMGs and for the conception of culturally tailored DEPs both HLC as well as aspects of religion might be important to consider.

Some researchers have examined religiosity and its impact on the occurrence and handling of depression, a common comorbidity of diabetes. But results are diverse (Kilbourne, Cummings & Levine, 2009, p.138). Koenig's (2007, cited in Kilbourne, Cummings & Levine, 2009, p.139) findings reveal that private religiosity (for instance prayer, reading scriptures) is associated with lower rates of depression and increased rates with public religiosity (including regular visits at

church).

The process of migration is accompanied by an enormous experience of deracination, which might lead to loss of orientation. A potential consequence can be stronger religious affiliation as it provides support and a connection to the home country and the culture left behind.

In terms of religiosity and health more research is needed to investigate how religious beliefs (the faith in predestination and fortune) impact self-determination (internal HLC). It is important to notice and presumably the reason for the lack of data, that religion is a construct of multidimensional nature and therefore extremely difficult to generalise, compare, and measure (Kilbourne, Cummings & Levine, 2009, p.2-3). The variety of different religions additionally complicates the matter, not to mention individual practices. As heterogeneous issues around religiosity and health can be as important is the consideration of such aspects for culturally tailored DEPs.

In conclusion, more research is required to assess the impact of religious factors on health and its mediating effect. Certainly religion can act in either way, like a resource enhancing supportive structures or restrictive, inhabiting one's internal HLC.

2.7 The Role of Culture in Health

2.7.1 Culture and Ethnicity

The aim of this work is to examine diabetes education tailored for EMGs from multiple angles. To do that the following chapter uncovers concepts hidden behind the terminology “culture” and “ethnicity”.

In scientific literature, political discourse and every day speech primarily the term “culture” is used though definitions vary. Cultural anthropologists are highly critical of the way “culture” dominates and influences the public dialogue on health, migration and ethnicity. Their criticism relates to the manner “culture” is used, leading to separation between “exotic migrants belonging to a foreign culture” and “us”. Indeed this concept tends to forget that everyone belongs to a culture themselves (Durieux-Paillard, 2011, p.207; Ingleby, 2011, p.235; Kleinmann & Benson, 2006, p.1674).

The Bophal's book “Ethnicity, race and health in multicultural societies” (2007) also hints at the approach to race ethnicity and social harm. The act to value ethnic aspects of others refers to one's own group affiliation as a given point of reference. To assume one's own culture as a standard accentuates on differences and retain the concept of social hierarchy. Both patterns counteract non-judgemental behaviour. Bophal (2007, p.17) gives voice to the danger of racism caused by the emphasis on dissociations.

According to Ballard (2002, p.11-13) culture can be understood as a combination of behaviour codes and language and both are socially transmitted and not attributed to genetics; thus, culture is mainly developed through societal influences. Furthermore by understanding that culture is neither homogenous nor static, stereotyping and aspects of discrimination can be reduced, thereby enhancing factors for non-judgemental communication between peers.

At first glance ethnicity seems to be used as merely a synonym of culture. In this respect it is crucial to carefully look at both terms. The construction and preservation of cultural differences acting in political and/or economic areas can be understood as ethnicity, meaning it normally occurs in consequence of patterns of inequality (Ballard, 2002, p.27). For example, SE and geographical segregation in the country of residence are often consequences of migration leading to environmental and SE disadvantages; hence, inequalities in health (Bhopal, 2007, p.152).

As already mentioned earlier, discordance exists between definitions and authors. Bophal's (2007) explanation of ethnicity exemplifies how definitions can deviate from each other. According to Bophal's (2007, p.13-14), book ethnicity enfolds rather inherited than biological factors. It comprises aspects like behaviour codes, dietary habits, and religion, which might be influenced by time and vary between generations. The definition further refers to features in common for instance a shared descent, culture and traditions, social background and language. All those communalities might be maintained between generations and increase the sense of identity and group affiliation.

The two discussed concepts are not contrary to each other but whereas Ballard (2002) explicitly distinguishes between culture and ethnicity, aspects of both definitions are embedded in Bophal's (2007) explanation of ethnicity. Although definitions differ between authors, a consensus exists that the understanding of behaviour codes and overcoming language barriers are tremendously important in order to offer high quality care for diabetic immigrants.

Nonetheless, while dealing with cultural aspects it has to be remembered that culture does not comprise a bunch of already-known facts, such as Turkish immigrants do not eat pork, but it is rather a set of variables affecting experience, which differ even within the same ethnic group (Kleinmann & Benson, 2006, p.1674). To sum up, in health care, the application of concepts like ethnicity or culture is only of value if it provides information that is conducive for treatment and/or interventions. To name an example, solely information about a persons' skin colour would not be of any use and therefore irrelevant for treatment, whereas other variables like origin and language could be helpful (Bophal, 2006, p.30).

Literature emphasises that ideas and attitudes concerning health are primarily influenced by the SES and religious affiliation and less by the country of origin (Durieux-Paillard, 2011, p.204-208). Kleinmann & Benson (2006, p.1673) also point out the fact that in medical settings the

consideration of cultural concepts is not necessarily helpful to a patient's conditions. On the contrary, sometimes it might even constrain the practical understanding of a case.

In the field of health promotion experts' agree on the relevance that promotion interventions and health education should follow a culturally sensitive approach. In 1999 Resnicow (cited in Cullen et al., 2002, p.7) established a framework to support practitioners while designing cultural sensitive programmes.

Resnicow's dimensions of cultural sensitivity in public health (Resnicow et al., 1999, p.10):

Surface: "matching intervention materials and message to observable "superficial" characteristics of a target population." "...using people, places, language, music, food, locations and clothing familiar to, and preferred by the target audience."

Deep structures: "...incorporating the cultural, social, historical, environmental and psychological forces that influence the target health behaviour."

Based in these two dimensions, health promotion interventions and materials would be considered as cultural sensitive if both superficial and deep structures have been incorporated in the design, delivery and evaluation (Resnicow, 1999 cited in Cullen, 2002, p.7).

In other words, surface structures are intended to address "superficial" characteristics of the target group and thus positively impact the acceptance of intervention messages. Deep structures aim to thoroughly understand the beliefs and values of a culture. In health communication it is intended to adapt intervention material on the level of deep structures.

To answer the research questions, the DEPs under investigation will be examined concerning adaptation on superficial and/or deep levels. In this regard it might be interesting to discover usage of the framework for multi-ethnic groups.

2.7.2 Socio-cultural Aspects: Gender, Eating Habits, Language

The previous sub-chapter discussed different definitions of culture and ethnicity whereas this section emphasises on socio-cultural aspects including gender, language and eating habits.

Eating habits are linked to traditions and social values, and are community specific. Especially among EMGs, dietary customs and social eating behaviours play a major role. Part of identification takes place through eating traditional food. The single aspect of sharing similar eating habits already generates a feeling of holding on to one's own culture and creates group affiliation (Kittler, Sucher & Nelms, 2012, p.4-5).

Women are, in general, more conscious about their eating habits and tend to eat healthier compared to men (Muff, 2009, p.130). According to traditional family structures, this is valid for every culture – women are responsible for their families' health and nutrition as well as to take care of the next in kin. This might lead to better health consciousness and an increased level of food related knowledge (Muff, 2009, p.127). However, contrary to expectations, DSM skills of women are not better than of men (Connell, Fisher & Houston, 1992 cited in Gallant, 2003, p.185). A possible explanation for that could be the gender specific role of women in a family context. The fulfilment of maternal care might leave little time to care about the one's own health and consequently affects the ability of women's DSM.

McLeans's research (1998) assessed by Gallant's review (2003, p.185) discovered a disparity between direct support and gender roles. In terms of dietary needs women tend to support their husbands to a greater extent than vice versa. Spouses adapt their cooking habits often to the necessities of their diabetic husband. Whereas diabetic women, even though they would describe their husbands as supportive, often have to prepare two sets of meals, one regular one for their husband and one that suits their own needs.

The issue of language comprises two main dimensions, the language based on one's country of origin or residence and the sociology of language. The latter refers to class and/or community specific communication, including group specific language codes, modes of expression, and the complexity of sentences.

For decades it has been known that social groups dissociate themselves from each other through linguistic differences. Forms of spoken language are assumed to be group specific. Bernstein's (1960, p.271) study even argues that the way of speech reveals the social environment and status of people. The greater the gap between the SES is, the more obvious his hypothesis becomes.

Considering the different dimensions of language (the spoken language, intellectual level and group specific wording/use of terms) might be conducive for inter-personal communication, health outcomes and thus DEPs.

2.8 Diabetes Education

Diabetes is a chronic condition and health outcomes strongly relate to disease self-management competence; hence, diabetic patients require knowledge and self-mastery over their own condition. For that reason, current debates and international guidelines (IDF: Global Guidelines for Type 2 Diabetes, 2012; National Evidence Based Guideline for Patient Education in Type 2 Diabetes, Australia 2009; Nationale Versorgungsleitlinie: Therapie des Typ-2-Diabetes, Deutschland 2013;

NICE Guidelines: The management of T2DM, UK 2008) acknowledge diabetes education as a core element that is attributed to good treatment outcomes. However, research is scarce on cost-effectiveness. Even so, economic perspectives ascribe diabetes education as relatively reasonable, in particular if lifestyle changes are maintained for a long-term (Jacobs-van der Bruggen et al., 2009, p.1456).

Due to the chronic nature of T2DM, it is recognised as being essential that diabetics understand the link between lifestyle factors and health outcomes. On these grounds people suffering from diabetes require life-long guidance, and they especially need to build up the capacity to manage their own disease. In the last decades a growing recognition of health disparities can be observed, which is particularly evident in matters of health comparing EMGs and the native population (Hawthorne et al., 2008, p.3; LaRosa & Brown, 2005 cited in Ujcic-Voortman et al., 2009, p.511; Rechel et al., 2011, p.4-5; Zeh et al., 2012, p. 1237).

„...minority ethnic groups often suffer a higher prevalence of type 2 diabetes mellitus than the local population. ...cultural and communication barriers increase the problems minority ethnic communities experience in accessing good quality diabetes health education, a vital aspect contributing towards patient understanding, use of services, empowerment and behaviour change towards healthier lifestyles.“ (Hawthorne et al., 2008, p.2).

As stated above reasons for the disadvantaged position of EMGs in health issues goes beyond formal barriers like health care coverage (Mladovsky, 2011, p.185). The increasing acknowledgement that health inequalities are also caused by informal obstacles (like language) stresses the need for cultural specific DEPs. This association is shown in the reduced benefit of EMGs from standard diabetes care (Hawthorne, 1990; Leedham, 2000 cited in Hawthorne et al., 2008; Zeh et al., 2012, p. 1237). Therefore, the importance to face the needs of immigrant populations and to fight T2DM is indisputable.

For the care of chronic conditions responsibilities have to be shared and role allocation newly defined. One key aspect is, that the patient should become the primary actor and the health professional the facilitator who supports the diabetic patient (OECD, 2012, p.21; Skinner et al., 2006, p.369). Encouraging health by empowering the target group and providing access to information are common principles seen in the field of health promotion (WHO, 2009b, p.2) and recommended for DEPs.

Although consistency exists that diabetes education require adaptation to the target groups' needs (Glazier et al., 2006, p.1687; IDF, 2012, p.21; Ingleby, 2011; Zeh et al., 2012, p.1237-1249) it

remains unclear which variables of culturally sensitive diabetes intervention make the difference (Hawthorne et al., 2008, p.3-4). Furthermore, Attridge's (2014), Hawthorne's (2008) and Zeh's (2012) literature reviews highlight the heterogeneity of studies and the difficulty to standardise and compare existing programmes.

However, this study focuses on variables that influence the design and implementation of DEPs on the basis of the current state of literature and in a country-specific context. Beyond that it will explore experts' perspective on programmes' feasibility and how these variables and structural circumstances influence and intersect with the vulnerable position of EMGs.

2.8.1 Language Barriers

Associated with cultural diversity is the endeavour to find a common language of communication. Conventional diabetes care is offered in the local language although among EMGs the language competence is often insufficient to follow medical explanations (Hanif & Karamat, 2009, p.30; Ilkilic, 2010, p.31; Kofahl et al., 2009; Uitewaal et al., 2004, p.15).

Informal ways of translation often by lay people such as children or third persons are common solutions to overcome language barriers. The neglected need for professional translators bears the danger of miscommunication, missing confidentiality, poor treatment compliance and ineffective therapy (Ilkilic, 2010, p.31-32).

Discussions include both ways to improve communication and how these services should be paid for. The NL enacted a law in 1995 that obliges health professionals to communicate with patients "in (a) language they can understand" (Ingleby, 2011, p.235). The UK introduced the "race equality obligation" implying the provision of language assistance in order to avoid "institutionalised discrimination" (Ingleby, 2011, p.235). However, there is little information about the enforcement of these legislations and if these legal instruments increase the provision of legal interpretation services.

Language barriers are one of the major concerns in medical encounters especially in multi-ethnic populations (Terraza-Núñez et al., 2010 cited in Durieux-Paillard, 2011, p.205). The importance to address challenges around language is supported by the assertion that unresolved language barriers increase costs because of lower treatment adherence, a higher likelihood of misdiagnosis and more disease complications (Jacobs 2004; Muela Ribera et al., 2008 cited in Durieux-Paillard, 2011, p.206).

2.8.2 Health Literacy

The Healthy People 2010 defined HL as the capacity to receive, process and understand health information and the capability of using this information effectively.

Research in the last decades has demonstrated that HL of patients poses a greater problem as pure issues of language contribute to miscommunication, late diagnosis and poor treatment outcomes (Kofahl et al., 2011, p.6; Vissenberg et al., 2012, p.2; White et al., 2010, p.1-2). In the EU the concept of HL has been relatively new, although studies have been done in the US, which yield alarming results. Safeer & Keenan (2005, p.463) detected that even high school graduates present literacy deficits with an increased age resulting from a declined cognitive function. For older people and foreigners the problem is compounded because of both variables age and the link between time span after schooling and level of literacy (Safeer & Keenan, 2005, p.463).

Easton, Entwistle & Williams (2013, p.9) conducted a qualitative study on how stigma of low literacy affects patient-professional interactions and treatment outcomes in the UK and found out that the spoken interaction is seriously impaired and even patients' potential to benefit from health care is reduced. The assertion supports that milieu specific communication is crucial for good health communication.

Furthermore, it is widely accepted that most patients would benefit from medical information in an easy and concise language including non-written material (Safeer & Keenan, 2005, p.463; Stone, 2005). A German study detected a linear relationship between the level of T2DM knowledge and the participation in culturally appropriated DEPs (Kofahl, 2011, p.5-6). The study emphasises low education as the main risk factor for low HL and poor diabetes management. On average diabetic patients with a low school degree are less content with health education, which indicates the need to modify DEPs to specific needs of the target group (Kofahl et al., 2009, p.27-28; Kofahl, 2011, p.5). The WHO (2012) calls to face the challenge of HL as it improves patients' access to health information and their ability to use it adequately, both vital elements to empowerment. The concept of HL can be even viewed as a precondition for empowerment, participation and social inclusion.

2.8.3 Empowerment

The WHO's Alma Ata Declaration set the goals of community participation and equity for the first time in 1978, and added empowerment in the Ottawa Charta and Jakarta Health Promotion Declaration in 1986 (WHO, 1986; WHO, 1997).

Empowerment enables individuals' and groups' to make decisions and to gain control of factors that shape their lives (WHO, 2009a). The process of empowerment can be understood as a multilevel

construct and hence it is normally part of a comprehensive approach. On the example of diabetes the following levels might play decisive roles in self-management: psychological empowerment meaning patient's self-efficacy to increase control of their lives; an action-oriented focus aiming for the removal of formal or informal barriers, and empowerment as an instrument to influence power relationships.

Empowerment cannot be given or taught; it is a process of individuals and hence cultural, society and population specific. Strategies require sensitive adaptation to the present conditions (Wallerstein, 2006, p.18).

2.8.4 Challenges in Tailoring Diabetes Education Programmes for Ethnic Minority Groups

The literature review of this study intimate that DEPs tailored for EMGs face multifaceted challenges. The difficulty derives from at least five different aspects:

- Disadvantaged groups/immigrant populations are very heterogeneous (high diversity of intra- and inter-group characteristics) demanding different strategies (Ingleby, 2011)
- Disadvantaged groups present a number of high risk factors (Kunst, Stronks & Agyemang, 2011, p.106; Ujcic-Voortman et al., 2009; Vissenberg et al., 2012, p.2)
- Health professionals are often not formally trained to meet the needs of vulnerable groups (Skinner et al., 2006)
- Diabetes care of people with a low SES/low HL level is time and cost intensive, even though there is little evaluation on the cost-effectiveness of culturally appropriated diabetes education (Attridge, et al., 2014; Hawthorne et al., 2008)
- Treating T2DM requires lifestyle changes which are tremendously difficult, especially at an adult age (Jacobs-van der Bruggen et al., 2009, p.1456; Vissenberg et al., 2012)

Chapter 3: METHODOLOGY

This chapter explains the methodology that has been used to answer the research question. Research methods, applied inquiry instruments, the process of data collection and data analysis will be described and limitations and quality criteria will be discussed.

3.1 Goal of the Empirical Research

As previously discussed, European health sectors, stakeholders and health professionals need to react to issues faced by the diabetic epidemic especially in multi-ethnic communities. Culturally sensitive guidelines are lacking and approaches vary greatly within the EU. This is largely caused by the heterogeneity of the target audience concerning their characteristics and needs as well as differences in HCS and policies. On the other hand empirical findings on that topic are conflicting and extremely difficult to compare (Attridge et al., 2014, p.27; Hawthorne et al., 2008, p.19).

Indeed many programmes have been evaluated and analysed in terms of qualitative and quantitative measures. However, barriers to implementation from an expert perspective have not been examined so far. Primary topic of interest is about the feasibility of strategies in practice.

By conducting a qualitative research, experts get the opportunity to elucidate their point of view upon this controversially discussed topic. The inclusion of two groups of experts (see section: “Definition of experts”, p.40) with either a theoretical or a practical focus of knowledge leads to a broader consideration of the research question.

The study aims to unravel issues around tailoring diabetes education to EMGs through the investigation of four diabetes interventions, in the NL and the UK.

Literature and field data was analysed to answer the research question and sub-questions:

Are the existing culturally tailored diabetes education programmes applicable and what are the influencing variables?

1. *Which attributes characterise diabetes education programmes tailored for ethnic migrant groups?*
2. *What kinds of barriers exist?*
3. *Which variables have a positive impact on implementation?*
4. *Do experts' solutions and suggestions in the NL and the UK differ and/or correspond?*

3.2 Research Method

The study is a comparative qualitative case study which combines expert interviews and document analysis. The Qualitative Content Analysis (QCA) was chosen as an adequate Qualitative Research Method (QRM) as it provides the facility to approach topics from an interpretative, case-oriented, naturalistic perspective (Schreier et al., 2012 p.20-27) and offers a pragmatic method of analysing field data that was extracted from expert interviews (Mayring, 2008b).

One of the major distinctions to quantitative research is the advantage of assessing underlying reasons behind outcomes. Flick, Kardorff and Steinke's (2009, p.14) work describes the possibility to discover unknown findings in apparently known facts. Since the study area "diabetes education for EMGs" is still not fully understood, QRM enables the researcher to discover unveiled aspects, synergies and obstacles that might impact such programmes. It is further particularly suited for research in the field of intersectionality theory.

3.2.1 Source of Data

Both sources of empirical data i.e. primary and secondary were analysed.

Information was obtained mainly from primary sources - expert interviews. Two groups of experts were recruited. One group presented field data from a theoretical perspective (categorised as "developer") and the other group had experience primarily in practice (categorised as "implementer"). The initial intention was to categorise the field data according to the two groups of experts. However, in practice, it became clear that experts' fields of functions were not strictly bound to either delivery or development. Therefore extracted data was not strictly assigned to the group of "implementer" or "developer".

Secondary sources of data were used to identify culturally tailored diabetes interventions and for document analysis. As aforementioned (see 1.1 "Source of Data", p.9) electronic databases were searched for the literature review and also conducted for identification of potential DEPs. Abstracts were examined for relevant interventions implemented in the UK or the NL. Studies published after 2004 were included.

In total 52 examples of culturally sensitive DEPs were retrieved and checked for inclusion criteria. After reading the abstracts 29 studies were excluded and a further 19 were considered unsuitable as they were not conducted in a European context. 10 articles and 8 interventions were included. Of those, 6 studies and 4 programmes were included for the empirical part of this study.

The included DEPs were analysed by reviewing the literature and research papers. Data was also derived from websites of organisations that run diabetes programmes. Also guidelines from various

institutions on diabetes education were analysed. These included the National Evidence Based Guideline for Patient Education in Type 2 Diabetes, Australia 2009; Nationale Versorgungsleitlinie: Therapie des Typ-2-Diabetes, Deutschland 2013; NICE Guidelines: The management of T2DM, UK 2008. The international diabetes guidelines showcased recommendations of best practice for the general population and therefore provided a benchmark for good practice in the context of this study. Secondary data was relevant to this research topic as both evidence-based knowledge and empirical findings form a holistic understanding of issues around culturally tailored diabetes care. Data about existing interventions for EMGs and the current situation in Europe was further investigated through correspondence with experts via email. In this context, the term experts encompasses persons working in the IDF Europe, UKE staff, persons in the research field from Germany, the NL, Austria, the UK, and experts who are involved in other DEPs.

3.3 Guideline-Based Expert Interviews

Field data was collected through guideline-based expert interviews. Interviews were carried out via the telephone communication. This provided a communication level which encouraged experts to share experiences, attitudes and existing barriers more openly. So far the study population “experts” have not been approached in scientific literature except for a Belgian study (Wens et al., 2005) that assessed problems experienced in T2DM treatment and possible solutions from physicians’ perspective. Instead, this qualitative study refers to experts who are involved in DEPs specifically tailored to immigrants. With the help of semi-structured guidelines information was gathered around experts’ experiences concerning EMGs, culturally tailored education strategies and perceptions about their interaction.

3.3.1 Definition of “Experts”

The study refers to the definition of experts by Meuser and Nagel (1991, cited in Littig, 2008 p.4) which highlights the fact that the status of an expert is assigned by researchers on grounds of an advance in knowledge in the research field of investigation. Hence experts can be understood as informants, persons who command knowledge, which is otherwise inaccessible for the researcher. These persons are often in leading positions or bear responsibility in decision-making processes. In the end any person with an advanced access to knowledge and responsibility can be understood as an expert (Bogner & Menz, 2005 cited in Littig, 2008, p.4).

For this study experts were recruited according to predefined selection criteria (table 3.). Persons who were defined as experts and appropriate to answer the research question live and work either in

the UK or the NL were included. They are or were involved in diabetes care and have work experience with EMGs. Thus the selected persons are well grounded in knowledge in the research field and therefore eligible as experts.

3.3.2 Selection of “Experts” and Culturally Tailored Diabetes Programmes

Prior to the recruitment of potential experts, selection criteria for experts as well as DEPs had been ascertained (table 3. and table 4.). It was intended to investigate three to four different diabetes programmes by conducting six to eight interviews, each with another expert.

During the recruitment process, programmes had been checked regarding inclusion and exclusion criteria and sequentially experts were identified. The sample of experts interviewed was guided by their practical expertise in planning and conducting culturally adapted DEPs.

Inclusion and exclusion criteria for the recruitment of interventions are presented in Table 3.

Table 3. Selection criteria for DEP

Inclusion criteria	Exclusion criteria
DEP specifically designed for EMGs including at least one aspect of the following: adaption to cultural or religious health beliefs, linguistic competence of the target community and/or HL levels	DEP addressing the general population
DEP that aim to promote self-management. Intervention should focus on some lifestyle factors (dietary advice, physical exercise, weight reduction, smoking etc.), increase knowledge, behaviour change (self-efficacy), self monitoring of blood sugars	Diabetes care that exclusively aims to improve intake of medications
The DEP has to be either formally evaluated or an evaluation plan has to exist	DEP without evaluation concepts
The DEP concept and evaluation need to be available in English, Dutch or German	Languages other than English, German or Dutch

Source: Own creation

In addition to the criteria listed above, one more criterion stating that DEPs should be currently implemented was initially included as a prerequisite. However, after an extensive period of selecting programmes this criterion had to be abandoned. In the NL it was unfeasible to identify any culturally sensitive DEP for EMGs that were evaluated and are currently implemented due to structural barriers and political decisions (see “Chapter 4: Results”). This finding will be discussed later but led to the decision to include programmes which are not implemented and/or specifically

target Turkish and/or Moroccan immigrants as it displays the current situation of diabetes education in the NL.

In contrast DEPs for EMGs that fulfil both criteria were relatively easy to recruit in the UK at least for the biggest EMG, the SAs. Admittedly, DEPs for Turkish immigrants were not found.

In Germany in particular one culturally sensitive DEP was identified. The reason as to why Germany was excluded from the data analysis is based on the fact that the SITD⁴ research project at the UKE included an extensive research including expert interviews in that field. In consultation it was decided that this work try to afford new insights instead of investigating existing DEPs all over again.

Inclusion criteria for the recruitment of “experts” are presented in Table 4.

Table 4. Selection criteria for “experts”

Persons who were involved in the development of the investigated DEP (planning process)
Persons who deliver/delivered the investigated DEP (implementation)
Language competence in English or German

Source: Own creation

Initially it was intended to have equal gender distribution among experts because of the assumption that participants’ reactions might be gender related and could affect DEPs. Theoretically this would be interesting. However, this study found that male health educators rarely delivered DEP. The possibility exist that the gender of health educators might influence outcomes but to answer the research question it was decided to maintain given circumstances and to stick as closely as possible to conditions of real life. Consequently, interview partners were selected independently from their gender, the balance of male and female experts was not of relevance.

3.3.3 Approach with “Experts”

Following the recruitment of suitable DEPs, experts who developed and/or deliver the included programmes were approached. Websites, scientific articles and recommendations of experts (snowball technique) helped to get in contact with potential interview partners.

Initial experts were contacted via a written notice (e-mail), which contained information about study’s content and goal as well as the estimated expenditure of time required for the interview.

⁴ SITD (“Entwicklung und Evalua at the Centre for Psychosocial Medicine and the department for General Medicine at the University Medical Centre Hamburg- Eppendorf (UKE).

The enquiry to participate in the telephone interview was clearly stated. If somebody agreed to take part, a short summary of the empirical study and a written consent was sent to the interviewee with the request to sign and return the document.

The interview partner was informed about the interview language being English prior to the interview.

3.3.4 Developing the Interview Guideline

The interview guideline should lead the semi-structured interviews whilst the natural course of conversation remains preserved (Gläser & Laudel, 2004, p.107). For that reason guideline structure was flexible, and sequence and phrasing of questions was not strictly adhered to (Gläser & Laudel, 2004, p.138).

Relevant topics and sub-topics to answer the research question were identified and specified on the grounds of previous literature research.

The guideline's content and structure is greatly influenced by the Cultural-Competent Assessment Tool (CCAT) (see Appendix E). The assessment tool helps to detect aspects that facilitate and/or hamper implementation of culturally sensitive health care interventions. The CCAT was originally developed by Kutob, Senf & Harris (2009) as a written self-assessment tool to evaluate a culturally tailored diabetes programme in the US. Appropriate items have been selected on the basis of existing and validated instruments, among others, the Multicultural Awareness/Knowledge/Skill Survey (MAKSS), the Cultural Self-efficacy Scale, and the Intercultural Development Inventory (IDI) (cited in Kutob, Senf & Harris, 2009, p.169). The final version of the CCAT passed two rounds of pre-testing and was considered as reliable.

In addition, the interview guideline established for the SITD project which investigated diabetes education in a German context, was considered in the process of development. The exchange of insights with the SITD staff⁵ further finalised the subject areas covered in the interview guideline.

To answer the research question at hand the group of experts were divided into two sub-groups:

1. Persons who developed culturally adapted diabetes programmes
2. Persons who deliver the education to the target group

The two guidelines cover the same subject areas, nonetheless some questions vary and sub-topics are emphasised differently.

⁵ Thanks to C. Mews, J. Wrede-Sach and Dr. rer. hum. biol. N. Pohontsch

Working out experts' wealth of experience and resulting recommendations for action, main subject areas have been defined in order to take stock of DEPs available for EMGs and expertise in the UK and the NL. The main topics are listed below in table 5.

Table 5. General structure of the interview guideline

<p>Introduction</p> <p>1. Personal data of expert</p>
<p>General Insight of Diabetes Education Programme (DEP)</p> <p>1. Conception of DEP for EMGs 2. Theoretical background underpinning DEP for immigrants</p>
<p>Internal Factors: Implementation</p> <p>1. Cultural influence 2. Difficulties associated with cultural appropriated DEP 3. Consideration of HL and/or SE factors 4. Barriers</p>
<p>External Factors</p> <p>1. Structural factors impacting the practicability of DEP</p>
<p>Conclusion</p> <p>1. Experts' recommendation</p>

Source: Own creation

The last question channels the amount of information that arose from the interviews. Asking the interviewee to name key issues, demand for action and solution approaches triggers the interviewee to prioritise items and reduces data material.

3.3.5 Proving the Interview Guideline

Before implementation the interview guideline was approved by Prof. Dr. Färber (head examiner / University of Applied Sciences Hamburg) and Prof. ret. Deneke (co-examiner / University of Applied Sciences Hamburg). Also the SITD staff (C. Mews & J. Wrede / University Medical Centre Hamburg-Eppendorf) and Dr. rer. hum. biol. N. Pohontsch (expert for qualitative research / University Medical Centre Hamburg-Eppendorf) counterchecked the closed and open questions.

The manageability of each interview guideline was pre-tested in three interviews. The aim of pre-testing was to improve item clarity. Aspects that caused difficulties during the pre-testing stage were identified and discussed with SITD staff and the head examiner. At the end some questions were changed and ambiguous ones removed.

3.4 Data Collection

3.4.1 Accomplishment of Data Collection and Study Site

All interviews were conducted via the telephone. The interviews lasted between 41:49-90 minutes excluding introduction and obtaining consent that the interview would be audiotaped.

Data collection was in Hamburg/Germany whereas the interview partners were in Germany, the NL and the UK. In total ten interviews (including the three interviews for pre-testing purposes) were conducted. Seven interviewees were at their workplace and three experts participated in the interview while being at home.

3.4.2 Interview Language

English was the prime interview language, nevertheless if interviewee switched to German and/or Dutch the interview continued without restrictions.

Of the three interviews during pre-testing, two were conducted in German and one in English. Seven interviews were included and analysed. One interview in the NL was excluded from data analysis because the interviewee was not completely involved in the development of the programme, and hence did not have the ability to provide information about most of the categories asked during the interview.

Further, English as the interview language caused problems. Even with the inclusion of German and Dutch communication remained complicated leading to an uncertainty about the significance of extracted data and the likelihood of bias due to interpersonal communication difficulties. At the end six interviews have been included in the data analysis. All of them were carried out in English, although one interviewee replied partly (single words) in Dutch.

3.4.3 Preservation of Anonymity

Prior to the interview all experts became assured that their name would not be mentioned in the study and their statements remain anonymous. Nevertheless, by stating the name of the assessed diabetes educations and with regard to the small number of programmes, experts might be identified easily at least among persons who are involved in the research field.

Grounded on that and for reasons of data protection it was decided to use code names for the experts, interventions, and locations.

3.4.4 Storage of Data

The interviews were audiotaped and saved on digital storage media for purpose of capturing the entire interview as well as specific statements (Gläser & Laudel, 2004, p.152). Whilst the interview was being conducted field notes were taken in case of important remarks.

3.5 Data Analysis

The generated data was analysed in the framework of QCA developed by Mayring. Mayring's content analysis constitutes procedures in order to structurally organise, analyse and interpret texts obtained through communication (Mayring, 2008a, p.42-43).

The concept offers three methods of interpretation: summary, explication and structuring. Furthermore, the form "structuring" consists of four techniques to structure data material: formal, content, standardising and scaling (Mayring, 2008a, p.58-59;). The technique "content structuring" has been chosen to be adequate for this study as the interview material is divided and summarised in specific topics, contents and aspects (Mayring, 2008a, p.85&89).

Mayrings' approach offers a unique way of organising, analysing and interpreting the data. Most notably is the adaptability to the subject of research.

„...Content analysis is not a standardized instrument that always remains the same; it must be fitted to suit the particular object or material in question and constructed especially for the issue at hand.” (Mayring, 2014, p.39)

The category system builds a central element of QCA (Mayring 2014, p.40; Schreier, 2012, p.58). The flexibility of building categories and coding allows the researcher to narrow down the large amount of generated data to the essential parts with relevance to the research question. In addition, a category system enables comparability of results and it provides criteria for evaluation, validity and the reliability of data analysis (Mayring, 2014 p. 40; Rustmeyer, 1992; Shapiro & Markoff, 1997 cited in Schreier 2012, p. 5).

The study followed the common "sequence of steps" that is used for QCA (Schreier, 2012, p.5-6):

1. Defining the research question
2. Selection of material
3. Establishing the coding frame
4. Dividing material into units of coding
5. Testing coding frame
6. Evaluating and modifying coding frame
7. Main data analysis
8. Interpretation and demonstration of findings

All nine interviews (including the three interviews that pre-tested the guidelines and without the interview that was excluded) were transcribed completely. The rules of “simple transcription” applying the “F5” audio transcription software (Dresing & Pehl, 2013, p.19-24) served as a guideline for transcription. The purpose of expert interviews is the generation of factual information therefore para-linguistic fill words and sounds such as hm, ähm etc. were excluded for the transcription.

The audio was repeatedly listened to in order to minimise errors and if needed to correct transcription inaccuracies. On condition that text phrases of the conversation were opaque a second neutral person was called in for clarification of statements. In parts the quality of replay was impaired because of background sounds, less-than-ideal sound quality, speaking with low voice or mumbling, and switching languages. After transcription was completed and checked for erroneous data it was saved in rich text format, which is software-compatible with the computer analysing programme MAXQDA. To ensure data protection pseudonyms were used to replace features like names, locations, and diabetes education interventions.

The computer-assisted software MAXQDA was used as an instrument for the content analysis. As aforementioned, the established category system including codes and sub-codes builds an essential framework for the analysis. The category system was developed in two steps, first main categories were defined building the general frame followed by the formulation of sub-categories. (Schreier, 2012, p. 58-60).

An attribute of QCA is the distinction in category building; categories are either based on inductive or deductive procedure. They differ from each other regarding their time of formulation. The main idea of the deductive procedure is to formulate the criterion before analysis, building a framework for the following text analysis. Whereas the inductive criterion is established after data collection, which means the criterion is derived from text material (Mayring, 2014, p.79&95).

For the work in hand prior to analysis, a set of deductive categories were established which built the framework for the two interview guidelines and secondly served as criteria for coding data. During data collection new information was revealed which could not be allocated to the already existing categories. Therefore, additional categories were developed applying the inductive technique post-interview. For each category and sub-category a name, a clear description and code rules were established in order to increase the level of consistency (Mayring, 2014, p.95).

Information was captured through reading the crude data meanwhile sentences and text phrases were systematically assigned to categories and sub-categories (Gläser & Laudel, 2004, p.192-194). In this way essential information was extracted from the material. The category system contained an extra category named “additional information”. To prevent the loss of relevant data all text sections

that were considered as relevant but not clearly classifiable to one of the other categories were allocated to “additional information”. The content was later included in “Chapter 5: Discussion” of results.

Beyond analyses the category frame was used for the presentation of results (Schreier, 2012, p.219). Field data was analysed within each category and sub-category and later discussed across categories.

3.6 Quality Criteria

The QCA, as with other research methods needs to be assessed regarding certain quality criteria in order to prove reliability and validity. This study will be discussed in the following text. The applied criteria are based on Mayring’s quality criteria for QCA (Mayring, 2008a, p.109-115; Mayring, 2002, p.144-148) and on Schreier’s recommendations for quality control (Schreier, 2012, p.250-253).

3.6.1 Reliability

The careful construction of categories as well as the assignment of data to those categories plays an essential role for reliability and inter-coder consistency Mayring (2014, p.109). Also Schreier (2012, p.250) describes the consistency of coding as the main criterion of reliability. The examination can be either done by more than one researcher or at different points in time.

Within a timespan of four weeks coding where repeatedly checked on both a spreadsheet showing each code in relation to the category and with the demonstration in MAXQDA software where the texts paragraphs and the assigned codes are presented each at one side of the screen. Together with a second assessor the application of categories to the material (coding) was discussed. Discrepancies were identified, code memos re-checked and if needed text paragraphs newly allocated.

3.6.2 Validity

The importance to assure scientific quality is beyond question, however, validity of qualitative research has been discussed from various perspectives (Cresswell, 2013, p. 244). The study in hand was tested in regard to accuracy and validity based on Mayring's (2002, p.144-148; 2014, p.109) six quality criteria for qualitative research.

I. Process Documentation:

Good process documentation is given when outsiders can reconstruct the applied methods that led to study results. In order to comply to the quality criteria "process documentation" the study in hand provides detailed description of methodology regarding procedures of data collection and analysis.

II. Interpretation Safeguards:

This criterion highlights that statements of interviewees need to be free of expectations and assumptions from researchers' side. Quality of qualitative research is assured if interpretations are reasonable and coherent. This study ensures both, as results reveal consistent as well as contrasting opinions instead of a biased demonstration of field data. In addition text material incorporated different angles of experts' views. Interviewees' statements (quotes) were used to facilitate understanding of analysis, interpretation and argumentation of results.

III. Closeness to Object:

Proximity to object means that data is collected in close vicinity to the study subject. This implies the consideration of the investigated population groups' (EMGs and provider) interest. The work in hand examines experts' wealth of experience and their point of views regarding diabetes programmes for EMGs. In addition it aims to identify barriers, reveal suggested solutions and finally to make recommendations. The intention to improve diabetes care offered to EMGs while taking account of provider and receiver side, confirms that closeness to object is provided.

IV. Adherence to Systematic Analytical Procedure:

Although an attribute of QRM is the openness to the study subject notwithstanding rule-boundedness is important for quality assurance. This work fulfils the criteria of "adherence to systematic analytical procedures" as rules and procedures of QCA were followed during investigation and data analysis.

V. Communicative Validation:

The quality criterion "communicative validation" is fulfilled when the entire data material (all interviews) would be revised and discussed with each single interviewee. Unfortunately this criterion was not within the bound of possibilities, in respect to time and human resources. Notwithstanding, all respondents checked on the tables 7. and 8. via email and experts were contacted again in case of obscurities and incompleteness of information.

VI. Triangulation:

Triangulation intends to answer the research question by looking for different solution approaches and comparing results, which in turn increases the quality of the qualitative research (Mayring, 2002, p.147). It is possible to compare several sources of data like different authors, opinions and theoretical approaches to come to a solution.

The work in hand does not apply “triangulation” in a classical way. But issues are discussed from different angles hence a triangulation of perspectives is given.

This study achieved to include more than one source of information. Two groups of experts were interviewed (developer and implementer of DEPs for EMGs), one group provided perspectives on theoretical conceptions and the other revealed practical issues around feasibility of theoretical concepts. Document analysis of DEPs was a second source of data. The analysis took place prior to interview taking, which enabled a comparison of responses concerning their consistency.

3.7 Discussion of Methodology

The following two sub-chapters are concerned with methodological challenges and limitations of this work. Among others, difficulties of recruiting appropriate diabetes educators, access barriers, uneven language competence and aspects of bias are elaborated.

3.7.1 Difficulties Recruiting Experts and Diabetes Programmes

Cresswell (2013, p.99) distinguishes between three types of case studies. The comparative qualitative case study was chosen as an adequate research method for this study because multiple DEPs were selected, at the same and at different research sites. With regard to present significant results the inclusion of representative cases is considered as good practice (Cresswell, 2013, p.99-100).

Initially it was planned to investigate each programme on grounds of three interviews, one with a person who developed the DEP and two with persons who deliver sessions. The idea was to reduce subjectivity and arbitrary results. Aspects such as personal background, level of education, occupation, and personal point of view might have had some influence on interviewees’ responses. Increasing the number of interview partners might reduce subjectivity. However, during the selection process of DEPs and experts it became apparent that sampling is extremely time consuming and a difficult part of qualitative research.

Ascertained obstacles to overcome were mainly country specific and rather grounded on the difficulty to identify appropriated DEPs than on the recruitment of experts. In the UK diabetes

education is well established and based on organisations that provide national wide DEP coverage. DEPs for EMGs exist under the same head of organisations and thus were easy to identify and recruit via e-mail. As discussed earlier, DEPs for EMGs are lacking in the NL. No programme could be identified that suited all pre-defined inclusion criteria.

To facilitate the recruitment process e-mail contact was established with persons that were by any means involved in the field but not appropriate as interview partners. Dexter's work (2006, cited in Littig, 2008, p.8) suggests, that having those contacts are beneficial as they might recommend other DEPs and liaised with potential experts. During the investigatory process about twenty experts in the EU were contacted, all of them indicated great interest in the study and tried their best to help with sampling. The resulting heterogeneity of included diabetes interventions for EMGs could be a weakness of the study if it is not carefully considered for the analysis of findings.

Furthermore the targeted gender distribution among experts could not be achieved. The inclusion of equal numbers for both genders was not practical as professions like "diabetes nurse/dietician" are traditionally female occupations and male health educator still very scarce. In that respect one limitation of this study is the missing information about gender related reactions of participants. From the above it becomes clear that there is a danger of selection bias as only a few persons met the inclusion criteria due to the limited number of eligible programmes.

Experts' being pressed for time is a well-known limitation for recruitment (Littig, 2008, p.8). However, once experts confirmed their participation, it was guaranteed. Not a single dropout occurred. Nevertheless the issue of time had an effect on the time schedule of this study.

3.7.2 Limitations

One limitation of the work relates to unequal levels of communication. English was the primary language for all interviews. The fact that English is not the native language of the Dutch experts might lead to insecurities, difficulties to express their points of view with accuracy and restriction in argumentation. Especially in QCA where interpretations are based on the spoken word, unequal preconditions for communication might affect data analysis. Even though the included experts had good language skills in English the imbalance in terms of verbal communication became obvious by comparing the time required for interview. Although the same guideline was applied, the required time for interview conduction ranged from 41:49 to 60:03 minutes in the UK to 82 to 90 minutes in the NL.

Some limitations deal with subjectivity of the interviewer. In few exceptions examples were given either for clarification or to maintain the flow of conversation. These could have influenced responses.

The two countries present differences in policy, HCSs and DEPs for EMGs. As a consequence an unequal amount of programmes/experts were recruited in each country. Four interviews were conducted in the UK and only two in the NL, which is not necessarily a limitation but leads to an imbalanced demonstration of interventions as more data material was gathered in the UK.

Within the scope of this study inter-coder comparison was not possible. The fact that one coder only coded data material increases the likelihood that researchers' perspective influenced the analysis process. Nonetheless, quality was assured. Cooperation with a second assessor ensured the overall data was reviewed, discussed and if necessary newly coded. Further reliability and validity criteria were largely fulfilled.

Chapter 4: RESULTS

This chapter provides an overview of the extracted data from the field. The findings indicate that diabetes interventions for EMGs have to deal with two main areas: cultural adaptation and barriers to implementation. Categories and sub-categories were developed to build a structural framework for data analysis and to classify data according to the area of focus. An overview of the category system is presented in Table 6.

Table 6. Overview of category system

Categories including Sub-Categories	Description
1. Personal data	This category provides an overview of respondents' background and their role.
2. Characteristics of DEPs for EMGs 2.1 Concept 2.2 Needs assessment 2.3 Communication 2.4 Health literacy 2.5 Methods and material	Characteristics of the four interventions are demonstrated, comprising the concept, findings and methods during the investigatory phase, issues around language and communication, inter-personal relations during sessions, and material.
3. Cultural Influence 3.1 Identity 3.2 Health beliefs 3.3 Lifestyle aspects 3.4 Organisational aspects	This category is divided into four sub-categories to reveal different aspects of culture. It shows the phenomenon of group affiliation, culture specific attitudes, beliefs and preferences, and the impact on interventions.
4. Factors conducive to implementation	Factors that contribute to successful delivery.
5. Barriers to implementation 5.1 Recruitment of participants 5.2 Challenges of implementation and evaluation 5.3 Financial restraints 5.4 Stakeholders 5.5 Resources	This category demonstrates different dimensions of barriers to implementation: from an individual or group-related perspective, from provider's point of view and on a structural level.
6. Solutions and Suggestions	Both solutions proposed by respondents, and already realised strategies to overcome obstacles, are presented in this category.

Source: Own creation

4.1 Category 1: Personal data of experts

Information on the six experts, their professional backgrounds, and respective roles within the field, are shown in Table 7.

Table 7. Profile of respondents

Subjects	Gender	D E P	Background in health	Background in research	Role
IP - 1	F	A	Dietician, specialising in diabetes	Developed & evaluated structured DEP for the English and the SA population	Chief exec of DEP A, Delivered on a patient level Trains up healthcare professionals and lay people
IP - 2	F	B	PHD in health services research	Developed & adapted the standard DEP to the SA community	Working at the University XX in research & holds lectures
IP - 3	M	C	GP	Developed & conducted several DEPs for the Turkish & Moroccan population	GP, Senior in the epidemiology department
IP - 4	F	D	Specialist diabetes nurse	Developed an EP to improve health embedding diabetes education for a multi-ethnic group with a low SES	Develops, organises & delivers education programme D
IP - 5	F	A	MPH	Translated the DEP for SAs in one region	Organises & delivers DEP A
IP - 6	F	B	Diabetes specialist dietician, Clinical Research Associate	Involvement in the development of structured education for SAs	Delivers DEP B, Trains educators and holds lectures for GPs and nurses

Source: Field data

The unequal gender distribution among respondents reflects the fact that professions like dietician and diabetes nurse are not only long-established female occupations, but are still more common among women.

A shared characteristic is the professional background in health. Three of them have degrees as specialised diabetes dieticians or nurses. Half of the respondents had a background in research prior to the programme under investigation; the other three started to participate in or develop the

education programme as their first research project in the field. Currently all of them contribute to research.

Similar distribution can be observed for the delivery on a patient level; three out of six are currently running interventions. Nevertheless all of them were involved in the delivery of sessions at some point, if only during the process of developing the diabetes programme. The task of delivering the interventions also comprises the organisation and planning of and around the sessions, as stated by three respondents.

In respect to language skills a distribution according to their role could be observed. In the UK both respondents who deliver the DEP to patients are able to speak the SA language and the Dutch respondent who runs sessions for multi-ethnic groups has some language competence in Turkish.

None of the three respondents who have their primary role in research can speak the native language of participants.

4.2 Category 2: Characteristics of DEPs for EMGs

4.2.1 Concepts

This chapter introduces the four culturally adapted diabetes programmes that were investigated. A general overview of interventions and a brief insight into inter-programme deviations and similarities is provided in Table 8. During the following chapters results are discussed in more detail.

Table 8. Overview of the included interventions

Programme	Country	Target group	Duration of DEP / Session	Content	Evaluation	Continued strategies	Discontinued strategies	Currently implemented	Programme coverage
A	UK	SA & other people at risk of, or diagnosed with T2DM	6 weeks; 2.5h sessions*	2h 10min interactive teaching (Discovery learning) *; 10 min. break 10 min. goal setting	RTC; Structured education audit	Empowerment approach, results showed improvements*, effort of local centres, entering data of each session in database	Translating questionnaires, length of sessions	Yes	National
B	UK	SA	4 X 2h sessions	2 h of interactive teaching; goal setting	Pilot study; Qualitative study**	Explaining the empowerment approach, education is fun and not like school, highly qualified educators, participants liked the DEP**	Wording of the DEP, length of sessions, educators who speak the SA language**, link workers	Yes	National
C	NL	Turkish	9 m. ***, Minimum of 10 sessions	Mix of individual-, sessions, telephone counselling & home visits***	Prospective controlled study***	Sessions with the GPs, participants valued the DEP as helpful	Follow up – high drop out rate, separated gender sessions, focussing mainly on language	No	-
D	NL	Multi-ethnic women with low SES	20 w.; 2h sessions	45 min. physical exercise & discussions and interactive teaching ****	Observational pilot study****	Building up a feeling of togetherness, to make lifestyle changes, check ups improved****	Flyer in English & Dutch for recruitment, educators being the expert, time & length of sessions, location, out-of-pocket payment	Yes	City

Source: Field data and literature. * 1. Source: Deakin, 2012; Deakin et al., 2006; ** 2. Source: Stone et al., 2008; Stone et al., 2005; *** 3. Source: Uitewaal et al., 2005; **** 4. Source: Neijens, 2010

Programmes differ regarding target group, duration of programme and sessions, and the set up of content. Leaving aside the fact that different evaluation methods were carried out, the application of one is a common characteristic. The two columns named, respectively, 'continued strategies' and 'discontinued strategies' present methods that are either considered to be feasible in practice or not working.

One respondent highlighted their extensive evaluation and the good results of their programme (A).

„We have now on our audit database as I said before the results of thirty-eight thousand patients that have gone through the programme and we see significant improvement in diabetes control, blood pressure, cholesterol levels, weight loss, empowerment scores, [...] health and well-being improvement.“ (IP-1)

Due to the improvements the concept and content of programme A was concluded to be relevant for the target group. In contrast one of the Dutch respondents (Programme C) expressed their disappointment regarding findings. Even in further studies after altering the study design, results showed no clinical significance.

„We did more evidence based studies one with only group sessions but the effect was zero. [...] but then not only Turks but also Moroccan and Indostanic patients and again we could not find any effects on blood level or weight or anything that we have measured. So it is a bit disappointing I must say, this kind of education.“ (IP-3)

The developer of DEP B questioned the significance of their first evaluation because of the small number of subjects and the absence of long-term follow-ups.

„We cannot, with any confidence say that we improved outcomes in people. Because you need a lot of people and you need to follow them for a long time to be able to show things, for example like a change in their HbA1c. But what we did get was a very positive qualitative feedback to show that people had liked the way the programme was delivered and that they found that they had learned a lot from it. And that they intended to make some changes but what we cannot do without that long-term follow-up is to show that people actually had made those changes and also sustained those changes.“ (IP-2)

All the same, findings of qualitative measures were good. Other respondents also stated positive feedback concerning interactive teaching methods, which confirms that participants liked the participatory approach.

„They really enjoy it and they will come back for more. Because, I think once they get to it they realise it is not like education at school. I mean programme X is all around a lot of participation from the group, a lot of games, a lot of food modules and when people come and find out what it is like they will come back for some more...“ (IP-2)

Programme C was the only programme that included appointments with the GP as an integral part of the intervention. The strategy was rated as mutually effective for participants and the GP.

„...the GP was enthusiastic. The patients they did like these sessions because now they had the feeling that they can express themselves clearer, so that was a good thing. I think the best thing of the whole education programme.“ (IP-3)

The developer of programme D observed the intervention as being beneficial for participants in making lifestyle changes.

„...people used our group as a starting point and after a while we saw people walking together, we saw people going to sport schools. In fact it was a starting point for them to work for themselves. To find a place where they could speak freely under professional support, that was a kind of key to the world which they would like to enter.“ (IP-4)

Programme C was mainly adapted in terms of language, which was later questioned by the respondent who developed the intervention.

„...we focused more on the language problem than on the cultural problem [...] So it was a bit naive I must say.“ (IP-3)

Three out of four interventions are currently implemented. The coverage of the diabetes programmes though varies huge between countries. The two DEPs in the UK are evidence-based interventions implemented nationwide for the native British population. The culturally sensitive DEPs are also delivered across the country and thus many locations and health educators are involved in those two DEPs.

The situation in the NL is very different. No common DEP was identified either targeting the white native Dutch population or for any EMG. One of the Dutch programmes (C) is not delivered but its findings and experts' expertise were regarded as important⁶. The coverage of the other Dutch programme is limited to only one city and targets a multi-ethnic group instead of one ethnic population. The country-specific differences confirm that a national HCS like the NHS in the UK enables national coverage of diabetes programmes.

The four DEPs share an important aspect regarding their starting point, the motivation to invent a programme suitable for EMGs originated from the observed need,

“...10% of the population are from the EM groups. [...] also I was aware of the prevalence in ethnic groups have been greater. So any programme that was developed would also have to be relevant for that sub-group of the population.“ (IP-1)

The Dutch programme D differs slightly in its approach, as it has been developed bottom up.

„I started from the request: "We want a better health".“ (IP-4)

The community expressed a wish to improve their health, and in cooperation with the social worker (target groups' reference person) the “right” person to develop such a programme was identified. Consequently this intervention differs from the others in two aspects; first it is tailored to the needs of a multi-ethnic community instead of one specific EMG and second, it is not exclusively a DEP although *„Because of the high prevalence of diabetes I could introduce a lot of diabetes.“ (IP-4)*

⁶ Programme C counts as a pioneer study in the research field. Further, post programme C the expert continued his involvement in many other research projects in the field of culturally sensitive diabetes research in the NL.

The other Dutch intervention (C) is distinct regarding its starting time and as aforementioned was one of the first studies that targeted EMGs.

„...we started in 1996, well about it. So at that moment there was hardly anything available that I know of, programmes for Turkish or Moroccan people.“ (IP-3)

The interventions are underpinned by different theories such as Discovery Learning (A), Peer education (A,D), Social Learning Theory (B), the ASA Model of behavioural change (C) and Maslow's Pyramide (D). However, it appears to be consistent that culturally sensitive DEPs in the UK and the NL are grounded on the concept of:

„...self-management and empowering the patients to take the ownership of their own health.“ (IP-5)

The duration of the intervention varied from six weeks up to nine months, also the length of sessions differs.

Three interventions (A,B,D) are exclusively group educations and one programme (C) combined group and single sessions. There is a common consent to invite relatives as shown:

„...because obviously it is a condition which the family lives with not just the person who is diagnosed with the condition. So we do really encourage people to bring along a family member if they can do“ (IP-1)

„...throughout the programme you know you do get interaction from the relatives as well as the patients, which I think works well cause it can only give you a fuller picture and I guess it is a support for that person who has come“ (IP-6)

The two interventions in the UK were developed on the basis of structured diabetes programmes, which existed already and were proven to be effective. In the culturally adapted version of the education participants *„...still get the same information [...] we have to deliver the same programme.“ (IP-5)* In contrast the education concepts (C,D) in the NL were developed completely from scratch.

Half of the interventions included among others link workers as health educators. Programme A works with different types of experts like link workers, lay educators, dieticians, diabetes advisors, and nurses. The Dutch intervention C included GPs but the major part of sessions were run by two link workers with the same ethnic background, because *„...the translator understood what were the problems because of their own background.“ (IP-3)*. By contrast, the respondent of DEP B explains that their strategy to use peers was discontinued after evaluation.

„...we used people of this sort as the educators when we designed the programme and we have tried these sort of approaches again and we have not actually ourselves found this very effective. I know some people have said that using link workers can be helpful but it is not something we found very effective in terms of increasing uptake.“ (IP-2)

Training of health educators could improve quality and effectiveness of DEP. In the UK extra training is required in order to deliver sessions. Intervention B also trains the translators to a certain degree. Intervention A similarly demands education, but health educators take part in training on

standard diabetes education and not on anything particular to the cultural-specific programme. Nevertheless the person who is running the sessions gets quality assured in the programme he/she delivers. Dutch respondents confirmed the importance of training health educators but as programmes are rather small, and not implemented nation-wide, education was not based on a fixed curriculum and happened mainly parallel to the delivery on a patient level.

„...we hoped [...] that they could bridge between the doctor and the patients. But how they should do that we had no idea at that moment. [...] So they were trained during the programme and they weekly saw each other and discussed what kind of problems they met and how they could solve that. So it was, well we did not design it all before but it was growing during the process...“ (IP-3)

The other Dutch programme (D) was mainly developed by one person, the same one that runs the sessions, therefore questions of training for additional health educators are not of relevance at this stage. In both countries findings do not clearly demonstrate that health professionals receive well-founded training on cultural tailoring and education.

4.2.2 Need Assessment

A number of strategies were applied during the process of need assessment comprising focus groups (A,D), warm-up group education (A), talking to people from the community (B,C,D), listening to target groups (D), patient and public involvement (PPI) (B), talking to experts in particular to people working in standard diabetes education (B), semi-structured interviews (A), piloting the education (B), systematic review of group based education programmes that have been done internationally (A,D), talking to the GPs (C,D) and talking to the target groups' person of reference (social worker) (D). Across interventions there was an agreement that focus should be on:

„...patient and public involvement, which is talking to people from the community, getting them to feed their ideas into our research.“ (PI-2)

„This was the necessary preparation before starting the programme. Listening, listening, listening and trying to find the keywords in these groups.“ (IP-4)

Among the four respondents who were involved in the investigation process, three made use of the above-mentioned techniques to reveal aspects that needed adaptation.

Areas for consideration are listed in Table 9.

Table 9. Overview of findings resulting from needs assessment

Areas that need adaptation	Illustrative quotations
Diet	<i>„...to find out from them what foods we could use to give the same messages.“ (IP-2)</i>
Communication	<i>„...there is a demand for these sessions to be delivered in South Asian languages.“ (IP-5)</i>
Material	<i>„...to ask them if they would like us to translate the handbook“ (IP-1)</i>
Necessities	<i>„...together with the target group I defined there is a need of physical activity.“ (IP-4)</i>
Groups' priorities	<i>„So mainly, high prevalence of diabetes was not the problem. The high prevalence of financial problems and other problems, social problems were dominating the diabetes and were dominating the acceptance of diabetes related education, [...] Me as a diabetes professional I find the diabetes education is the highest, highest priority but those people were of absolutely another opinion.“ (IP-4)</i>

Source: Field data

One of the four admitted that even after the needs assessment, *„...we could not pinpointed the exact problems in this group at the moment that we started...“ (IP-3)*

This might be partly explained by the fact that the investigations focused on the health professionals' rather than the EMGs' point of view as stated below:

„No, we did not ask them, what are the real problems that you have, not at that moment. It was more or less the problem of the doctor, the general practitioner. He had difficulties to explain himself to this people...“ (IP-3)

The question whether participants would benefit from separate gender sessions was raised during all investigatory processes and is still considered by most respondents before implementation. Issues around gender specific learning and roles, social hierarchies or cultural aspects could be indicators for the requirement of single sex sessions. Five out of six respondents argued with reference to cultural preferences. Only one DEP (C) revealed gender differences in their evaluation. However, the fact that women were profiting more from those lifestyle interventions was not proven a second time.

„...in this study the women were doing better than the men. [...] later on we tried to prove that it is really better but we could not prove it a second time.“ (IP-3)

From a cultural perspective the respondents rated the offer of single sex sessions as important for certain communities. But most of them came to the conclusion that for their particular target population it was not a requirement.

„...for example the Bangladeshi community down in city XX. You would need to offer separate gender sessions there, but here in city XY we found that is not something that we would generally need to do.“ (IP-2)

Although it was stated that it would be offered „...where relevant. Where the cultural preference is to have single sex sessions we do hold single sex sessions.“ (IP-1), none of the interviewees who delivered the sessions in the UK was offering separate gender sessions to their community, „...they are always mixed.“ (IP-5)

That means that in this respect, the recruited experts cannot refer to their personal experience. Further, responses might indicate that the demand for single sex sessions is not that dominant, as none of the British respondents assessed the need. Whereas one Dutch programme (C) offered single sex sessions but questioned the necessity from today's stand.

„...we were advised by Turkish people and then they said: 'Well, it is better to plan separate sessions for men and women.' But now I am not so sure about it if that is very necessary.“ (IP-3)

„...I had some experience with mix-groups and it is my impression that mix-groups work as well as separate groups. We were afraid that the women did not dare to say anything if men were present in the room. But by now I know it is just not true...“ (IP-3)

The same respondent further noted the existence of groups that might require single sex sessions (e.g. the Moroccan community in the NL) but allocated the need rather on how traditional the specific group was than on ethnicity.

The other Dutch intervention targets only females. The debate about single sex sessions came up when participants were encouraged to invite their relatives.

„The participants and everybody said: 'No men please, no men please.' And I said: 'Well, invite who you want.' And nobody invited a man. So it was not defined before, but this happened.“ (IP-4)

The above statement makes clear that this group of multi-ethnic women preferred separate gender sessions. The contradicting observations confirm that the need to offer single sex sessions requires assessment in the particular context (location, target population, intervention).

4.2.3 Communication

Communication for culturally tailored DEPs is complex and multifaceted, hence applied strategies and respondents' experiences differ. The following category comprises four dimensions of communication: the language competence of educator and participant, inter-personal communication, the use of translators, and challenges.

Agreement exists on the importance of considering EMGs language competence as mentioned,

„Obviously in South Asian population we needed to look at language problems, [...] because we have quite a lot of difference languages actually.“ (IP-2)

„We check, so that we can try and group the right languages into one session.“ (IP-6)

From the above statements, it seems that aspects of communication start prior to implementation. DEPs try their best to adapt to local needs and structural conditions as stated,

„We have eighty-two centres in the UK that deliver programme X. Now, some deliver in ten different languages and some deliver solely English. It depends on the organisation and the demographics in that geographical region. [...] they are trying to deliver in the groups own language, but where that is not possible they will bring in a translator.“ (IP-1)

This assertion confirms that there is no uniform way of overcoming issues of language competence. As aforementioned the application of link workers was detected as a method for bridging gaps of culture and language. Although most respondents applied educators that could speak the language of participants, one DEP (B) identified obstacles related to bilingual health professionals. In the end this led to the decision of running the sessions with professional translators.

„We tried using interpreters [...] and we tried using educators with the South Asian language skills. But unfortunately we found that the people with the language skills were not able to develop sufficient skills as educators and so the module went forward to be ruled out to general practices where it is the one with the interpreters.“ (IP-2)

Another common strategy is the appointment of translators (A,B,D). One respondent articulated the association between success of interventions and skills of the translator.

„I delivered with a translator [...]I found that it is absolutely acceptable as long as you have a translator that is very good.“ (IP-1)

Respondents reinforce the importance of the translator being highly educated by their recommendation of extra training in the DEPs' content. As elucidated in this statement:

„...they are trained in, you know they have to be familiar with the education programme [...] And they do have to be professional interpreters not just somebody coming in and putting in their own interpretation on it because that is probably the most important thing.“ (IP-2)

Delivering in the participants' language is another method that is preferred by most respondents though for different reasons such as language, culture and time.

„...we deliver it in their language. If they would have come to English programme they probably would not understand as much as when they come to something which is in their own language.“ (IP-5)

„...the translator also had a Turkish cultural background herself so we figured out that there would be automatically a cultural translation of messages.“ (IP-3)

„...it is so much better if it is delivered surely in that persons' own language rather than being delivered in English and then translated because it takes so much longer. (IP-1)

The latter statement confirms that not only does cultural knowledge of the participants' background benefit implementation, but also has the positive side effect of saving time.

As articulated by one respondent the use of a second bilingual educator was helpful. In that particular group Turkish was the main but not the only language this obstacle was tackled by, *„...talk as little as possible.“ (IP-4)*, using film material when possible and *„...I had enough women who were bilingual.“ (IP-4)*

Translating a DEP bears the danger of miscommunication, in particular when contents are translated literally rather than within a cultural context. To maintain the programmes' content, finding the

right translation and considering the cultural background of participants was clearly noticed as difficult during all interviews, regardless of whether persons were professional translators, lay people, or bilingual educators. One respondent stated:

„...it is [...] the same programme but it is just being translated in their language...“ (IP-5)

The same respondent added,

„...some people find it difficult to understand [...] what diabetes is and sometimes we use some of the terminologies that they are not familiar with [...] Sometimes they are not exact translations of the words like carbohydrates. [...] So I try and obviously do simplify it as much, but sometimes we have to obviously use the same terminology like carbohydrates or pancreas or different organs of the body which have not been translated literally in their language which they have not heard either really because it is not always just the language it is just how you explain things.“ (IP-5)

The two statements above depict the challenge of translating the content of a DEP, which was originally established for the white native population, into the target groups' language.

Inter-personal communication between health professionals and participants is another dimension of language. Difficulties attributed to language competence occurred not solely during DEPs but were also faced by, *„...the general practitioner. He had difficulty to explain himself to these people so that was a language problem...“ (IP-3)*

Other inter-personal communication problems find their root in health professionals deciding over the heads of participants without their consultation. One respondent admitted that initially she saw her role as deciding what was best for their patients.

„...as a diabetes nurse, at the very beginning of course I knew everything better [...] Well, that was my biggest mistake.“ (IP-4)

For good communication between participants and health educators the following has been advised:

„...speaking their language and noticing their level of communication.“ (IP-4)

Adaptation on levels of language might increase understanding, for instance, speaking in a simple and concise way. Findings emphasised the importance of tailoring communication, which does not mean that information should be omitted during the interventions.

The UK and the NL noted a shortage of staff with both good diabetes-related knowledge and the ability to speak the required language. Consequently, fewer educators deliver DEPs for EMGs than for the white native population.

„...usual in the English sessions we have two people running the sessions, [...] But the South Asian language one, I run the whole programme myself.“ (IP-5)

Time is stated to play a role for DEPs that are implemented in EMGs' native language. This is compounded by the fact that those interventions are delivered with fewer human resources. For instance material that is only available in the language of the host country requires extra time for translation by educators and that is often missing. Other strategies have been used as noted,

„...if we do not have time then I will ask one of the family members to translate it to them and then

they can fill it out and then maybe bring it with them next week. [...] That is how we do it just to save time.“ (IP-5)

This shows that the lack of time cannot be properly addressed due to low staffing and consequently sub-optimal alternative strategies (informal translators) are applied.

4.2.4 Health Literacy

Matters of HL dominate discussions about communication and health education. This sub-category highlights the significance of HL for DEPs, the frequent occurrence of low HL levels with EMGs, and related obstacles.

It is agreed among respondents that HL was down to SES rather than ethnicity of a person.

„...we have some quite deprived white communities in city XY where there are similar problems as health literacy. So I do not think it is just around ethnicity...“ (IP-2)

Interestingly, low literacy was observed as a characteristic of the target groups of such programmes as stated,

„...most people who are living this way they are not highly educated, a lot of them are illiterate or low educated so that is a characteristic of this group.“ (IP-3)

Those who noticed the lack of HL as a frequent characteristic indicated the need to simplify the language during sessions.

„...the way which the programme is delivered [...] we try to do it in such a way that it is in its simplest form that it can possibly be and so the use of language and health language we try to keep it as simple as possible.“ (IP-6)

„...the sessions are delivered that anybody and everybody can understand.“ (IP-1)

Respondents reported also that dealing with HL does not solely mean considering level of language, but also taking into account issues of reading and writing competence.

„...although people may speak their native tongue, some of them do not actually write or read that language [...] Quite a lot of the South Asian population particularly the older women they do not necessarily read and write...“ (IP-2)

The statement further reveals gender specific inequalities regarding HL levels. Two interviewees from the UK pointed out that even after simplifying language and translating material, communication was still restricted due to low HL levels, as shown in the following example:

„...we did try to translate the questionnaires in their own language but sometimes we found that even they could not read their own language.“ (IP-5)

Experts take the view that using pictorial aids is critical to overcoming obstacles of HL during sessions. That is not true for the available take-home material. When experts were asked if educational take-home material and validated questionnaires used for reasons of evaluation were

adapted, some of them stated that these were neither in the participants' native language nor predominantly visual. Controversial opinions and experiences can be observed between respondents, though most approaches for solutions were not defined as the best option.

„...we do offer that in leaflet form, [...]but leaflet rely on that person being able to read.“ (IP-6)

Due regard must be given to potential discrepancies between results of need assessment and occasional demands of participants as stated by two experts who present both sides. On the one hand information that was gathered during the process of investigation,

„...ask them if they would like us to translate the handbook to their own language and loud and clear we were informed that if they could not read English they also could not read their own language and that it is preferred to be in English so that their children could read it.“ (IP-1)

On the other hand observations while running the sessions showed,

„...sometimes we get asked if they can have a translated book but we obviously do not have them. But mainly we try throughout the programme [...] that they can get this information or they can get help from their family member to read for or with them” (IP-5)

The two contrasting requests above illustrate that groups consist of a number of individuals who differ in their preferences, abilities and needs. Establishing a DEP on a proper need assessment will not guarantee that the target groups' wishes are necessarily satisfied.

In addition, both sides (educator and participant) noticed and drew on support of relatives as a compensatory strategy.

In the NL one respondent questioned the commonly applied method of using symbols for medical explanations as described,

„...but then these pictures are very, I would say abstract. They try to be simple but in a way that they use symbols for what is happening in your body and for people who are used to think in an abstract way that is easy to understand but for someone who is low literate or illiterate? I think that is very difficult to imagine how a symbol is reflecting something that is happening in your body. [...] it is for me difficult to say if someone who is not used to symbols if he really thinks that there are keys and locks in the blood vessels or that he could go beyond this and think: 'Okay that is a mechanism, I understand that.' So sometimes I think, well the simplifications on how we try to express this illness is making it more difficult to understand it.“ (IP-3)

The above statement doubts that images will automatically be easier for illiterate people to understand, as they require the ability to think in an abstract way especially when it comes to complex processes that occur in the body.

4.2.5 Methods and Material

With regard to the possible positive impact that empowerment of participants might have on their diabetes care, all respondents share the view that health education should be approached by using *„The empowering patient centred style rather than the more traditional prescriptive didactic style.“ (IP-6).*

This implies that,

„...the educator is not supposed to come across as the expert. The patient is the expert. [...]it is not around the educators standing up there as an expert and telling them what to do. Because we know that will not change peoples' behaviour.“ (IP-2)

Three respondents (programmes A,B,D) from both countries outlined difficulties encouraging participants to come up with their own solutions. Explanations are levelled at providers and participants as stated below:

„...many people have never done that before because we as health care professionals have never allowed them to do that before. So it is quite new...“ (IP-6)

„...certainly for the BME community we had to factor in that [...] it is a bit of a foreign concept being taught how to look after your diabetes...“ (IP-6)

The change of health professionals' role in health education and associated attitudes and teaching methods are mentioned as one possible explanation. This is not attributed as culture-specific. On the other hand, the latter statement identifies the empowerment approach as foreign to EMGs and hence as a relevant element for cultural specific ibid interventions.

Educators had noted the frustration of participants caused by the fact that their questions were not answered. The following solutions were chosen and reported as successful.

„...now [...] at the very beginning we explain, the programme might be quite different to what they normally being used to and that we will asking them a lot of questions because you have a lot of diabetes knowledge in the group sitting in front of us. [...] So we explain that at the beginning so they understand the format of the programme...“ (IP-6)

All respondents repeatedly described their concept as comprising three major components: identification of challenges, goal setting and establishment of an action plan. Empowerment of the individual plays an important role for all three components.

„We help them to come up with their own solution. [...] We do a process of facilitation that helps people to identify what their possible solution could be for their challenges...“ (IP-1)

Given the responses above we can conclude that although there is a core curriculum for each DEP every session might be different as participants *„...could give kind of priority.“ (IP-4)* to topics, which obviously vary. Further educators independent of the target group stated that they *„...try to make it personal to who ever is sitting in front of us. And whether it is mainly the so called Caucasian group we work hard to do that.“ (IP-6)*

The respondents who are currently implementing DEPs on a patient level highlighted the correlation of building rapport with participants and acceptance of educational interventions. The example below encapsulates the educator-participant-relation and its influence on behaviour change.

„...people like to learn but not like to be taught. [...] It is common that we as human beings like to learn, ...to imitate, we do but we imitate those who we feel connected with. So if I create a certain distance:

'I am the professor and I know better'. People will not watch me as being the one who they want to imitate, [...] But when I try to speak their language, when I try to hear what their discussion is between each other then I can try to find connection...' (IP-4)

One expert raised the issue that prior to the provision of information a persons' state of knowledge has to be considered to increase individual adaptation and understanding.

„...they really tried to understand where was the position of the patient at the moment and tried to see what at that moment was important to do.“ (IP-3)

Moving to topics that address intervention contents and strategies to convey those contents, another described consistent strategies that exist across countries to enhance participants' motivation.

„They should get the experience that physical activity is not bad, but that it is fun.“ (IP-4)

„...that A there was some fun activities in each session to keep people interested in coming along every time, ...“ (IP-6)

Both statements highlight the experience of having fun either during the sessions or while being physically active as good methods. Additional strategies considered to be helpful are listed:

„...we stimulated them to help each other. [...] give them a kind of map, how to find information or where to find certain information.“ (IP-4)

„...the support from the group...“ (IP-5)

„...we try to offer practical advises...“ (IP-6)

„...a lot of repetition within the programme...“ (IP-6)

The number of responses that were extracted from raw data confirms that the four programmes applied comparable didactic styles and materials in order to overcome obstacles of language and HL. Interactive modules and visual teaching material were commonly used. These comprise the use of symbols, pictures, sticker images, picture card games, visual aids, games, and dvds.

The combination of written language with pictorial aids (symbols) and games seems to be consistent for all DEPs but not necessarily specific for one EMG. This becomes clearly recognisable by the statement of one respondent.

„...so we had a lot of pictures that we commissioned, which is still used actually in the standard programme because they worked so well.“ (IP-2)

It can be concluded that the integration of symbols works better for both the EMGs and the native white population. Notwithstanding that some material was used for the native population the existence of culturally tailored material was stated as well, for instance food modules for demonstration of portion size of carbohydrates were changed to rice and Chapatis. Two further respondents, one from each country, stated that if needed additional material from other sources was added.

„...the material variety is excellent the visual aids and the sort of modules they have, they are very good. But again we add our own materials from source YY according to the groups' needs.“ (IP-5)

Although pictorial aids substitute for most of the written language, some responses revealed that

certain evaluation processes rely on the participants' ability to read or write; solutions were also provided.

„It were written questionnaires but I asked them myself and I had a Turkish, a double language student, half Dutch.“ (IP-4)

„...we still have to use the same questionnaires because they are validated. [...] is in their own language [...] If they do not understand they can always ask questions while the session or in the break.“ (IP-5)

„...they have simplified it so it is very, very easy to read a statement and then just tick if they agree or disagree with the statement.“ (IP-5)

One implementer was enthusiastic about the fact that material was steadily updated and information added whenever new findings came up.

A strong deviation between countries can be seen regarding the extent of the written curriculum. Both DEPs in the UK have a detailed curriculum that provides structure and support for educators in their delivery. By comparison Dutch programmes have rather short ones. In general it might be assumed that a longer curriculum equals higher quality but size of DEPs in both countries is quintessentially different. In the UK we find both DEPs to be implemented in many regions by several educators whereas in the NL interventions coverage is restricted to one city and only a small team is involved in delivery. In conclusion, the extent of written curriculums for health educators correlates with coverage and size of intervention.

4.3 Category 3: Cultural Influence

With respect to cultural influence several sub-categories have been developed to intimate respondents' views in a structured way. However some statements could not be allocated to either of the categories but are still rated as essential to get the full picture of cultural influences on diabetes education. For instance, most respondents confirmed that certain characteristics regarding group affiliation, level of schooling, age at disease onset, and occupation, could be attributed to EMGs.

„...they are well organised, they are acting as a community, ...“ (IP-4)

„...there is a tendency particularly in the older community who are likely to be the ones with type 2 diabetes [...] the women may have had less education...“ (IP-2)

„...it is a relatively young group compared to the Dutch [...] I think it is about five, six years younger than the Dutch that they get diabetes. [...] the diversity within the Turkish people is less than in the Dutch group most people they have jobs in industry and well not high educated jobs, ...“ (IP-3)

From the above descriptions one could not be sure whether characteristics find their origin primarily in culture or in SDH. The latter and the statement below support the correlation between belonging to a disadvantaged group (EMG) and a lower SES.

„...this group with a lot of poverty, [...] People have no influence on their situation, they have no power, ...“ (IP-4)

In addition to SDH, one respondent broached the importance of being mindful of canons if necessary. Some cultural aspects that could be of relevance when dealing with Muslim population are: *„...to respect Ramadan. Not to deliver on Fridays when it is pray day.“ (IP-1)*

Where religious traditions affect diabetes care it is crucial to address those aspects. However, religious practices can neither be attributed to a certain culture nor to someones country of origin.

4.3.1 Identity

Merely the fact of living in a foreign country might contribute to loss or imbalance of a person's identity and is often compensated by a reinforced need for group affiliation. A strong feeling of belonging to a group was reflected by most responses, and particularly emphasised by the Dutch respondents. One of them described the EMGs in the NL as,

„The Turkish group in Holland is very to themselves. They have really a Turkish community within the Dutch community. [...] They are more or less separated not all of them of course but quite a few.“ (IP-3)

„The Moroccan group is more traditional, [...] That means that the Moroccans are on one hand more integrated in society but on the other hand they are also forming a kind of community themselves and that is very close and very traditional. [...] The older women they are very, very traditional and not easy to reach, more difficult than the Turkish group.“ (IP-3)

The other one endorse the statements above but adds the opportunity to use the power of being a group to facilitate change.

„...to know where you can influence people decisions. [...] these people live from the community“ (IP-4); “The group is their reference...” (IP-4)

„The additional value of supporting each other [...] because changing yourself in a community where everybody is fat and not motivated is very, very tough, very difficult. But when you are two in a group, [...] you can discuss things.“ (IP-4)

„But when the community is not supporting them [...] people can not take responsibility for their own personal health because they are functioning in a group.“ (IP-4)

The last two responses imply advantages but also the difficulty of influencing participant's behaviour if the community is not supportive. That means belonging to a group can either help or harm for an individual.

Identity can be also looked at from different angles, as one respondent demonstrated. On the one hand having the same ethnic origin might contribute to identification between participants and educator.

„I think there is something about traditional Asian People when they see an Asian person in front of them, [...] Because I am Asian and if they see me they might make the assumption that I understand their lifestyle and therefore they can justify it to me. [...] So they can see someone similar to them but is doing something different.“ (IP-6)

And the fact of having different cultural backgrounds can even become an obstacle.

„...not often, there might be that perception that an English person does not understand me. And that is not necessarily the case but that might be their perception that they hold in their mind and therefore whatever is advised to them they may or may not listen to it. But I think there are English educators that make an effort to build bridges and build a rapport with people, and that can certainly makes a positive difference to someone from the South Asian community...“ (IP-6)

As given above, the gesture of appreciation towards participants' culture was described as beneficial for strengthening self- and/or cultural-identity and inter-personal trust.

4.3.2 Health Beliefs

This sub-category identifies health beliefs and how they differ between communities.

The awareness of existing differences is presented in the statement below:

„...within the sessions we explore beliefs because we all have beliefs across any community and the beliefs are quite different amongst the South Asian community when you compare it to Caucasian community.“ (IP-6)

The heterogeneity of health beliefs between and within groups made it difficult to unravel the data. Experts in the UK looked at attitudes around education and revealed that,

„...they have particular attitudes to education, or they do not see it as something that they need.“ (IP-2)

Further they unveiled that the word education plays a role as well.

„...people actually do not like the word education. The word education is something that is associated with their school days which were not necessarily something that they enjoyed or, you know perhaps they found it challenging...“ (IP-2)

Moreover, results flag up fatalistic belief systems among EMGs, expressed in statements like the following one: *„...a very common belief is [...] when my time is up, my time is up.“ (IP-6)* The external HLC described in this statement confirms that the concept of empowerment and self-mastery is rather foreign and not embedded in their health beliefs.

„...self-management and empowering the patients to take the ownership of their own health. [...] I find it quite hard to translate because it is culturally quite different. Because a lot of Asian people sort of just relying on what the GP says and what medications they have to take, they would just take that but their will not even think about, you know doing something about health.“ (IP-5)

Experience from the UK showed that the medical model was culturally preferred to the empowerment approach by most SAs. Contradictions were noted regarding attitudes to medication. While the statement above highlights patients' willingness to take any prescribed medication, the one below shows sceptical attitudes towards insulin and drugs.

„There are also particular attitudes to medication, there is a lot more interest in herbal remedies for example. [...] there is a lot more reluctance to excepting insulin as a treatment [...] I think there is also a general sort of difficulty with [...] the concept of self-management. I mean this is a generalisation but overall

I think that people from the South Asian community prefer what we call a medical model where the doctor and the nurse are making the decisions rather than the empowerment module where patients make the decisions.” (IP-2)

The Dutch respondent who also delivers sessions faced similar obstacles and argued that traditional values of EMGs might have adverse effects on empowerment.

„And then I tried to start a discussion about making choices, [...] This was a very controversial topic because people tended to hold on to their traditional values.“ (IP-4)

In conclusion, transnational results confirm that the empowerment approach is rather difficult to implement when working with EMGs. Furthermore, the medical model was identified as the model of preference in the UK.

Another aspect noted by most respondents was, *„...attitudes to physical activity are different.” (IP-2)*

This was specified and extended by the respondent of programme D, which integrates physical activity as part of the education. Both attitudes towards the body itself and the requirement of single sex sessions played a role for physical activity.

„Well there was a shame about body. [...] it was very necessary to let them define the group.“ (IP-4)

While dealing with EMGs the consideration of health beliefs is critical for implementation because a profound understanding might lead to better communication and the application of strategies that are accepted and understood by the target group. The following statement exemplifies the importance of cultural adaptation.

„...we did not know if our messages were fully understood but we also did not know if they were accepted. [...] some advices that I give as a doctor, for example: 'You have to go to sports' or 'Go cycling every day'. Well if it is not part of your culture, you cannot go walking or cycling [...] then this advice is understood but you cannot do that because, yeah it does not suit you.“ (IP-3)

4.3.3 Lifestyle Aspects

Consistency exists about the importance of lifestyle aspects for diabetes education and that those are highly influenced by cultural factors. Apart from programme C that additionally deals with aspects of stress, all focus on diet and physical activity.

„...obviously with diabetes diet is very important. So there were a lot of sessions that are about food.“ (IP-2)

„...you should focus on lifestyle because that is the main problem especially in Turkish, also in Moroccan people because you know that lifestyle is causing a lot of the problems. [...] a lot of Turkish people are far to heavy and that is one of the things that we think why they get diabetes, ...“ (IP-3)

In addition to finding obesity more prevalent in EMGs, respondents noted lower physical activity levels compared to the native white population, and considered the latter culturally based. One respondent observed that, *“...there is a reluctant to undertake physical activity in that community.“ (IP-2)*

Others added gender issues, aspects that were noticed for EMGs in both countries.

„I think with the females is the problem of dress for physical activity and also safety, going out walking that is when it comes to safety. And things like going swimming and things like that, it has to be female only sessions that they went to, so obviously it restricts their participation in physical activity.“ (IP-1)

Almost all respondents discussed the correlation between lifestyle aspects and gender roles. They further underlined that aspects restricting physical activity are typically seen in EMGs.

„...the women do all the cooking [...] And that is more an issue in the South Asian population than it is in the white Caucasian population. So for women it might put a challenge about their time and care. [...] That diabetes is the you now lack of opportunity to do the physical activity.“ (IP-1) ...

„And exercise is another thing which we find really hard. [...] especially women when they are so bound in the house and you know looking after the children, which I am sure the white population does as well but it is just culturally, they are sort of more tend to stay at home and do the cooking and look after the kids at home [...] compared to the white population they might be more open to going out and doing exercise...“ (IP-5)

„...the wife who does all the cooking [...] I would say the only real gender difference because I think the diets are quite similar.“ (IP-2)

The typical role of women who care for the family in terms of preparing food comprises two dimensions as stated by one respondent. Because the woman does all the cooking she has the power to influence the dietary intake of the entire family. On the other hand, the respondent also describes situations where family members complained about “healthy food choices”.

„...many husbands say: ‘Well, I am not a rabbit. I do not like to eat those vegetables’. And even the children say: ‘I am not a rabbit I do not like this stuff.’ [...] When the mother knows how to buy her food [...] she can influence the health of the whole family.“ (IP-4)

In addition to portion size and food choice, social interactions related to eating habits were also observed. Two respondents identified social barriers to healthy eating as typical for the SA community.

„...I mean one of the big problem is around social eating in the South Asian population because food is such an important part of the social sort of interactions. I mean it is with everybody but it is particularly emphasised in that community, [...] and it is considered to be extremely rude not to accept food if you are offered it.“ (IP-2)

All respondents emphasised the importance to factoring in cultural aspects when dealing with lifestyle aspects and the general difficulty of changing adult behaviour once habits of eating have been established.

4.3.4 Organisational Aspects

This category extracts information about organisational aspects that were identified prior to or during implementation. The main findings can be divided into time, venue and distance whereby respondents addressed different dimensions of time.

One suggested that DEPs were not started during holiday time in summer or over Christmas. Some experiences demonstrated that the length of sessions as well the time of the day to offer sessions required modification as elucidated by the following statements:

“Practical things like [...] how long the session would be, [...] what time of day they will be held to fit in with people family commitments for example.” (IP-2)

„...we tried to make them shorter because again we find people having to leave early [...]it seems to work better [...] in terms of keeping people coming.“ (IP-5)

Also from the providers' point of view, issues of time have to be factored in. The statement below presents one reason: *„...to use the stickers as an educator, it is a bit more time consuming...“ (IP-6)*

Transnationally it was noted that family commitments and extra time needed for translation have an impact on the length of sessions. *„...version, which runs with interpreters that is [...] shorter [...] because it takes a bit longer with interpreters.“ (IP-2)*

In the NL interventions can be only realised in a short timeframe. This results from a newly introduced policy as revealed by this respondent:

„...most people get the children at half past eleven from school, so then we have to be finish [...] And there is another aspect because of the social system in the Netherlands, at the moment people are obliged to do voluntary work.“ (IP-4) *„They are obliged to help for instance at school, [...] as a contribution to the social system.“ (IP-4)* *„...therefore it is difficult to make appointments.“ (IP-4)*

This could be a gender specific problem, as women are often the ones taking care of children after school. However, answers cannot be given as the investigation included exclusively women.

Taking all responses into account we can conclude that both structural and personal factors affect the available time window of participants for DEP. In addition, practical things like locations for delivery were highlighted as relevant for designing interventions.

„...from the work that we did we knew that people like things to be held in a sort of local community venue rather than having to travel...“ (IP-2)

Locations ranged from all kinds of different community venues to GP practices and private nurse practices. One respondent insisted that the evidence showed the distance to venue playing a primary role for participants.

„The biggest obstacle was the distance from the quarter where they lived. We had to move from one location to the other location and then, we had to start completely new because the distance and being in the direct neighbourhood seems to be the most important factor. To have the information very close to them.“ (IP-4)

There was general agreement that community venues are preferred and distance is crucial for attendance. This assertion is true for multi-ethnic groups as well as specific EMGs, thus the preference for community venues is likely to be due to disadvantage, not ethnicity.

4.4 Category 4: Factors Conducive to Implementation

„So we think that success is largely down to the organisation of the programme and delivery of the programme rather than down to demographics.“ (IP-1)

The statement above identifies that making an effort to organise and implement DEPs is conducive to success. Furthermore, adapting food modules to culturally specific food preferences have been observed to work well.

„...food [...] is the thing that people want to know about most. [...] ‘What should we eat, what do we need to do?’“ (IP-2)

It shows that tailoring the programme is beneficial as the content becomes relevant to the target population. Several respondents confirmed that and added that consideration of individual needs is a key aspect for successful implementation. The statement below elucidates that,

„...try to find the starting point of your audience. [...] which is the main need of your audience? And a target group is a sum of individuals, that is the lesson learned by myself. Everybody has his individual target.“ (IP-4)

Appreciation of participants’ knowledge and sharing experience among peers supports successful implementation as noted by another respondent,

„...it is the support from the group if there are other people in the group who managed to loose weight and they have done very well with the diabetes because they followed the diet and exercise then they share their experience and that really helps with people. It helps people to understand why it is so important so when it comes from the group and people share with each other then it makes sort of more sense to them rather than one person telling them, who is the health profession.“ (IP-5)

The positive feeling of being supported also comes from the inclusion of relatives as explained below:

„...the value, the support aspect that people feel they got support with them. So yeah I think it works well.“ (IP-6)

More aspects that enhance successful implementation are:

„...speak the language of your students.“ (IP-4)

„...try and group the right languages into one session. Because of course if you had four different languages it does not work within the session.“ (IP-5)

„...some fun activities in each session to keep people interested...“ (IP-6)

„...make it more available in their local community. So if we had delivered the sessions in their local centre, or mosque, or where ever it might be, community hall and people felt more comfortable to come they were possibly more inclined to attend.“ (IP-6)

„...very much patience [...] by the professional.“ (IP-4)

Furthermore, good culturally sensitive communication and training of health professionals showed effective results in the Dutch and British context.

In both countries it was observed that the health educator-participant relation impacts success of DEPs for EMGs. Respondents identified that making an effort to build up a connection is conducive to the effectiveness of intervention. In that respect one Dutch expert rated the communication with

target groups' person of reference as very helpful for building up good rapport with EMG. „...the cooperation with the social worker was very, very needed.“ (IP-4)

4.5 Category 5: Barriers to Implementation

Experts discussed corresponding and deviating experiences of barriers that inhibit successful implementation. The umbrella term “barriers” was divided into the following five sub-categories: recruitment of participants, challenges of implementation, stakeholders, financial restraints, and resources. Evidently, dealing with barriers is a concomitant of DEPs as clearly stated, „...we come across obstacles every day...“ (IP-1)

4.5.1 Recruitment of Participants

The first and probably one of the „...biggest obstacle is getting people to take part.“ (IP-2) as observed by several respondents in both countries. One response even highlighted that recruitment of SAs is more difficult compared to the white native population, thus it can be assumed that the challenge of attendance might result from low levels of acculturation, system knowledge and being unfamiliar with health services.

„That would be both in the, you know the white population and also in the South Asian population because attendance can be a problem in both populations it is just a bigger problem in the South Asian community.“ (IP-2)

Some respondents hold the view that obstacles to recruitment find their root in target groups' preconceptions and that DEPs are not deemed important. Three are quoted below:

„...well of course it is something new and they have to experience this. Some people they do not think beforehand that they need this kind of education so they do not see the benefit of it and refuse.“ (IP-3)

„...for the BME community we had to factor in that [...] it is a bit of a foreign concept being taught how to look after your diabetes and sometimes there is a bit of anxiety about whether they want to come in the first place.“ (IP-6)

„...it is actually very difficult to get people to come forward and be involved in these sessions. People have other commitments, they have particular attitudes to education, or they do not see it as something that they need.“ (IP-2)

One of the Dutch respondents describes, in complete contrast to the others, how EMG women voiced the need to improve their health, and from this, the programme evolved. Therefore recruitment of participants was not a barrier until they had to change the venue.

Additionally aspects of how DEPs are communicated impacts attendance. This starts with a programmes' name and continues through to the person and how this person is selling it.

„So there can be some problems in the people who are offering it not being pro-active in selling it in the right way. Because it does need to be sort of sold to the patients in the right way in order to encourage them to take up the offer of education.“ (IP-2)

Another respondent disagrees. Although challenges might be caused by the way GPs are offering DEP obstacles start even prior to that. This respondent argues that the main problem results from the unawareness that programmes worth offering exist.

„...getting the message across that there is an intervention that you can offer to your patients that might help them, but if people do not know about it.“ (IP-6)

„Again it is the areas that deliver, they organise it and so some areas are very good and they have some self-referral leaflets in churches, and cafes, and mosques, and supermarkets. But in the main it is down to the doctor or nurse to refer people.“ (IP-1)

The above statements confirm that doctors and nurses have a key position between participant and DEP. However, it also shows examples of recruitment independent of GPs and/or nurses.

Not only recruiting participants poses a problem, but also the fact that many drop out. *„...obviously we sometimes get drop-outs...“ (IP-6)*. Another response related that to, *„Sometimes because of holidays, because they were going abroad for a long period...“ (IP-3)*

As already mentioned in category “Organisational Aspects” (see 4.3.4) time plays a crucial role. Having other commitments and the distance to venue have enormous influence on available time and hence participation.

„We also know that people from that community tend not to be able to give up a whole day because they tend to have family commitments, you know.“ (IP-2)

„Yes the distance. In fact the crucial distance is two kilometres. This is what people walk, people are not cycling and because of poverty they have no drivers license and neither a car. So they need to walk...“ (IP-4)

The first response classes “having family commitments” as a typical characteristic for EMGs and in particular for women. With regard to distance, the reasons listed do show clearly that issues relate to SE factors. The next assertion discusses another SE factor, a persons’ labour conditions and its influence on time.

„...sometimes people cannot take time off from work, so that is one barrier. And if they do shift work, so it is not the same time every week they cannot come, that is one of the barriers.“ (IP-5)

Shift work is more common in low-paid jobs and associated with lower SES. Because both seem to be prevalent in EMGs the obstacle of changeable working hours was noted.

Further, informing and inviting participants were stated as challenging and more of a barrier in particular with the presence of low HL. One respondent noted the lack of access to information as an associated obstacle: *„...when people are low literate they do not know where to ask for certain information.“ (IP-4)*

In addition low language competence and absence of the ability to read and/or write requires modified strategies of recruitment as observed by the same respondent.

„Well, due to the low literate situation [...] we had a flyer but it did not work. Of course we distributed it house per house, but this did not work because we set it up in Dutch and in English.“ (IP-4)

Responses clearly showed that issues around attendance are existing barriers associated with EMGs although they are not cultural specific.

One respondent called for the other experts to keep on improving recruitment strategies because if people in need are not showing up for education they will not profit.

„...increasing uptake because that is really a big problem and that is something that needs to be considered in adapting it. [...] obviously if people will not come even if it is suitable for them are not going to benefit.“ (IP-2)

4.5.2 Challenges of Implementation and Evaluation

This chapter reveals responses regarding specific obstacles that affect realisation and evaluation of culturally sensitive DEPs. Challenges are discussed from two angles, the health professionals' and participants' perspective.

Delivering lifestyle-focused intervention is a difficult task. One respondent highlights the wide spectrum of problems faced by participants and its adverse effect on success. As a consequence, T2DM does not always have a priority in the target groups' life.

„...the education is focusing on [...] just a few items and that is overruled by all the things that people have to deal with. [...] you ask people to change their behaviour and are they ready to do so and to what extent is there a possibility to do so. [...] possibly they can change a little bit but not as much as we would like them to change. So I think that is one of the problems why we did not see that much effect.“ (IP-3)

„...of course if people have financial problems and they have problems with their children and they live in a lousy home it worries the people. And if they have also diabetes at that moment then you have to decide what is the place that diabetes takes? How important is diabetes for this patient in this moment? It is just one problems that they have, so you must realise that as a doctor,“ (IP-3)

Challenges for empowerment of participants and for the application of teaching material include levels of education and HL, as identified by experts.

„I think the less education people have the less likely they are to be able to easily adapt to that empowerment module. Because if people do not have the knowledge it is difficult for them to make informed decisions and choices.“ (IP-2)

„I mean the action planning is difficult because obviously it uses images and I do not know whether that could be done in a different way.“ (IP-6)

The Dutch respondent whose programme (C) was implemented sooner than the other DEPs lists additional obstacles due to inadequate or missing teaching material.

„...you have to make pictures and trying to adapt the education material for them, videos or things like that you need that for this group. And we did not have that at that time...“ (IP-3)

Experts discovered that issues of mix-methods impact implementation and results of evaluation as demonstrated in the two responses below:

„...people find it difficult when they have diabetes and all of this, they get different mix-methods from the GPs and the practice nurses.“ (IP-5)

„...we were educating the patients but were not educating the GPs and the nurses, the practice nurses. As so patient were understanding the diabetes a lot better then going back to their GP and practice nurse and getting very out-dated old-fashioned advise. So that is still a problem.“ (IP-1)

The assertion given argues from a patients' point of view, whereas a third response confirmed that problems around mix-methods negatively impact smooth delivery of DEP but described the issue from a health educators' perspective.

„...a lot of them went abroad for a longer period and then sometimes also went to a Turkish doctor and got advice from them and you can see that interfered sometimes with a lot of things that you planned to do with them.“ (IP-3)

Insufficient need assessment and certain professional attitudes were considered to be another obstacle for smooth implementation as explained by the next statement,

„We really believed that it would help so, on the other hand we did not know anything about diabetes and Turks that was a bit strange. The problem was not clear and we thought we had already the solution.“ (IP-3)

Some DEPs include some kind of evaluation in order to re-assess and improve the programme. An obstacle to evaluation originates from inadequate material for participants with low reading and writing competences. Through closer examination of how written questionnaires for evaluation purposes are handled in regard to the target group the responses demonstrated that,

„To be honest I do not know whereas that happen with the BME. [...] In fact, to be fair I am presuming it does not actually because if people cannot write the language you cannot really ask them to write any thoughts down. Do you understand what I mean?“ (IP-6)

Although it is not clearly stated this finding indicates that culturally sensitive interventions are, for practical reasons, not likely to be re-assessed. The next statement highlights the difficulty associated with HL during evaluation. The respondent adds that the process of simplifying questionnaires to fit target groups' abilities affects the validity of material and results. From a researcher's point of view it is doubted that changing evidence-based material is useful.

„...for research it is just difficult to, mostly you work with interviews and all kind of questionnaires and most of the questionnaires are not validated within the group and so you have to be inventive how you adapt the questions. Because you know that some of the questionnaires that exist and are validated, you cannot use them simply because they are too difficult or you have to translate them and that kind of things that makes it a bit dodgy I would say.“ (IP-3)

It was also noted that evaluation of lifestyle interventions is extremely difficult, and although participants described changes those were difficult to measure.

„Measuring these kinds of things, measuring changes in eating behaviour, also exercise behaviour that was very difficult to do and I still do not know what is the best way to do so. So if you focus on these, on

changes in lifestyle you as a researcher have to know what people eat and how their diet is before this programme and after this programme. Very difficult to measure.“ (IP-3)

This obstacle was not confirmed by the other responses.

4.5.3 Stakeholders

In relation to the question as to whether stakeholders could be a barrier to implementation respondents highlighted a variety of aspects. This category demonstrates different dimensions including stakeholders' role, their influence on DEPs, and also their attitudes and behaviour.

In order to receive backing on a structural level stakeholders need to see the value in culturally sensitive diabetes education. Also programmes' publicity increases the likelihood of support.

„...the commissioners, the people who control the budget for the year have to see value in that. So here in city XY we do because we are commission to deliver so many a year and obviously it makes perfect sense to deliver not just the English but the South Asian as well [...] But also you have to remember that the head of programme X is in city XY.“ (IP-6)

The statement above confirms the extent of stakeholders' influence on DEPs for EMGs; and also the need for those with influence to be convinced that interventions make a difference to their community. All respondents from the UK identified the lack of cooperation with GPs as a major obstacle as clearly revealed in the following assertion.

„...that is another problem that we thought of been highlighted by the PPI work, the work we have been doing in the community is that people from that community say that their GPs actually do not offer it to them. They do not have not even heard of programme Y [...] And that is because what they saying is that the GPs are making the decisions for them that they would not want to go. [...] So they are not even bothering to offer it to them. Or it is maybe that, you know some of the GPs do not think it is a very good idea.“ (IP-2)

The above statement highlights the presence of stereotyping and stigmatising people from EMGs as being not interested or motivated to improve their DSM skills. This is then used to justify the lack of money spent on the education programme.

One response suggested backing up diabetes educations with research, and raising awareness among stakeholders and participants, as potential strategies to increase uptake.

„...getting the GPs and the practice nurses to refer patients, because I do not think that they absolutely understand the benefit in what education can do. We have now on our audit database as I said before the results of thirty-eight thousand patient that have gone through the programme and we see significant improvement in diabetes control, blood pressure, cholesterol levels, weight loss, empowerment scores, [...] health and well-being improvement. But that is not uniformly accepted and recognised and so in the UK I think around two per cent of people with diabetes have attended structured education, which is dreadful. And so that is an obstacle, a problem that we come across everyday. We are trying to raise awareness of the benefits of education.“ (IP-1)

One respondent broached the topic of how GPs circumvent recommendations of guidelines.

„The NICE guidelines do recommend that all patients are offered structured education but you can put different interpretations on what you mean by structured education.” (IP-2) „They may say: "What our

nurse is already doing in the diabetes appointments that counts as structured education". They may not feel that people need to go to an outside session...“ (IP-2)

Experiences of Dutch experts regarding cooperation with GPs run counter to this. This might be grounded in the different embedding, designation and structure of programmes and the different HCSs. One of the two DEPs included GPs as part of their treatment team and used GP practices as a venue. The other intervention is not communicated as a health care programme and hence viewed rather as a beneficial supplement to treatment than competition.

„Because I am not in the treating team, I am outside, I am in another phase, in another programme and usually the GP is very, very enthusiastic because he or she is aware of the additional value of this programme.“ (IP-4)

The UK implemented a strategy to persuade GPs to refer diabetic patients to diabetes education. One respondent commented on that:

„It is better now and I think obviously they have an incentive because they get paid if they refer through. So that is their biggest incentive. The person did not have to attend even if they do not attend but they refer them they will get paid for that. A bit of a shame really, but that is the way it is. So, I think doctors are more on board...“ (IP-6)

Even though the response indicates a lack of understanding for doctors' behaviour the top-down strategy seems to work. Issues of budget allocation by stakeholders were argued from different perspectives. One remarked that time plays a role for stakeholders' decisions.

„I guess it is, you know the people who control the finance and having a better understanding [...] And of course [...] here it is barely looked for the year coming because it is the budget for the year that they have to spend. But if you look at it long-term, long-term structured education can help to reduce complications which means keeping people out of hospital which is a money saver.“ (IP-6)

The contrast between stakeholders' actions and programmes' benefits becomes obvious through the explanation above. Stakeholders focus on goals that are driven by time, while DEPs save money primarily on a long-term perspective for instance by preventing complications.

When it comes to budget allocation for education programmes tailored to EMGs the situation becomes desperate in the NL. The NL stopped funding DEPs for EMGs and explained the change in policy with their new solution - learning Dutch.

„...the reason why they are not implemented is first of all there is not much money available. In Holland it is not very popular to ask money for educating these kinds of groups. The general idea is that they have to learn Dutch and then all the problems will disappear.“ (IP-3)

All respondents agree that stakeholders' influence on DEPs for EMGs is decisive for implementation.

4.5.4 Financial Restraints

Financial limitations include different aspects, for instance additional costs incurred due to extra training of health educators required to deliver the culturally adapted DEP. These costs have to be covered either by the educators themselves or by their company. One response noted supplementary cost as a barrier.

„...for those people who initially went for the training it was a cost for whoever they are working for to send them off to the training. But then there is an additional cost to send people to become BME trainers [...] they already paid an x-amount of money, amount XX [...] to become an educator and there you say you need an extra amount XY to become a BME educator. So there is a cost implication,“ (IP-6)

The respondent further adds that cost implication might limit the number of black and ethnic minority (BME) educators and thus the number of culturally adapted DEPs being delivered. *„I guess it is around financial issues of putting people through the training...“ (IP-6)*

All four programmes are offered without any out of pocket payments for participants. During the investigatory process programme (D) took the step of providing education with a contribution of one Euro per session for each participant and reported:

„...when they had to pay just one Euro per time it was a problem for many people to come.“ (IP-4)

In consequence the programme was offered for free. Additionally respondents stated that financial issues affect their scope of action as demonstrated in the two statements below,

„...we would be doing so much more development, if financially we have more backing. So, obviously financial restraints do impact on implementation.“ (IP-1)

„Yes, because I am not in the situation to expand it, [...] because there is no finance for it. I would love to make it larger but I cannot.“ (IP-4)

The responses above are an indication that scarcity of financial resources restricts both the amount of on-going research and programme coverage. One of the experts discussed aspects of costs in relation to group and one-to-one sessions and noted that costs will be always a criterion for design and delivery of interventions as elucidated in the two statements below:

„...we are looking at whether that is something that we need to offer people as an alternative. Some sort of one-to-one session, but the problem with that is that it tends to be a lot more costly than group sessions.“ (IP-2)

„But then if you organise a group session and only two people turn up then again that is not very cost-effective.“ (IP-2)

None of the four DEPs evaluated their intervention in respect of cost-effectiveness. Nonetheless Jacobs-van der Bruggen (2009) investigated the cost-effectiveness of various DEPs and included the two English programmes.

Although funding of DEPs for EMG differs between both countries, all six interviewees confirmed that the financial situation depends on stakeholders and affects implementation.

“I think a big, a big question also is around costs. Because, you know it costs quite a bit of money to buy the education programme and [...] is paid for by the, well now in the UK we have something called clinical commissioning groups [...] what used to be primary care trust so it will be paid for by the primary care organisations. They would have to buy programme X sessions. They would have to pay for educators to come in and deliver it. So you know there is a cost implication so that is a barrier.” (IP-2)

It becomes clear that even though there is no access barrier for participants in terms of cost, issues around budget allocation remain a barrier to implementation. One added the uncertainty about whether funding will be continued or stopped in future.

„I mean in terms of funding for this programme so far we have been okay but again it is sort of yearly we are, our contract are renewed so we will find out next year.“ (IP-5)

From the results in the UK it is not possible to say whether the uncertainty of funding is specific for culturally tailored DEPs, or also applies to diabetes education in general.

The situation in the NL is different. One respondent described the difficulty of getting funding for an intervention that targets EMGs.

„...the reason why they are not implemented is first of all there is not much money available. In Holland it is not very popular to ask money for educating these kind of groups.“ (IP-3)

„It was something new at that moment and we thought that education in the native language that it would improve the health care for minority groups. So it was something that was promoted by then and well they just wanted to know if this kind of education was successful [...] But by now after about ten years then all these programmes stopped, the money stopped...“ (IP-3)

In the UK primary care organisations (clinical commission groups) pay for culturally tailored DEPs whereas in the NL it seems like there is a lower likelihood to get any funding for such interventions. The following assertion shows how the NL used to finance culturally sensitive DEPS and how it changed over the last years.

„Yeah there is really a financial problem. The people themselves they do not want to pay for it, not extra and the health insurance they, at this moment they do not want to pay any extra for it. So in the past there was a triple party that financed the educators, that was the health insurance one third, [...] the city they financed a part and a part was from a special fund from the general practitioners and that is how it was financed. And now all these parties they say: ‘Well we do not finance that anymore.’ The first was the insurance company, they said: ‘Well we do not want to finance it because it is also a benefit for people who are not insured with us, so we will not finance that.’ Well then we only had the cities themselves and the funds of GPs and they said: ‘Well this is too expensive, we do not want to finance it anymore.’ So that is how it developed and now there are simply no funds...“ (IP-3)

The other Dutch respondent confirmed the situation outlined above. Currently intervention D has uncertain prospects of continued funding though some stakeholders are described as motivated to implement and probably expand it.

„...we are in a painful situation. How to continue? [...] our town is very motivated to start it up for the whole town, to implement this. But they tried to find the right policy [...] So there is a motivation but now the question is, is this health care or is this social care, social work?“ (IP-4)

The question whether the problem is around being responsible or financing the intervention for EMGs was clearly answered with: *“...it is always the financing.“ (IP-4)*

Aside from HCSs the other source of funding for culturally sensitive interventions is: „...by research funds.“ (IP-3)

In conclusion, both Dutch respondents highlighted that programmes are financed either through research funds or have to be positioned in the context of social work rather than health care. In contrast, findings showed that culturally sensitive DEPs are funded in the UK. Nevertheless financial restraints also exist in the UK, which affects the amount of on-going research.

4.5.5 Resources

This sub-category addresses obstacles related to resources. Experts stated that barriers included time and human resources. Several of them noted that the availability of health educators who are trained and speak the native language of participants is not always given, this applies to both countries. The limited number of health educators who combine both competences has an impact on staffing levels. In summary, compared to the interventions for the native white population, often fewer staff provide DEPs tailored for EMGs as elucidated in one response:

„So usual in the English sessions we have two people running the sessions, [...] But the South Asian language one, I did it very myself.“ (IP-5)

It was further reported that the fewer staff the higher the workload, during as well as prior to implementation. In this context language competence is crucial for tasks like recruitment, writing invitations, answering calls, organising community venues etc. Though workload is high the same respondent described it manageable.

„...it is a quite big workload like sending out invites to bring in patient for all these weeks and getting all the room bookings [...] we have to put in a lot of effort to run it. And again in other areas where they do not have the staff that I make, you know totally dedicated to deliver this programme [...] then they could not even think about doing this sessions. So staffing is very, very a key to deliver the programme...“ (IP-5)

„I mean so far it is being okay but if there is more demand of running more sessions then it might be difficult so at the moment we are managing with the resources we have.“ (IP-5)

The available time for implementation was considered to be rather short, particularly by the respondents who run sessions on a patient level. *„Sometimes it feels like it is quite a rush then you know a little bit more time would be good.“* (IP-5)

Shortage of time affects the content that can be covered.

„...there are certain things that obviously we cannot cover just purely because of time which certainly would be a value to patients.“ (IP-6)

4.6 Category 6: Solutions and Suggestions

The above category “4.5 Barriers to implementation” identified several obstacles. This category looks at suggested solutions that were given by respondents as well as steps that were achieved to overcome barriers. The most common topics to emerge from the suggestions were the urgent need to increase uptake and cooperation with stakeholders. As intimated below, one approach to tackling attendance is to target health professionals. „...getting the GPs and the practice nurses to refer patients...“ (IP-1)

One respondent had observed that solely the fact that a DEP is evidence based increases the number of referrals by GPs.

Reminding potential participants can also approach the issue of uptake as noted,

„...one thing that I recognized is that the South Asian community they often want a reminder the morning or the night before. So it is something I have never been asked for with white Caucasian participants before. [...] So what we tended to do is just phone them up the night before or the morning of the session to remind them and then the attendance rate was as good as it was to the white Caucasians.“ (IP-1)

Based on the statement above it can be concluded that reminding participants before sessions seems to be a culturally specific request. Another respondent added the strategy of sending text messages.

„...we send them an invite, they do receive a text message a couple of days before the sessions. It is like a reminder text...“ (IP-5)

As already stated, the adaptation of time and making programmes more available in the local community are rated as successful strategies to reduce access barriers for EMGs. One feasible solution to overcome obstacles of time was the possibility of switching intra-programmes as suggested,

„...what we do for somebody with time issues because we are running so many sessions in different times and days of the week we give them to mix-match the programme and then they can come to different sessions at different times.[...] it works out. Somebody who cannot take time off work, we do some employ letter that they can give to the managers, [...] because it is their right to get this treatment. [...] If the employer does not allow it then it is there right again, to ask them permission. [...] if they cannot do sessions then again we give them dates and times to catch up at a later date when it is more convenient for them. So there are lots of ways we have sort of come up with to try and overcome the barriers of attendance.“ (IP-5)

The statement given above also touches on solutions in case participants are not released from work for the DEP. Additionally, suggestions were considered and realised in order to raise awareness and interest of target populations in diabetes education as demonstrated,

„...to try and get people on board, is going to their local communities and maybe just sort of set up stalls and stands. And then displace some of the results that we use within the programme to try and target people to come along. So putting up the food models is often a good one because they get very curious and quite excited by the fact that it looks like it is something quite different...“ (IP-6)

One respondent approached the issue of attendance differently. The distinct way of communicating the intervention becomes clear and explained as,

„ ...when you ask people to come up for the topic diabetes, well it is not fun. Feeling better, that is fun that is one of peoples' purposes, goals and personal aims. [...] And diabetes education was constructed within the programme, [...] 'I want to be here because it is fun and because I have some exercise and I come here with my friends or with my neighbour.' And that is why people come and I think this is the main message, [...] do not point to diabetes but point to feeling well, feeling healthy and getting better.“ (IP-4)

It was further suggested that:

„Sometimes I think, having a chronic disease is a bit shameful [...] And I like to be as discrete to people with diabetes as to people with HIV. And not to touch them always on something which has the sound of failure. 'They are getting type 2 diabetes, it is for loser, it is for fat sort of people.' This is not what people like to hear. When you have diabetes type 2, you just have it. Let's improve your common health, feeling healthy. And then we can discuss [...] diabetes or lifestyle topics.“ (IP-4)

The two statements show that highlighting aspects of well being and having fun can be a successful strategy for approaching participants. Transnational respondents considered the understanding of target groups' thinking and actions as key elements for building rapport and good communication. For that reason some proposed solutions tackle exactly those issues. In general consistency was found for the requirement of extensive need assessment as clearly recognisable in the following statement:

„...explore what is required first. Do a process of investigation to find out what needs and how people need to learn. But also because it takes years, and years, and years of development to find out I also think why reinvent the wheel when there are structured education programmes out there that have been demonstrated to work.“ (IP-1)

The above and following assertions suggest that experts can learn from each other and strategies of best practices could be taken on by other DEPs.

„But you know what we are learning from one sort of thing that we are doing such as that is also applicable to things like programme XY.“ (IP-2)

This is complemented by the recommendation to learn from others in terms of strategies that have failed as stated, *„ ...Do not try the way of educating the same thing all over again...“ (IP-3)*

Learning some words in the participants' language is recommended as one strategy to build bridges and connect to target groups. Respondents from both countries mentioned that understanding participants' priorities is a useful strategy to enhance mutual understanding.

„...people will not change because we tell them to, it is a different way of thinking. We need to try and to understand what their thoughts are and why they are being like that.“ (IP-6)

„...problem, when we as health professionals with special topics try to connect to our patients when the patients have completely other priorities. [...] they will turn their back to us and walk away because we do not understand their prior needs.“ (IP-4)

Including different levels of literacy to overcome low HL was suggested as conducive because

„ ...you need well literate people in the group to help the others. [...] we stimulated them to help each other.“ (IP-4)

The inclusion of relatives was strongly recommended because it is assumed to strengthen the feeling of being supported, as presented in the following response:

„...actually much better because it is not just one person with diabetes the whole family should support them [...] that both understand the sort of health eating concept. [...] we quite appreciate if they bring a family member.“ (IP-5)

Experts share the idea that regular exchange of experiences and knowledge among participants reinforces learning and supports lifestyle changes. Nonetheless the power of a group can also be restrictive. One respondent stressed the importance of strengthening the individual in order to offer opposition to adverse health effects caused by groups' attitudes and habits.

„...the most successful factors in programme YZ. Not to be suppressed by group ethics and not to be suppressed by group values and beliefs. Trying your own way and permitting someone to find her own way out.“ (IP-4)

The difficulty that the empowerment approach is rather foreign to EMGs and thus participants got frustrated as they had to come up with their own solutions was solved in the following way:

„So we explain that at the beginning so they understand the format of the programme.“ (IP-6)
„...we all took the curriculum to include this bit in and really to try and deal with that saying, you know: 'That is the reason why we use this line of questioning...'“ (IP-6)

One respondent described the difficulty of finding exact translations for some medical terms as well as the problem that participants did not understand some of them even though they had been translated into their native language. The exchange with other bilingual health educators and explaining rather than translating the technical terms is advised.

„I was also talking to my colleagues [...] So I try and obviously do simplify it as much, but sometimes we have to obviously use the same terminology like carbohydrates or pancreas or different organs of the body which have not been translated literally in their language which they did not have heard either really because it is not always just the language it is just how you explain things.“ (IP-5)

Another respondent added that thinking over the choice of words could be a solution to increase acceptance of DEPs as explained,

„So we have been trying to think of other words that we can use when we are inviting people to come to things. So for example [...] 'learning about insulin' because we found that people prefer the word learning to education. So little things like that, you know sort of using the right words so it will not put people off.“ (IP-2)

Issues of HL can be overcome by application-oriented solutions; those include helping participants to answer questionnaires and strategies to compensate for lacking time.

„...either in the group like when I am translating it [...] or they can give it to somebody at home to help them out. That is how we do it just to save time.“ (IP-5)

„...they have simplified it so it is very, very easy to read a statement and then just tick if they agree or disagree with the statement.“ (IP-5)

Retrospectively one respondent identified the obstacle of time taken to compile information (material) for participants and the difficulty of language for multi-ethnic groups and suggested:

„I would have used health education material from their own country much earlier, [...] and I would have liked to ask them: 'Please ask your relatives to find some education in you mother language.' And then it is not a problem of the participants only, because they share it already with their family [...] This is what have cost me too much time. I have focused on my own language, which was not known by the main participants so I should have asked for the involvement of relatives. [...] Because then you open the door to information in their own language...“ (IP-4)

The application of symbols for low literate people was not consistently rated as feasible therefore it was proposed that material should be *„...develop it with people who are illiterate.“ (IP-3)*

Giving practical advice rather than explaining complex medical processes was also stated as a possible solution.

„Involve them and see how they explain each other what it is and try to understand that, [...] I think that is better to understand than all this technical explanations what diabetes is and how it works [...] They really need some very concrete advices: 'How should I cope with my diabetes?' 'What should I do when I visit my uncle and he offers a lot of nice food on the table and how can I say: 'Well I should not eat too much without insulting him?'“ (IP-3)

The category “4.5 Barriers to implementation” discovered already that challenges occur not only during sessions but also due to external structures and stakeholders. To improve cooperation with stakeholders respondents remarked that, *„We are trying to raise awareness of the benefits of education.“ (IP-1)*

Educating health professionals is one strategy, which is carried out to solve the existing unawareness of DEPs in both countries.

„...we do lots of teaching on the masters programme here. We have some programmes here to up skill GPs and we do some of those activities from the programme with them and they enjoy it. And we say to them: 'If you enjoy it how do you think the patients will?' So we try and sell it in that respect because if they enjoy it they are more likely to refer patients through.“ (IP-6)

The above solution builds on the positive experience made by health professionals others approach stakeholders by presenting evidence-based results.

„...it is getting to the people who have control with the finance and trying to show them the evidence. Actually we know that attending education can change believes, it can help with weight loss, it can help with stop smoking we have got evidence to show that now from the original programme...“ (IP-6)

The response given implies that existing evidence helps, though major parts are extracted from the standard DEP and not from the culturally specific one. However, other experts share the idea that evidence is a good tool to convince stakeholders of the importance of those interventions.

„...all the data we collect from these groups we put it on the name X database.“ (IP-5) “Now we trying to just do more on name X database and generate reports from it so that we can report to our own sort of commissioners and line managers.“ (IP-5)

Another respondent raised the issue of maintaining the programmes' content as it has been proven to be effective.

„...important is that they do deliver something that is consistent. Because that programme is being evaluated and we know that it works so if you put that changing that is not longer the same...“ (IP-2)

On the other hand keeping the content the same might be advised. On the other hand it can be assumed that a strict curriculum inhibits the possibility of coming up with individual solutions.

Financial restraints were perceived as a major obstacle. One respondent suggested:

„...we are changing that slightly now. So for someone, for example who want to only deliver BME they would not have to go through the programme X (name of the standard DEP) training and then the BME training. They could just go through BME training. [...] which is cheaper for my manager.“ (IP-6)

This solution reduces the cost implication for companies or individual persons of becoming an educator. Another response describes the approach that was taken to overcome the lack of DEPs for EMGs,

„...it is difficult to get funding and that is why we looked for programmes that are more, well cheaper. And that is one of the reason why we started the programme of Mrs. X because we thought, well if we could manage to get groups together of patients and first we train these groups but later on these groups can provide themselves [...] So we will facilitate the formation of groups but then the groups have to act more and more as an autonomic group and less be dependent on money from outside.“ (IP-3)

„That is something that we try at this moment, that more or less we try to tell the community how to help themselves. It is more appropriate at this time of scarce financial resources. [...] we changed the focus a little bit from the individual help to more community help.“ (IP-3)

Different is the attempt at a solution, which considers getting around financial restrictions by using other sources of money. The question which source covers the costs of the intervention (D) was responded as followed: *„No, it was not by the health insurance it was by the social organisation in town.“ (IP-4)*

4.7 Summary of Results

The detailed data presented above will be summarised in order to provide a better overview and highlight the main issues within each category.

Category 1: Personal Data

All experts have a medical background and are involved in research. Three had and/or have their main role in research, two are primarily implementing sessions and one developed and delivers the intervention to the same extent.

Category 2. Characteristics of DEPs for EMGs

The findings show that all programmes followed an extensive need assessment. Only one of the Dutch respondents admitted that their investigation was probably insufficient as it focused more on GPs than on the participants.

All DEPs thought about offering single sex sessions. In the UK no respondent had personal experience with single sex sessions even though they considered it as relevant for some communities. But in the NL one respondent revised the requirement for the Turkish community and the other observed the need to exclusively approach women.

Issues of language, communication and HL were present in all DEPs. With regard to language respondents commented on different strategies: the use of native speakers was noted as adequate provided they had a professional background in health, and one DEP found that the use of translators is more effective but only when interpreters are professionals and trained in the DEP. Experts revealed that HL is down to demographics rather than ethnicity but allocated it as a common characteristic for EMGs regardless. Respondents stated that due to low HL information should be maintained but delivered in a simple form. There was general agreement that the empowerment of participants is a central element.

Although empowerment is rated as successful two respondents in the UK described the concept as foreign to the SAs and hence difficult to apply. Especially respondents who deliver sessions underlined the importance of building up a rapport and adapting language level to participants in order to increase acceptance. DEPs used interactive modules and various visual aids.

Category 3: Cultural Influences

With regard to cultural influences various differences and similarities were found. The strong community-orientation of EMGs was emphasised by Dutch respondents. The functioning in groups is stated as both supportive and inhibiting. Respondents from the UK noted that attitudes to education were often negative among SAs.

Many participants preferred the medical model where GPs make the decisions instead of the empowerment approach. All respondents identified physical activity levels as low; especially women are less active compared to the native white group. Difference in diet presented probably the clearest aspect of a cultural specific characteristic. Findings identified that gender specific roles and social eating have an adverse effect on DSM.

In both countries organisational aspects including time, length of session, venue and travel distance affect attendance and implementation but are not attributable to any particular culture.

Category 4: Factors conducive to implementation

Making the programmes' content relevant to the target group and supporting individual goal setting was seen as enhancing successful implementation by most respondents. One respondent from the UK highlighted the positive influence of organisations that make an effort to promote and implement sessions.

Findings show consistency among expert opinion that the inclusion of relatives increases the support system of diabetic participants. The same can be observed for the implementation of group sessions where participants support each other. Further key aspects for smooth implementation include: Building rapport with EMGs, training health educators in culturally sensitive communication skills and tailoring, and including fun activities.

Category 5: Barriers to implementation

The information gathered from the experts demonstrated that lack of attendance was one of the major obstacles. Respondents from both countries stated as one potential reason that participants are not aware of the benefits of a DEP. This is different for the Dutch Programme D where the community articulated the need for an intervention. Barriers to participation further included family commitments, travel distance to venue, lacking access to information and being unacquainted with offers. The latter was strongly associated with GPs who are not pro-active in informing and referring patients to DEPs. This was particularly seen in the UK.

The Dutch interventions noted that often EMGs face multiple problems. This leads to the fact that diabetes is not being regarded as a priority, which impacts attendance and successful implementation. Additional respondents in the UK and the NL remarked that smooth delivery was prevented by the provision of mix-methods from health professionals.

All respondents noted financial restraints. In the UK experts wished for more financial support to further develop research. In the NL respondents described the difficulty of getting funding for any diabetes programme that targets EMGs. In order to receive support at any level stakeholders need to see the value in DEPs for EMGs as observed by all respondents. Another barrier that was identified is the lack of human resources within the interventions.

Category 6: Solutions and Suggestions

Respondents presented a broad variety of suggested solutions and efforts that were already accomplished to tackle barriers. On the level of delivery respondents presented the option of mix-matching programmes, writing employment letters and sending participants a reminder before

sessions as solutions for overcoming barriers to attendance.

Most respondents suggested raising awareness of DEPs in order to convince participants and stakeholders. Respondents from the UK proposed the use of evidence to demonstrate effectiveness. In contrast, one of the Dutch respondents argued that the lack of significant clinical outcomes is, among others, a reason why the NL ceased to finance DEPs for EMGs. Both respondents from the NL suggested the option of looking for additional sources of funding as a possible solution for financial restraints.

The majority also remarked that learning from other experts and evidence-based strategies are good options for improving DEPs.

Chapter 5: DISCUSSION

In this chapter the main findings of the expert interviews are explained and discussed in the context of research and theory. This work investigates the availability of DEPs for EMGs in the European region and provides a well-diversified demonstration of aspects that impact the feasibility of interventions.

One major finding of this study is that only a few culturally adapted DEPs exist in the EU. A couple of the DEPs tailored for EMGs were identified in the UK and the NL⁷. Results present extensive inter-country variation regarding size and coverage and the structural embedding of programmes. In the UK structural diabetes education is recommended by the NICE guidelines since 2003 and supported by the NHS and policies. The two major diabetes interventions (programmes A & B) for EMGs are based on large and well-evaluated programmes that existed already for the native white population. Experts investigated the target groups' needs from scratch; however, the embedding in existing organisational structures, a national HCS that emphasise on evidence-based practices and having an evidence-based programme as a basis seem to be supportive structures for the spread and recognition of DEP for EMGs.

In contrast, the recruitment of culturally adapted DEPs is already a major obstacle in the NL. This is not only based on the scarcity of offers but also on the fact that individual persons or small groups often provide diabetes education to EMGs without a large supplementary body of evidence, a single source of funding or organisations backing up those interventions. The expertise of five experts from five different organisations approved the finding that in the NL currently DEPs are either properly evaluated research projects but not delivered or vice versa. The result is most likely explained by the structure of the Dutch HCS and the availability of funding that impacts development and implementation.

In this context the study reveals Dutch strategies to compensate with the shortage of financing: (i) approaching EMGs by targeting communities with a low SES, (ii) incorporating diabetes related topics in general lifestyle interventions and consequently changing the source of finance from HCS to the social security system, and (iii) changing the target group from people with T2DM to populations at risk by offering prevention programmes.

The overall data indicate that in the EU DEPs for EMGs very seldom have high evidence level and are implemented. This finding is in line with Hawthorne's worldwide review (2008, p.19) that identified only a few culturally appropriate diabetes educations for EMGs with high quality data in

⁷ Additionally DEPs for Turkish immigrants were identified in Germany. One of those was included for reasons of pre-testing the interview guidelines.

Europe. An important issue emerging from these results is that both DEPs for EMGs that fulfilled the criteria (high evidence level and being currently delivered) were found in the UK. From this one can infer that existing structures in the UK in terms of policies and HCS are conducive for development and realisation of culturally adapted DEPs.

The situation in the NL exemplifies the association between policy and financing and how Dutch policies have changed over the last years. This study has shown that it is very difficult to get funding for DEPs that target EMGs in the NL. These results concur with Euwal's (2007) findings that observed a shift of the Dutch government towards an "incentive-orientated" approach that claims for assimilation from immigrants, for instance, by learning the Dutch language.

Not only policies and HCS affect DEPs for EMGs but also evidence-based results were identified as critical for decisions on a structural level. Opinions are divided on the issue of measurable effectiveness. Whereas most experts accentuated good results in their evaluation including that participants liked the sessions, increased their level of knowledge and intended to make lifestyle changes, one of the Dutch respondents admitted that it was not possible to find significant results⁸ in the form of clinical outcomes (glycaemic control (changes in HbA1c), changes in serum lipid concentration, blood pressure and Body Mass Index) at one-year follow up. Even with 10 years of diabetes research and investigation of different DEPs for EMGs, evidence-based results remain inconclusive. On the contrary to the Dutch interventions, those in the UK also show significance outcomes in clinical measures.

However, empirical findings and literature emphasise that culturally sensitive educational interventions for EMGs with T2DM can improve diabetes-related outcomes although findings vary concerning clinical outcomes and evidence for long-term effects is missing (Attridge et al., 2014, p. 29; Baradaran et al., 2006, p.6; Hawthorne et al., 2008; p.17; Ricci-Cabello et al., 2014, p. 5).

The study shows that the NL had shifted their focus as a response to the situation described above. Nowadays Dutch interventions approach entire communities (multi-ethnic groups, disadvantaged groups) rather than specific EMGs and intend to include the social environment (community) in diabetes care. More research (and time) in this area is necessary before results and effectiveness of these relatively new Dutch interventions can be compared to long-established DEPs for EMGs.

In that context it is important to highlight intra-diversity of each EMG and understand the two dimensions of heterogeneity. One dimension is about grouping. For instance, the term SAs lumps together groups of people from different countries (such as India, Pakistan, and Bangladesh) with different cultural backgrounds and often these population groups are not even well disposed towards each other in their home countries. However, in the country of immigration they become

⁸ In this study women presented positive HbA1c changes but findings could not be proved a second time.

allocated and treated as one group with common cultural characteristics (the same counts for the group of Turkish immigrants). The second dimension describes social hierarchies. In this regard, grouping is based on ethnicity rather than on the SE position of a person. To name an example; having the emphasis on dissociation, means that a manager with a SA (Turkish) background has more characteristics in common with SA (Turkish) people who work in and live under poor conditions than with his white native colleague.

This raises two questions: How culturally sensitive can DEP actually be tailored? Is the inclusion of a multi-ethnic group really that different compared to a group of SAs or Turkish immigrants? More research is needed to answer these questions. However, it leads to the conclusion that immigrant population are easily ethnicized.

The findings revealed that one of the major challenges is participation. Consistent results are presented for both countries, that attitudes of stakeholders have a great impact on participants' attendance and thus on feasibility of DEPs. The study found out that especially in the UK GPs and practice nurses often did not refer patients. It was shown that DEPs were not offered to EMGs because of preconceptions that patients would not go to the education. This finding shows that immigrant populations encompass multiple identities (e.g. class and ethnicity) and hence several forces intersect and act on their daily life (theory of Intersectionality. van Mens-Verhulst & Radtke, 2006, p.4-6).

The investigated oppressiveness by health professionals becomes apparent in form of prejudices against EMGs and people with lower SES, for instance by the assumptions that health offers will not be used, making decisions for them instead of offering options, and the idea that they would not understand either the offer nor the education. The finding is in accordance with Bhatt's study (1992, cited in Hawthorne, 2008, p.3) that discovered health professional's behaviour as decisive for patients from low SES and EMGs often with very little reference to the target groups' necessities. These findings confirm the existence of social hierarchies and the vulnerable position of EMGs.

Results confirm previous findings in literature (Ingleby, 2011, p.232; Kofahl, 2011; Nørredam & Krasnik, 2011, p.71; Onwudiwe, et al., 2011 p.30; Safeer & Keenan, 2005 p.463) that EMGs lack knowledge where to find information and health offers. This emphasises even more the importance of good communication and the provision of access to information about interventions and the HCS.

Whereas in the UK GPs and practice nurses refer patients only reluctantly and sometimes deliver diabetes education to their patients themselves, the situation in the NL is different. The findings described the GPs as accepting and thankful to hand over responsibilities for patients that are often stigmatised as difficult to approach ("hopeless cases").

Economical reasons and overlaps in areas of professional responsibilities might be underlying reasons for country-specific differences. In the UK a financial incentive for each referral was indicated as conducive to increase number of referrals. In the NL the clear distinction between lifestyle-based education programmes including topics around diabetes and diabetes care in health settings reduces inter-professional competition and enhances good cooperation.

Another aspect that related to cooperation with GPs was identified. Findings demonstrated that diabetic participants received mix-methods from different health professionals, which in turn had a negative influence on smooth implementation. It became apparent that information provided by GPs did not always correspond with the content pertaining to diabetes given during DEPs. The approach to train GPs and medical students was mentioned as already established strategies to overcome the described obstacles.

The four interventions were investigated with regard to the repeated request that, ideally all elements of health care interventions should be tailored to immigrants' needs (Rechel et al., 2011, p.6). Results show substantial consistency concerning attributes that were adapted to meet the needs of EMGs. With reference to Resnicow's dimensions of cultural sensitivity in public health (Resnicow, 1999, cited in Cullen, 2002, p.7) the study reveals that superficial and deep structures have been incorporated in the design and delivery of most DEPs.

All matched their intervention and material to superficial structures like preferred location, language, food, and time. In the UK both DEPs further based their material on deep structures, like target groups' health beliefs. Programme (C) did not consider adaptation at a deep level but assumed that delivering information by peer educators automatically leads to a cultural translation. The intervention for the multi-ethnic group of women (Programme D) was tailored at a deep structural level concerning environmental factors, social, and psychological forces. In that programme culture does not refer to the country of origin but rather to class specific culture based on SDH in common.

This study identified typical characteristics of EMGs and rated them as essential variables for cultural sensitive DEPs. For instance, subjects' behaviour codes, dietary habits, attitudes to education and health, social background, presence of gender roles and language were investigated and considered while designing programmes. Literature and empirical findings clearly show that aspects of social identities, the issues listed above and comprehensive assessment strategies are elementary aspects of investigation when working with EMGs (Bophal, 2007; Ingleby, 2011, p.233-237).

Although findings demonstrate that each target group is associated with certain characteristics, the study highlights also that emphasis on dissociation might lead to forms of stereotyping and oppression. The assumption that a group of people is characterised by fixed attributes was disproved by experts' experience. For instance, effective teaching methods that were developed for EMGs worked to the same extent in the native population. In addition, in each intervention different variables were modified to the target group but in an inter-county and inter-programme comparison a number of variables command for the same adaptation although ethnicity differed. This supports the fine line between tailoring diabetes education to the needs of a particular target population (disadvantaged group) and ethnicizing of people.

The study showed that non-judgmental communication and knowledge are good responses to issues of cultural barriers.

Not only was needs assessment recognised as an integral component for designing adequate programmes, but the advice to investigate and direct interventions to those who are unlikely to attend offers were also highlighted by findings.

Findings of the study will not clarify whether increased T2DM prevalence of EMGs is mainly attributed to demographics or ethnicity. Nevertheless it became apparent that aspects of ethnicity and culturally related habits are faced with the SES and its effects on the SDH (Durieux-Paillard, 2011, p.204; Oldroyd et al., 2009, p. 487; Vissenberg et al., 2012, p.2).

The example of HL clearly displays that those aspects are closely intertwined. In the NL and UK agreement was seen that HL is rather dependent on the SES of a person than to ethnicity. However HL was described as a common characteristic for EMGs. Findings among the multi-ethnic group presented similar observations, which further corroborates the association of EMGs and low educational levels. The fact that most patients would benefit from the provision of medical information in a simplified and concise language (Safeer & Keenan, 2005, p.463) is attested by results. Teaching methods (non-written material and games) were borrowed for standard diabetes education. In short, every diabetic patient benefits from interactive sessions and simplified language.

Changing the communication strategy does not imply that content of the DEP should be altered. The act to withhold information from disadvantaged groups including EMGs bears the danger of racism and preconceptions that certain groups of people have fixed characteristics and less ability to understand medical explanations.

In addition, study results show that aspects of HL are often compounded for EMGs, as they present limited reading and writing competence in their own language as well.

The study encourages the view that inclusion of visual aids and symbols, and applying rather interactive modules instead of teacher-centred didactic methods are useful strategies to overcome challenges of HL. This finding is in line with previous studies (Easton, Entwistle & Williams, 2013, p.9; Kofahl et al., 2013, p.810; Safeer & Keenan, 2005, p.466-467; Stone, 2005). With regard to HL, immigrant populations tend to have less knowledge about the HCS and their entitlement to certain health services. The familiarity with the local health system and the level of implicit knowledge is likely to increase in correlation with the time spent in the host country and, hence, varies between immigrants.

Contrary to expectations, this study did not find decisive difference between countries regarding aspects that need to be considered for the design of culturally appropriated diabetes education. Indeed, nutritional habits like specific dishes and ingredients might differ but all experts defined the same sub-categories as important to adapt. Food preferences, attitudes to physical activity and gender roles were attributed to someone's culture and are distinguished from the native white population.

Gender proved to be relevant concerning preparation of meals and caring for family health: women for one part play a key role in food preparation, but also female diabetics often refrain from preparing a healthy diet for themselves due to the little time left to care for one's own health. In consequence, women have a key function of regulating family's dietary intake, which was assessed as difficult if diabetes adequate food was not accepted by the family and social network. Literature reveals that women, in general, tend to have better nutritional habits (Muff, 2009, p.130). However, neither previous studies nor empirical data reported gender specific outcomes after participating in a DEP (Connell, Fisher & Houston, 1992 cited in Gallant, 2003, p.185), which confirms that a persons' ability to improve DSM skills is multifactorial and not solely ascribed to aspects of gender roles.

Gender was further examined with regard to the patient-provider relation. The fact that sessions are run almost exclusively by female health educators were confirmed twice, once during the sampling of experts and by their experience. Gender imbalance of health providers was certainly not identified as an obstacle for communication, programmes' acceptance or during implementation. Nevertheless, it is beyond the means of the study to proof the opposite, as only one male expert was included.

Health communication is a relevant predictor for successful health outcomes. The findings revealed that issues around language play one of the major roles for cultural sensitive interventions, as also stated by other studies (Jacobs 2004; Muela Ribera et al., 2008; Terraza-Núñez et al., 2010 cited in Durieux-Paillard, 2011, p.205-206; Rechel et al., 2011, p.6). Strategies, approaches and research

findings vary between programmes. Some argued in favour of translating the intervention and delivering in the groups' native language and others preferred the use of translators. Regardless of preferences, the study discovered that strategies were often chosen on grounds of human resources. Both countries noted a lack of bilingual professionals.

Literature and empirical findings support the assertion that translating health interventions and medical terms are challenging, and hence trained educators and professional translators are crucial for implementation (Durieux-Paillard, 2011, p.206; IDF, 2012, p.21-23; Whiting, Unwin & Roglic, 2010, p.84). Interesting was the observation that ways of communication, speaking the participant's language (wording, intellectual level, empowering the patient, and valuing participants' beliefs and worries) and understanding the priority that T2DM takes in someone's life are similarly as important as the isolated consideration of language. The finding is in line with international studies (Kreps & Sparks, 2008 p. 330; Zeh et al., 2012, p.1250).

Strong consistency exists among experts that the ability of culturally sensitive communication skills is crucial for good health communication and the application of familiar and accepted language conducive for the build up of a health provider-patient relation. The importance of building a rapport with participants was identified as group/cultural specific. It can be assumed that this is grounded on experienced pattern of discrimination resulting in an increased demand of trust and that professionals' acknowledge their culture. In conclusion, not only DEPs require adaptation to target groups' needs but health educators need to be trained in effective intercultural communication as well.

The intent to tailor the content to the target group was revealed as effective. This includes the incorporation of participants' priorities, requests, and personal goal setting – all crucial elements to facilitate empowerment of diabetics. International guidelines (IDF: Global Guideline for Type 2 Diabetes, 2012; National Evidence Based Guideline for Patient Education in Type 2 Diabetes, Australia 2009; Nationale Versorgungsleitlinie: Therapie des Typ-2-Diabetes, Deutschland 2013; NICE Guidelines: The management of T2DM, UK 2008) emphasise on self-management. Indeed, the empowerment of participants and the improvement of DSM skills has a central role within the investigated interventions.

The results disclose for the first time the link between EMGs and the empowerment approach. Experts assessed EMGs to be rather unacquainted with the empowerment approach and that the method was not understood as individualised and problem-oriented but led to frustration. To place the explanation of the concept at the beginning of the first session was noted as a helpful response to the culture specific challenge.

The study investigated different dimensions of social support and group affiliation and how these influence diabetes education. Like in literature, results demonstrate that psychosocial mechanisms of social environments comprise both, the potential to be supportive or inhibiting (Berkman & Glass, 2000 cited in Vissenberg, 2012, p.2; Gallant, 2003, p.186). Especially in the NL EMGs were described as strongly connected to their community and social network, which was observed as contributing to successful implementation. Besides, sharing experience and achievements among participants was rated as conducive. However, norms and values of communities can have also a negative impact on behaviour structures of population groups and thus lead to adverse effects of DSM. Findings demonstrate some psychosocial mechanisms, such as pressure of social eating. A cultural specific example describes that declining food when offered is seen as more rude in some countries than in others.

In contrast to the majority of investigated programmes, the strategy to work with peers was ascertained as ineffective by one intervention (B). The most likely explanation for the negative finding is that the study compared health professionals delivering the intervention with interpreters to lay people that could speak the native language. The finding indicates that the absence of a professional background in health is an important precondition or that training has to be more extensive and delivery well assisted as implemented by DEP A. The result that involvement of peers can be conducive for implementation as noted by the other three DEPs concurs with the systematic review of Ricci-Cabello (2014, p.5) that identified peer educators as beneficial.

The empirical findings can contribute considerably to the development of recommendations to overcome challenges particularly regarding attendance and around organisation. Aspects like starting time, length of session, family commitments and choice of venues were identified as barriers for attendance. Also the distance to venue counts as a predictor for attendance as presented by study results. The impact of travel distance is known in health service uptake (Ensor & Cooper, 2004, p.16; Hayton et al., 2013) and because the issue occurred in the multi-ethnic group it can be concluded that results are being based rather on SES and geography than culture-specific.

Furthermore, the study has shown that the request to receive a reminder before sessions was predominantly examined in EMGs. Results of the present study are consistent with findings of Chen's (2008) Randomised Controlled Trial (RCT) that describes phone calls and text messages as effective reminders for increasing attendance.

Except for one, all other included diabetes programmes were group-based educations. Findings displayed several advantages although some studies present contrasting results that favour individual treatment (Ricci-Cabello et al., 2014, p.5). Besides effectiveness, economic reasons are also components that influence the decision whether to finance group or one-to-one treatment.

It is not the scope of the study to compare group versus individual educations and more research is required to go further into that question.

Four different educational interventions in two countries that approached EMGs were investigated. Both, educations and target groups varied greatly. This confirms that, inter-group characteristics are heterogeneous and intra-group diversity exists. An important issue emerging from this awareness is that tailoring diabetes care is conducive for feasibility. The findings in this study reinforce the advantages of introducing EMG-specific programmes although experts' opinions vary on whether it is best to target multi-ethnic groups, disadvantaged population groups or specific EMGs.

However, considering the diversity of EMGs and addressing all EMGs with a specific culture-tailored approach leads to very small target groups. This bears the challenge of shortage in staff and funding, and an over-emphasis on differences, thus, supporting segregation.

Stakeholders (Government, HCSs and health providers) on all levels need to decide on the appropriated balance between target groups' needs, evidence-based strategies and possibilities given.

Chapter 6: RECOMMENDATIONS AND CONCLUSION

6.1 Recommendations for practice

Recommendations are grounded on findings of the work and experts' perspectives on good ways to go for practice. In general it is emphasised, that all interventions, approaches and health professionals should be mindful of the balancing act between tailoring a programme and ethnicizing people. For DEPs to be effective they need to include vulnerable groups, hence, experts recommend either targeting multi-ethnic groups, disadvantaged groups or specific EMGs. Regardless of the target group, experts' recommendations broadly concur.

Structural level

- DEPs should be backed up by solid evidence. This should manifest the effectiveness of the intervention.

Evidence-based results provide a solid base for argumentation. Positive outcomes might convince stakeholders. These results should include individual (net gain for diabetic patients), societal (reduction of health disparities) and economic (saving costs through the prevention of complications and comorbidities) perspectives.

- Intervention design should be modified to structural systems in order to overcome obstacles of funding.

HCSs, policies and possibilities to receive funding for the realisation of DEPs are diverse. In light of existing informal barriers, it is advised to look for other forms of interventions/sources of funding.

- Awareness should be raised on all levels to improve multidisciplinary cooperation and to increase attendance.

To ensure good cooperation between health professional disciplines the following should be incorporated: Education on diabetes interventions should be provided for GPs and practice nurses to match information on diabetes. Furthermore, understanding of the interventions benefits should be increased to facilitate the amount of referrals.

- To increase the likelihood of action, concerned parties on all levels should aim for the same target.

Conditions of disadvantaged population groups are influenced by intertwined synergies that impact their ability of DSM. To counteract these structures, to reduce preconceptions and to

improve the health of immigrant populations, stakeholders at all levels should support the realisation of DEPs for EMGs and, thus, contribute to the reduction of health disparities.

Planning level

- Interventions should be tailored to the target groups' needs on a "superficial" and "deep" level (Reniscover et al., 1999).

A careful process of tailoring is characterised by the consideration of the following aspects:

1. An extensive needs assessment that includes the target group; PPI is suggested as a good inquiry tool.
2. It must be ensured that the act of tailoring does not contribute to artificial ethnicizing and segregation. The reinforcement of social and racial exclusion or defining traditional roles should be avoided.
3. Adaptation should go beyond aspects of language. Health beliefs, customs, religious practices, group specific values, cultural preferences (diets), inter-personal structures (gender roles), priorities etc. are also matters of consideration.

- Health professionals and translators should undergo appropriated training prior to delivery. This should encompass training in the programmes' content as well as on cultural sensitive tailoring and teaching skills.

Communication strategies to impart diabetes knowledge (content) should be tailored to the target group. However, it has to be assured that the target group understands the relevant information while maintaining all parts of the content. It is crucial to notice, that EMGs have a right to the same information and that content should not be reduced because of the preconception that EMGs have lower intellects, less formal education and lack compliance.

- Recruitment strategies of participants should be an important aspect before and after the development of DEP.

The team organising the programme should be encouraged to get in contact with potential participants by informing people in the community, involving persons of references, speaking the native language of the target group, and reminding participants before the sessions.

- Programmes should be communicated in an appealing way.

The way in which the intervention is communicated should increase attendance, for instance, by highlighting the aim to improve the general health condition instead of drawing focus on diabetes, as well as the use of words with positive connotations.
- Organisational aspects like venue, time, length of sessions and frequency should be tailored to the target groups' possibilities.

Taking account of these organisational aspects increases attendance in educational interventions, independent from any ethnic background.

Implementation level

- Empowerment and a participatory approach should be central elements of DEPs.

Educational interventions should aim to improve self-management skills and enable participants to make informed decisions.
- A core element should be good communication between health professionals and patients.

Good communication addresses among others levels of language competence, group specific language codes and modes of expression, mutual understanding and appreciation.
- Diabetes programmes should focus on accessibility of participants.

With regard to access, the following aspects need to be considered: geographical access, language, educational level and thus, HL, gender, household responsibilities and roles at work. In addition, these variables support the process of allocating participants according to their needs.
- DEPs for disadvantaged groups (including EMGs) should provide access to system knowledge.

The incorporation of system knowledge empowers participants to make informed decisions and reduces low acculturation. After the DEP EMGs should be equipped with knowledge about the local HCS, where to get information, who to address in case of questions, how to inform yourself about health services, which offers are provided, who is entitled to which health service, issues around costs and out-of pocket payments, and requirements that need to be fulfilled to receive treatment.

- The demand for single-sex sessions should be examined and if required provided.
 - Organisations and health professionals should be aware of the fact that separate gender sessions could be a requirement for certain population groups. This is not necessarily based on religious and/or traditional motives but on structures within the social environment or family.

- Provider-patient role allocation should be as followed: the participant plays the primary role and the health professional is the facilitator who supports change.
 - That means, the health professional should understand which priority diabetes takes and which other factors impact patients' ability to manage their diabetes, to support their empowerment.

- The didactic style should be interactive rather than teacher-centred and relate to personal experiences.

- Content should be simple, in an easy and concise language, and embedded in fun activities. For reasons of sustainability (long-term outcomes) key messages should be applied repetitively.
 - The programmes' framework should contain all relevant information but still be understandable for a person with a low HL and acculturation level. This would be beneficial for all other participants (from disadvantaged and advantaged groups) as well. Furthermore, such an approach focuses on inclusion rather than on differences.
 - In general, medical explanations should be complemented through practical advices.

- Material should be adapted to target groups' need. The use of visual aids, film material, games etc. is recommended.

- Education should include relatives to support lifestyle changes of the diabetic participant.
 - The better understanding of diabetes-related lifestyle factors might have an additional benefit for the entire family and their diet, which could reduce children's risk of acquiring diabetes in future.

- Interventions should be grounded on an evidence-based curriculum, but flexibility to adapt to each group should be maintained.

Each DEP should consist of a fixed frame (aims, content, curriculum), which remains unchanged independent from target groups. Group specific tailoring occurs in terms of communication strategy, cultural specific diets, and religious practices; like a changeable costume with an unchangeable corpus.

Level of resource allocation

- Stakeholders should allocate more funding to address the needs of disadvantaged groups.
- Research should be also funded to further evaluate the effectiveness and requirement of interventions, and to extend the provision of diabetes care.
- More research is needed to investigate programmes that include multi-ethnic communities and other models of diabetes educations (individual, online programmes etc.).
- Research is required on the capability of self-help groups.

6.2 Conclusion

The study has investigated different culturally adapted diabetes education interventions in the NL, the UK and Germany⁹. An important finding is that interventions vary greatly and actions strongly depend on structural embedding and the local context.

However, many experiences are transferable to both countries. For instance, those structural barriers can be divided into questions of HCSs, policies, funding, cooperation with stakeholders, and structural oppression. Informal barriers encompass issues of language, communication, socio-cultural variables, acculturation and preconceptions.

The investigated target population presented divers intra- and inter-group characteristics and different ethnic backgrounds. However, the study has shown that in the NLs and the UK EMGs have a disadvantaged position in society and, thus, face similar obstacles when it comes to diabetes care, which are mostly down to SES and the accessibility of disadvantaged groups.

The Dutch approach of diabetes education, addresses socio-cultural issues of multi-ethnic populations and/or disadvantaged groups that are rather class related than based on a certain ethnicity. British programmes target particular EMGs.

In general, findings support that underserved population groups (including EMGs) would benefit from culturally tailored DEPs. With regard to tailoring DEPs, this study is significant in three aspects:

1. It adds to the understanding that interventions should follow an inclusive approach that builds on an educational content that is beneficial for the general public rather than on an over-emphasis on differences and ethnical segregation. The programme design, didactic methods and content should be well suited for everyone. On grounds of this fixed content, group specific variables can be tailored to the target groups' needs.
2. It highlights that a profound understanding of cultural sensitive tailoring, teaching and communication skills is one of the major precondition for successful diabetes care. That means, health professionals (including GPs, nurses, dieticians, health educators) require an extra training.
3. It substantiates that improving equity in health services does not mean improving the access to standard DEPs but providing disadvantaged groups a whole picture of diabetes care including DSM skills, knowledge of HCS, and the usage of supportive structures. Furthermore, content should be

⁹ Germany was mainly included during the pre-testing phase of the interview guidelines

tailored to cultural specific characteristics but also explicitly address aspects, other than diabetes-related, that matter to the target group.

Considering cultural variables is indeed of value for an educational diabetes intervention as long as the assessed group-specific variable provides relevant information that enhances successful implementation and outcomes.

This research confirms previous findings and contributes to the understanding of aspects that are beneficial or inhibiting for smooth implementation. For instance, in both countries experts suggest that it is effective to empower participants and apply a participatory approach.

One major barrier is attendance. The findings present that issues of attendance require encouragement on levels of stakeholders, other health disciplines, organisations that provide DEPs and the community. Furthermore, recruitment strategies should be carefully tailored to overcome issues of accessibility. This study indicates a number of important findings around good cultural sensitive communication and emphasis on the positive effect of building rapport with participants.

This study reveals that the overall situation in the NL and the UK vary greatly; however, variables that impact feasibility are consistent to a great extent. The same is true for most solution approaches.

In a European context further research is needed in the field of culturally tailored diabetes education. Nevertheless, this study implies that a lesson learned in one country/intervention and for one target population can contribute to benefit others in similar contexts. For that reason findings that arose from this study are presented in forms of practical recommendations for good practice.

In conclusion, this study provides a holistic picture of diabetes programmes that target EMGs. On the basis of the data the study recommends culturally tailored interventions. It is hoped that by applying an inclusive approach, the health of diabetic patients in general and for diabetic EMGs would improve.

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APPENDICES

Appendix A. - Code System

1. Personal Data

2. Characteristics of DEPs for EMGs

- 2.1 Concept
- 2.2 Need Assessment
- 2.3 Communication
- 2.4 Health Literacy
- 2.5 Methods and Material

3. Cultural Influence

- 3.1 Identity
- 3.2 Health Beliefs
- 3.3 Lifestyle Aspects
- 3.4 Organisational Aspects

4. Factors conducive to implementation

5. Barriers to implementation

- 5.1 Recruitment of participants
- 5.2 Challenges of implementation and evaluation
- 5.3 Stakeholders
- 5.4 Financial restraints
- 5.5 Resources

6. Solutions and Suggestions

Appendix B. - Introduction to Guideline-based Expert Interview



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Good morning. Thank you for your consent to take part in my interview.

How are you?

I will shortly introduce myself, and why I asked you to participate in the guideline-based interview. My name is Miriam McHardy and I am studying Public Health at the University of Applied Sciences (HAW) in Hamburg. Currently I am writing my master thesis on the topic: **“Necessity, Concepts and Feasibility of Culturally Tailored Diabetes Education for Migrants in the Netherlands and the United Kingdom”**. Diabetes is a major public health concern. Diabetes prevalence rates are high especially among immigrant groups and participation in conventional diabetes education programmes low. Implementing cultural sensitive diabetes education programmes might improve access and outcome of diabetes care. Nevertheless the availability of cultural appropriated diabetes education programmes in the European region is scarce and offers are divers. My thesis attempts to identify potential challenges and strategies to overcome obstacles. It will acquire expert’s wealth of experience and embrace the opportunity for learning across context to improve future diabetes education programmes for ethnic minority groups.

My master thesis will be realised in cooperation with the HAW and the SITD project at the Medical Centre Hamburg-Eppendorf (UKE).

All persons who are involved in the development and/or implementation of a cultural appropriated diabetes education programme are considered to be experts, so are you.

For that reason, I would like to ask you some questions. The conversation will take approximately fifty minutes.

I will not judge any answers, and there will be no right or wrong...I am interested in your point of view and your personal experiences. Do you have any further questions?

Thank you for your consent to be interviewed.

As discussed will I audiotape the interview, I will start the audiotaping now!

Expert: Someone who was involved in the development (process) of the DEP

INTRODUCTION

1. Personal data of expert

Please tell me something about yourself, your occupation, and your professional background?

Did you have already experience with developing DEPs? What did you do differently for the development of the culturally appropriated DEP?

How get it happened that you developed a DEP for EMGs?

GENERAL INSIGHT OF DIABETES EDUCATION PROGRAMMES (DEPs)

2. Conception of DEP tailored for ethnic minority groups (EMGs)

How did you proceed to develop the concept of “NAME OF DEP”?

On which concepts and theories is your DEP based on?

On which grounds have you chosen the topics/the content for you DEP?

Did you extract/remove any contents from “conventional” EP?
If so, which ones?

Could you describe cultural-competent elements that are applied in your DEP?

Is the DEP (NAME OF DEP) only applicable for group sessions or also for individual sessions?

Of how many sessions consist your DEP?

How would you describe the relationship between health experts who deliver the programme and patients?

Did the DEP planned to involve patients actively in decision-making processes? If so, how?

Is the DEP conceptualised for same- or mixed-gender groups or does that not play a role?

Was there any difference to your previous experience and if so, which?

Which attributes differ between your intervention and conventional DEPs?

Now I will ask some questions related to the target group. How does the target group differ to the culture of the “native” population?

Could you explain an element of specific EMG culture that you would ascribe to the target group?

3. Theoretical background underpinning DEP for immigrants
<p>Would you describe your programme as cultural sensitive? If so, why?</p> <p>Did you assess the needs of the target group previous to developing the DEP? If so, how? Interviews, focus groups, how many, with who, did the interviewee had a migration background themselves?</p> <p>Does a written curriculum for your diabetes education exist, that supports diabetes advisors who run the sessions?</p>

INTERNAL FACTORS: IMPLEMENTATION

4. Cultural influence
<p>I would be interested to understand the variety of aspects you considered for your programme. Let's start with communication, have you considered language competence and communication difficulties? (Linguistic abilities, writing-, and reading competence, HL, educational level)...?</p> <p>Have you assessed patients' communication levels prior to developing teaching material?</p> <p>Does health care workers deliver the intervention in participants' first or second language?</p> <p>Is the intervention delivered via an interpreter/translator?</p> <p>Is the DEP and/or your teaching methods considering patient's cultural beliefs and behaviours? Which ones? How?</p> <p>Did you address other lifestyle aspects (eating habits, physical activity...)? If so, does specific teaching material exist?</p> <p>Is the DEP or are the teaching methods addressing cultural differences? Which ones? How?</p> <p>Could you imagine, that gender might play a role in cultural appropriated DEPs?</p> <p>Have you noticed or received feedback of problems that occurred due to female health educators?</p> <p>What is your opinion about the inclusion of relatives?</p>

5. Difficulties associated with cultural appropriated DEPs
<p>Please tell me, have you been confronted with obstacles while developing the DEP?</p> <p>According to your opinion, which aspects caused these obstacles?</p> <p>Which steps have been taken to solve these problems?</p>

6. Consideration of health literacy (HL) and/or socio-economic (SE) factors
<p>Do you think health inequities might have an impact on the outcome of your DEP? How?</p> <p>Do you think SE factors (levels of education, working conditions...) should be</p>

considered for the development of DEPs/ training material?
If not, why? If so, how?

Do you have the impression that the reading and writing competence of participants (target group) impacts the outcome of the DEP?

What kind of training material is applied?

7. Barriers to implementation

Are you aware of barriers regarding the attendance? Which one have you recognised?

Can you think of possible reasons for these access barriers?

What is your opinion about involving key persons (link worker, peers, mediators...) to improve communication and/or access?

Do you think key persons could increase acceptability of DEPs among target group?

EXTERNAL FACTORS

8. Structural factors impacting the practicability of DEP

Are you acquainted with structural barriers that might affect the implementation of DEP for the target community? (Guidelines, resources, the public, stakeholder)

Has the implementation of the DEPs been evaluated?

How did the evaluation look like? What have been assessed?

What was the result?

Did you assess objective and subjective intervention outcomes reported by users and service providers? If so, what did they report?

Do all outcomes of the DEP show a positive effect or did you observe outcomes that had no effect or presented negative results?

Is the programme being evaluated regarding cost-effectiveness when compared to standard care procedures?

CONCLUSION

9. Experts' recommendations

We are almost at the end of our interview, if you could give one hint/ advice or recommendation to another DEP, what would you say?

In hindsight would you do something differently?

From your point of view are there any questions we did not touch on during the interview, which you consider as important?

CLOSURE

10. Acknowledgement

To voice many thanks for the interview, to assure delivery of the final report

Thank you! I will stop the audiotaping now.

Expert: Someone who is/was involved in the implementation of DEP

INTRODUCTION

1. Personal data of expert

Please tell me something about yourself, your occupation, and your professional background...?

Since when do you deliver DEPs? How many DEPs do you run per month?

Do you deliver other DEPs apart from the program (NAME)? Which ones?

Do you have any experience with cultural appropriated DEPs with South Asian (Turkish/Moroccan) immigrant groups?

GENERAL INSIGHT OF DIABETES EDUCATION PROGRAMS (DEPs)

2. Conception of DEP tailored for ethnic minority groups (EMGs)

Now I will ask some questions related to the target group. How does the Target group differ to the culture of the “native white” population?

Could you explain an element of specific ethnic minority group culture that you would ascribe to the target group?

Which requirements did you have to fulfil in order to deliver DEPs for EMGs? (Extra training)

Which aspects of your the DEP (NAME) differ to conventional programmes?

3. Theoretical background underpinning DEP for immigrants

Would you describe the DEP (NAME) as culturally appropriated? If so, why?

IMPLEMENTATION

4. Difficulties associated with cultural appropriated DEP

Implementation:

Is the DEP (NAME) only applicable for group sessions or also for individual sessions?

Do you use the DEP (NAME) for same- or mixed-gender groups or does that not play a role?

Do relatives participate in DEPs? What is your opinion to that?

Of how many sessions consists your DEP and within which timeframe?

According to your opinion, do you think the DEP (NAME) suits the target group?

Are there any problems/ obstacles during implementation process? If so, what kind?

If you could, what would you like to change?

To your opinion, is there any content that is missing?

Evaluation:

Do you perform an evaluation at the end of the DEP?
If so, How? What is measured? How often?

What happens to the results?

Which steps have been taken (so far) to overcome obstacles?

5. Influence of culture

From your experience, does the participants' origin/culture influence the DEP?

Have you noticed any difficulties in communication?
If so, how do you notice them?

Which other lifestyle aspects have you recognised as different compared to the "native" population? (diet, physical activity)
Is there any specific education material available?

Do you think that gender aspects play a role in DEP for Turkish/Moroccan (South Asian) immigrants?

Does your programme (NAME) react to gender specific differences?
Which experience have you been gained?

Have you or your colleagues experienced situations where participants rejected the DEP due to a female health educator?

6. Consideration of health literacy (HL) and/or socio-economic (SE) factors

Have you noticed, that reading and writing competence of participants (target group) impacts the DEP?

Have you observed a difference between participants reading and writing competence of conventional DEP and of those taking part in cultural appropriated DEPs?

Do you ask participants if they are able to read and write English/Dutch?
At what point in time do you ask: during or prior to the session?

Does the result (if patients are illiterate) affect the choice of material applied during the session? If not: do you notice HL during the delivery of sessions?

Is the DEP well suited for people with different educational levels? Or would you say, the DEP (NAME) is suited better for a particular group? Which?

Can all participants understand/use the material?
Have you noticed gender differences?

7. Barriers to implementation

Access:

Which barriers regarding attendance have you identified?

Which would you rate as the most important ones?

What aspects have to change in order to improve attendance rates/access to DEP?

Material:

How would you rate the existing variety of training material tailored for the target group?

Does any material cause difficulties during implementation? If so, what could be the possible reasons?

Is there any kind of material that is lacking?

Does your team have the possibility to modify educational material?

If so, what kind of modification did you undertake so far?

Communication:

What kind of communication difficulties do you face during?

Which strategy are you applying to overcome communication difficulties?

Workload:

Do you perceive the workload of the DEP (NAME) differently to conventional DEPs?

EXTERNAL FACTORS

8. Structural factors impacting the practicability of DEP

Do you have the possibility to adapt your DEP (NAME) during the implementation?

CONCLUSION

9. Experts' recommendations

We are almost at the end of our interview, could you please summarise the strategies that according to your opinion, have been proven to be effective?

What could be reasons for the effectiveness?

Which methods failed according to your opinion?

Have you further ideas or wishes related to concept, content, and/or material to improve diabetes education?

From your point of view are there any questions we did not touch on during the interview, which you consider as important?

CLOSURE

10. Acknowledgement

To voice many thanks for the interview, to assure delivery of the final report

Thank you! I will stop the audiotaping now.

Appendix E. - Cultural-Competent Assessment Tool (CCAT)

Cultural-Competent Assessment Tool (CCAT) for Healthcare Interventions in Ethnic Minority Groups

1. Does the intervention have a clear focus on ethnic minority groups?

HINT:

- The studied population must be the minority of the majority population of the host country
- The primary aim/objectives of the intervention must be clearly defined to the culturally-competent element or elements
- An element of specific Ethnic Minority Groups culture must be described
Delivery staff group or health workers should be made clear

2. Is the intervention sensitive to specific linguistic needs of the participants?

HINT:

- Is the intervention delivered in participants' first or second language by healthcare workers or expert patients?
- Is the intervention delivered with the aid of translated audio-visual aids for participants who speak or understand little of the service providers' first language?

3. Do the service providers demonstrate cultural awareness?

HINT:

- Do they demonstrate self awareness of their own personal and professional cultural biases so as to understand how they influence their interactions with patients and other clients?
- Are they sufficiently aware of their own cultural values, cultural identities, and traditional health and belief practices to assess the influence of culture on a patient's or client's health beliefs and interpret the patient's explanatory model of their illness based on their cultural backgrounds (Shiu-Thornton, 2003)?
- Are they sufficiently aware of cultural diversity to deal with ethnocentricity?

4. Do the service providers have cultural knowledge?

HINT:

- Do they have knowledge of cultures other than their own to understand the diversified needs of patients or clients?
- Do they value cultural diversity and the need to treat patients or clients as individuals?
- Do they demonstrate an acknowledgement of stereotypes, health inequalities, health beliefs and behaviours?
- Do they have clinical, cultural and humanistic knowledge to understand and collect relevant data on patients or clients, and undertake individual culturally based physical assessments of patients or clients?

5. Do the service providers have specialist knowledge in the clinical condition?

HINT:

- Do they have a sound scientific knowledge in the clinical condition under investigation?
- Have they undertaken relevant training to be competent in the delivering of the

intervention?

- Can they use clinical and evidence-based knowledge to develop, assess, deliver, implement and evaluate individualised patient and client care?

6. Are the linguistic needs of patients or clients met by:

- Health workers speaking the patient's/client's main language?

7. Are the health literacy needs of patients and/or clients met by the delivery health workers or expert patients (patients with full knowledge of the clinical condition)?

HINT:

- Are they communicating at the appropriate level of the patients or clients?
- Is the scientific and/or health information understood by the patients or clients?
- Is the comprehension of the topic by patients/clients being assessed?

8. Are the service providers culturally-competent in the delivering of the intervention?

HINT:

- Do they have self cultural awareness (please see #3 above)?
- Are they using clinical, assessment, and/or diagnostic skills appropriately?
- Are they taking into consideration the patient's/client's cultural beliefs, behaviours and care needs and addressing them where appropriate?
- Are they addressing cultural differences of patients/clients?

9. Are the service providers culturally sensitive?

HINT:

- Do they deliver care services and treatment in a non-judgmental manner?
- Do they show empathy in delivering care services to patients or clients?
- Do they consider patients or clients as true partners in their own care and involve them in decision-making?
- Do they have appropriate interpersonal relationships with patients and clients?
- Do they use effective communication skills to facilitate and negotiate the care needs of patients or clients?

10. Does the intervention work?

HINT:

- Does the intervention improve the quality of life (from primary and/or extrapolated evidence from secondary sources)?
- Is the intervention cost effective when compared to standard care procedures?
- Is there evidence of objective and subjective intervention outcomes reported by users and service providers (e.g. satisfaction with care, improvements in laboratory parameters, improvement in knowledge of the clinical condition)?

Appendix F. - Statutory Declaration

I hereby confirm that I have written the submitted master thesis myself. I did not use any other sources than declared in the text/references. Any literal quotations are clearly marked and referenced.

The Master Thesis was not used in the same or in a similar version to achieve an academic grading or is being published elsewhere.

Location / Date:

Signature: Miriam McHardy