

# **Cities Changing Diabetes**

## **Vulnerability Assessment in Copenhagen**

**University of Copenhagen**

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## Summary

The overall objectives of the Vulnerability Assessment is to gain in-depth information on what attributes the most to vulnerability seen from the perspectives of vulnerable diabetes patients and citizens at risk. In Copenhagen, we focused on how everyday life influences the perceptions and experiences of health risks and illness among fifty vulnerable patients and citizens at risk in the city. We aimed at investigating how the local environment and practices influence individual practices and behavior, and how the management of diabetes is influenced by social factors. Also, the analysis addressed how the vulnerable population perceived and experienced the availability of the healthcare services in their local community. In order to get sufficient knowledge about the most vulnerable patients we also conducted focus group discussions with seven healthcare professionals. The research questions were analyzed within the three domains defined in UCL's Vulnerability Assessment Tool, i.e. the Formal domain, the Community domain and the Vulnerability domain.

The Vulnerability domain: The analysis showed that there are several degrees of vulnerability. The healthcare professionals characterized their patients as vulnerable due to a complex combination of social and physical issues. Even though only some of the patients participating in this study could be described by this complex set of characteristics, they had all experienced a range of problems in their everyday life which affect the prioritization of diabetes or health issues in general. Vulnerability was closely associated with the Danish term "manglende overskud", in English 'lack of reserves of energy'. Due to a range of issues and worries in everyday life, such as comorbidity, unemployment, economic problems, major life events and loneliness, management of diabetes and healthy lifestyle practice could be 'just too much'. Among the vulnerable patients diabetes was not on their mind because of pain and discomfort caused by other diseases. Some found that diabetes is not a severe condition compared to other diseases. As long as there were no symptoms, the patients in this study did not react to the disease. The importance of diabetes in everyday life as well as the management of it was influenced by social factors and life events.

Compared to other chronic diseases, diabetes 2 did not represent a serious health risk among citizens at risk. Unemployment was a very important factor that attributed to the overall vulnerability of the informants and living alone and lacking social support further made it difficult to cope with small everyday tasks. Both informants and health professionals emphasized how important it is that lifestyle changes and self-care management are as tangible and easy as possible.

The Formal domain: Patients received assistance from their GP, the out-patient clinic at the hospitals, the Diabetes Association and the Community Health Center (CHC). Compared to the patients, the citizens at risk did not have the same regular contact with the healthcare system. The majority of the citizens at risk had no knowledge of the prevention services and courses provided by the CHC. The GPs had a decisive role in the vulnerable patients' and citizens' access to healthcare services through information and referral. Information on healthy lifestyle was appreciated by the informants but they also stated that they did not need more lectures or knowledge. It was not lack of knowledge that made lifestyle changes difficult. The informants were worried that the limited time periods at the CHC were too short for them to keep on practicing a healthier lifestyle when finishing the courses. In addition, some informants found that the opening hours at the CHC and other health facilities did not match well with their work life. Travel distances to healthcare facilities also seemed to be a barrier for those who had physical limitations. Some patients with non-western background had difficulties applying for financial support for their diabetes medicine because they did not understand the applications forms. Some mentioned economic challenges when paying for their medicine, but most of the informants had not experienced major economic problems in relation to their diabetes.

The Community domain: Almost all informants enjoyed the green areas near their neighbourhood which gave them the possibilities to meet up and do social and physical activities together. Due to physical limitations only few liked to do more vigorous exercise. Gym facilities in the local area were sometimes used and it was important that they were free of charge. Many female informants with non-western background found that the social network initiatives provided them with a purpose in their everyday life, while especially men and some of the female informants of Danish origin did not find that social activities in their neighbourhood met their interests. Managing diabetes and keeping the prescribed diet was difficult when participating in social activities with friends and family. Some felt uncomfortable talking about their diabetes as they did not want to draw negative attention to themselves. Only few had the need to share their experiences with other diabetes patients. Some of them did not know where to find such opportunities, while several female patients with non-western background had this need met at the social network initiatives.

## Background

Copenhagen is situated in a country based on a welfare state model, which is characterized by equalitarian institutional features that have been shown to produce equalitarian outcomes. Within the Danish healthcare system coverage is universal and compulsory as all registered as residents in Denmark are entitled to healthcare that is largely free at the point of use. In general, Copenhagen is expected to have high levels of average health and minor social inequalities in health and in the prevalence of diabetes. The Rule of Halves analysis (RoH) for Copenhagen did indicate that the 'halves' rule does not apply to Copenhagen for most of the RoH levels. Copenhagen is doing better than that.<sup>1</sup> *However*; the results from the analysis have shown that there are major socioeconomic differences in the prevalence of risk factors and in the occurrence of diabetes in Copenhagen. Low educated citizens have twice the prevalence of high risk score and diabetes compared to high educated citizens, unemployed citizens have as much as 80% higher rates than employed citizens in the same age, and populations with a non-western background have twice the risk compared to populations with a western background.<sup>1</sup> The analysis has also shown that only around 50% of those who receive diabetes care achieve the treatment targets and of these only around 50% achieve the desired treatment outcomes.<sup>1</sup> Furthermore, one out of four citizens with diabetes has not been diagnosed, and approx. 40-60% of the population with diabetes experience poorly regulated diabetes or diabetes complications.<sup>1</sup> Significant socioeconomic differences in the prevalence of diabetes was found between the 10 administrative districts in Copenhagen.

Persistence of social inequalities in health in highly developed welfare states of Western Europe is a paradox for which various explanations have been suggested.<sup>2</sup> One explanation for social inequality in health in Nordic welfare states such as Denmark is that inequalities in overall access to material and immaterial resources have not been eliminated by the welfare model. The existence of a significant social class gradient in exposure to social stress due to economic hardship has been suggested.<sup>3</sup> The risk of sustaining the illnesses that contribute most to inequality in health in Denmark is greater the more one is exposed to an unhealthy diet, smoking, physical inactivity etc. Inappropriate health behaviour and related biological risk factors are increasingly concentrated among the socially disadvantaged. This may indicate a differential exposure to the different risk factors, but also a risk of differential vulnerability, because the socially disadvantaged are exposed to several interacting behavioural and environmental risk factors for the same illness.<sup>4,5</sup> Due to the change in epidemiological regime, in which consumption behaviour and self-care management has

become one of the most important determinants of ill-health, the marginal benefits of the immaterial resources to which a higher social position gives access have increased.<sup>2</sup> Appropriate self-care management is closely associated with consumption behaviour, which is related to socially rooted differences in attitude, knowledge and competency between socioeconomic groups.<sup>6</sup>

When addressing social differences in achieving treatment targets and desired outcomes among diabetes patients, an important question is how vulnerable groups use the healthcare system and why social inequality persists in the access to healthcare and in treatment outcomes, in spite of the equal access to the Danish healthcare system. Several explanations have been suggested and the concept 'candidacy' has been introduced, describing the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services.<sup>7</sup> Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receive care and adherence to treatment regimes. The social patterning of perceptions of health and health service, and a lack of alignment between the priorities and competencies of disadvantaged people and the organization of health services may create social inequality in both getting a diagnosis, receiving care and achieving the desired outcome of medical care. The present assessment will address these questions and is conducted and presented in this report by the Department of Public Health, University of Copenhagen.

The social, environmental, cultural, economic, and political contexts in the local community and in society at large are important attributes affecting attitudinal and behavioural change potentials and processes of ordinary people. Contextual factors may relate to the circumstances of everyday life as perceived by population groups targeted by public health action. In this case, context may comprise very local barriers and opportunities at the level of the household, classroom, or local community. Since contextual factors often influence the outcome of public health action they should be understood and, if possible, addressed in the planning and implementation of public health initiatives. This requires direct interaction and dialogue with citizens about their perceptions of existing barriers and opportunities for healthy living with a view to identify interventions that are locally meaningful and realistic to implement. The vulnerability assessment will therefore describe contextual conditions pertaining to the local, social and structural environments as perceived by

active citizens representing vulnerable population groups. These issues will be addressed by Steno Health Promotion Research, Steno Diabetes Center in a separate study and report.

The analytical approach of the 'Mapping'-phase in the CCD-initiative is composed of the RoH analysis and the Vulnerability assessment. The primary aim of the quantitative RoH analysis was to estimate the population risk of diabetes, the prevalence of diabetes and actual diagnosed patients, and patients receiving care and achieving treatment targets. The Vulnerability Assessment tool is a qualitative research instrument that identifies and verifies the presence of diabetes-specific social risk factors and examines the experience of health and illness among individuals with diabetes or at risk of getting diabetes.<sup>8-9</sup> The analysis takes place across three domains: the formal domain (e.g. services available, use of services as a function of capability, opportunities to make changes), the community domain (e.g. existence of non-governmental organisations, local systems of support, local models of understanding and addressing problems) and the vulnerability domain (e.g. standard vulnerability indicators of unemployment, cohabitation status, feeling financially secure and coping). Informants for the vulnerability assessment included vulnerable citizens at risk of developing diabetes, active and resourceful citizens, patients with diabetes, and healthcare professionals. The recruitment of citizens and patients was guided by the recruitment criteria (case filters) agreed for all project cities and based on the preliminary results of the RoH analysis for Copenhagen. Consequently, RoH results guided the recruitment of informants in the two districts that were identified by the RoH analyses to be among the most vulnerable in the municipality of Copenhagen.

The Vulnerability Assessment in Copenhagen will be integrated into the global mapping of urban diabetes challenges for the five cities in the Cities Changing Diabetes programme. The Vulnerability Assessment will contribute to a better understanding of the interaction between material infrastructure and individual and collective social functioning and practices in different areas in Copenhagen. The assessment addresses the research questions listed below and mainly provides the views of citizens and patients rather than a mapping of existing health and social services.

Based on a discussion among the local partners in the CCD programme in Copenhagen, the following research questions were agreed upon:



<b>Research questions</b>	<b>Data</b>	<b>Research team</b>
<i>How is the local community perceived in relation to safety, trust, norms, values – and social support?</i>	Focus group discussions and 'go-along' interviews with citizens	University of Copenhagen Steno Diabetes Center
<i>What characterize the collective lifestyles in the local community and how do they influence self-care, nutrition and exercise?</i>	Semi-structured interviews with citizens	University of Copenhagen
<i>What are the risk- and illness perceptions among vulnerable citizens and patients?</i>	Semi-structured interviews with citizens	University of Copenhagen
<i>How do vulnerable citizens in Copenhagen view social initiatives and health promoting facilities in their local community?</i>	Focus group discussions and 'go-along' interviews with citizens	Steno Diabetes Center University of Copenhagen
<i>How is the interaction on health matters between vulnerable citizens and the healthcare service perceived?</i>	Semi-structured interviews with citizens	University of Copenhagen
<i>How is the interaction between patient and the healthcare service perceived concerning diabetes care? (incl. access, availability and navigation in the healthcare system)</i>	Semi-structured interviews with patients and focus groups discussion with healthcare professionals	University of Copenhagen
<i>How do citizens with diabetes view health initiatives and health promoting facilities in their local community?</i>	Semi-structured interviews with patients	University of Copenhagen
<i>How do collective lifestyles influence the management of diabetes? (self-care, medicine adherence, nutrition and exercise)</i>	Semi-structured interviews with patients	University of Copenhagen

### **Study objectives for the present report**

The objective of this analysis is to gain knowledge on how everyday life influences the perception and experiences of health risks and illness among the vulnerable patients and citizens at risk in Copenhagen. Moreover, the aim is to investigate how the local environment and practices influence individual practices and behavior, and how management of diabetes is influenced by social factors. Also, the analysis will address how the vulnerable population in this study perceives and experiences the availability of the healthcare services in their local community.

The analysis is an integrated part of the global mapping of urban diabetes challenges for the five cities in the Cities Changing Diabetes programme. This implies that the overall objectives of the

Vulnerability Assessment are to get in-depth information, based on detailed accounts, on what the study population finds attributes the most to their vulnerability and how their possibilities to avoid health risks and to handle illness can be improved. This will be addressed across the three domains mentioned above (the formal domain, the community domain and the vulnerability domain).

### **Structure of the report**

The structure of this report is based on a tentative template set up by UCL. The methodology section will include a brief description of the research team from University of Copenhagen, the data collection and recruitment of participants. Following this, details on the location, the conduction of fieldwork and the development of interview guides will be described. Also, the section includes a description of the analytic procedures and relevant ethical consideration. The findings from the analysis will be illustrated in three subsections based on the previously mentioned domains. Finally, the report contains a conclusion and considerations on strengths and limitations of the study.

## **Methodology**

### **Establishing the research team**

For the Vulnerability analysis two research teams were established, one from the Steno Diabetes Centre and one from the Department of Public Health, University of Copenhagen. The team from UCP consisted of associated professor Ulla Christensen and pre-graduate research scholars, Gritt Marie Hviid Malling (GMHM) and Elisabeth Clare Kristensen (ECK). Both GMHM and ECK have passed a bachelor's degree in public health science and are both enrolled as master's students (public health science) at the University of Copenhagen. The curriculums for both the bachelor- and the master programmes at UCP include extensive training within qualitative methods and as such both fieldworkers are qualified within qualitative research (including fieldwork, doing qualitative research interview and data analysis). MSc Public Health Camilla Faldt Thomsen joined the research team for a period as a student assistant and was involved in interviewing, transcribing and writing the final report. The fieldwork conducted by Department of Public Health has consistently been supervised by associated professor Ulla Christensen.<sup>10</sup>

## **Conduction of interviews**

Data consisted of semi-structured interviews and go-along interviews with a) citizens at risk of getting diabetes; b) patients diagnosed with diabetes; and c) focus group discussions with healthcare professionals within the municipal and regional healthcare system.

All interviews with vulnerable citizens, patients and healthcare professionals were conducted by ECK and GMHM together or individually. The interviews took place according to the informants' preferences, e.g. in their private home or in the facilities offered by the local, social initiatives. The 'go-along' interview is an in-depth qualitative interview in which the researcher interviews the informant while walking.<sup>11</sup> The informants participating in the go-along interview decided which parts of their neighbourhood they wanted to show during the interview. All interviews conducted with vulnerable citizens and patients were semi-structured, while the interviews with the healthcare professionals were conducted as focus group discussions. After each interview session, notes related to immediate observations and impressions were taken. All interviews were audio recorded and fully transcribed. Both transcripts and reflection notes were used in the analysis.

The study incentive for both citizens and patients was a 150 DKK pre-paid grocery card, handed out after the interview and administered by the University of Copenhagen. All potential participants were handed a sheet with general information on the project. Those, who agreed further, signed an informed consent form with a description of participation conditions, ethical research procedures including Novo Nordisk' procedures concerning safety reporting (see appendix 2).

## **Interview topics**

Based on the site-specific research questions for Copenhagen, thematic interview guides were developed in close collaboration with the working committee in Copenhagen and UCL (David Napier and Anna-Maria Volkmann). For each group of participants (vulnerable citizens and patients) the interviews were based on interview guides, derived from the Diabetes Vulnerability Assessment Tool (D-VA) (see appendix 4). However, the topics used in Copenhagen are not completely identical to the D-VA<sup>8</sup> as some topics and questions were not relevant in a Danish context. As an example, we excluded the question on access to free drinking water and the question of whether the informant had a health insurance as all citizens in Denmark are covered by the National Health Service. Instead we asked the informants if their diabetes related expenses were a challenge and whether these expenses had an influence on the everyday management of diabetes. For further descriptions of which questions or topics that have been excluded see appendix 3.

The RoH analysis for Copenhagen provided a statistical description of the social risk factors among vulnerable citizens and patients. Denmark is well-known within the research community for its ability to conduct register-based health- and welfare-oriented population studies, and during the last decade a close collaboration has been established between the Danish municipalities and several Danish research institutions. This means that health surveys are being conducted regularly, and especially for the municipality of Copenhagen, data is available on a wide range of the themes being suggested in the formal domain in the Diabetes Vulnerability Assessment tool. Consequently, more focus was directed to in-depth interviews on the perceptions and experiences of the vulnerable study population. However, in order to ensure that all relevant aspects of the global vulnerability assessment were included and analysed, the topics for each interview guide were discussed with UCL. Those topics and questions that were left out in the Danish study for each of the three domains in the D-VA was agreed upon with UCL.

The interview guides for the focus group discussions with healthcare professionals were based on Dixon-Woods' synthesis on access to healthcare by vulnerable groups.<sup>7</sup>

## **Topics of the interview guides**

Interview guide-themes used in interviews with vulnerable patients:

- Interaction between patient and healthcare service
- Self-care management and the influence of collective lifestyle
- Risk perception
- Perception of local health initiatives

Interview guide-themes used in interviews with vulnerable citizens:

- Perception of social initiatives and health services offered in/by the local community
- Self-care management and the influence of collective lifestyle
- Area specific characteristics

Interview guide-themes used in ‘go-along’ interviews:

- Perception of the local community in relation to the physical environment
- Perception of the local community in relation to safety and trust
- Perception of the local community in relation to norms and social support
- View of local health initiatives and health promoting facilities

Interview guide-themes used in focus group discussions with healthcare professionals:

- Perception of who are the most vulnerable patients
- Healthcare challenges in relation to the vulnerable patients
- Perception of access and availability to diabetes care for the most vulnerable patients
- Perception of coordination between primary and secondary healthcare and vulnerable patients

### **Ethical considerations and data protection**

According to the Danish Act on Research Ethics, projects based on register or survey data do not need approval from the National Committee on Health Research Ethics. The interviews with diabetes patients in Copenhagen were reported to the Danish Data Protection Agency as these interviews might include confidential communication on health matters. (Approval nr.2015-54-0933)

Data was stored locked up and separately, so that only members of the research team could link data with the actual informants. Furthermore, the following procedures were taken:

1. Key files with informants’ names and addresses were stored separately and locked up.

2. The interview transcripts on paper were stored separately and locked up. The transcripts only existed in anonymised form.

4. Files were locked up so that only members from the research team (and the two transcribers) had access to them when transcribing the sound recordings. As soon as transcription of the files began, the names of the informants were changed in order to ensure their anonymity.

## **Data collection**

### **Definition of recruitment criteria**

As mentioned in the introduction, the criteria for recruitment of patients and citizens at risk were based on the results from the RoH analysis for Copenhagen. The analysis also contributed to the definition of the case filters (recruitment criteria) for the global vulnerability assessment agreed for all project cities. These case filters focused on biological factors that increase the risk of diabetes (e.g. BMI and age), social factors (e.g. education and employment status), cultural factors (e.g. ethnicity and community norms) and other factors such as gender. Most of these filters corresponded well with the results of the preliminary, local RoH analysis, which pointed out a number of socio-demographic factors affecting the prevalence of diabetes. For the population at risk of developing diabetes, the most significant of these factors were: age, BMI, hypertension, employment status, gender, ethnicity (defined as western or non-western background)<sup>a</sup>, education, cohabitation status and whether the person had children living at home. For patients already diagnosed with diabetes, the RoH analysis also identified certain factors associated with a higher risk of having developed macro-vascular complications. Many of these factors were the same as the risk factors for developing diabetes with the most significant factors being: age, BMI, employment status, ethnicity, gender, education, physical activity level and cohabitation status. Biological risk factors were excluded in the recruitment process due to practical and ethical issues. Ideally, the final recruitment criteria for this study focused on citizens at risk of developing diabetes and patients with diabetes with a combination of the following factors: male gender, older than 45 years, short education, unemployed, BMI >30, non-western background and cohabitation status (living alone). All study participants met at least two of these criteria.

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<sup>a</sup> Background is defined by Statistics Denmark based on country of birth and nationality. Western background includes

Patients and citizens at risk of diabetes were recruited from two of the ten districts in the municipality of Copenhagen. The two districts were chosen based on the incidence and prevalence of diabetes and diabetes risk factors in the districts. The RoH analysis showed that the risk of having diabetes was especially elevated in the two districts Brønshøj-Husum and Valby compared to the more affluent Inner City district (*see table 5 in the RoH analysis for Copenhagen*). A recent assessment from the Capital Region supported the focus on these districts, showing that Brønshøj-Husum was the district with the highest incidence and prevalence of diabetes in 2012, whereas Valby had the second highest prevalence and the third highest incidence (unpublished regional data). Brønshøj-Husum is characterized by ethnic diversity, while Valby is a traditional Danish working class neighbourhood.

The study population included citizens at risk of developing diabetes participating in semi-structured interviews and go-along interviews and patients diagnosed with diabetes. The vulnerable citizens participating in the semi-structured interviews met the recruitment criteria defined above. Also, the recruitment of vulnerable citizens participating in the semi-structured interviews intended to include citizens who did not use the activities provided by the social network initiatives in the local areas.

Healthcare professionals participating in the focus group discussions worked in the two chosen districts of Brønshøj-Husum and Valby. The healthcare professionals included local home visiting nurses, diabetes nurses from the regional out-patients clinics and staff from the local community health center. No general practitioners (GP) accepted the invitation to participate in the focus group discussions. In total seven health professionals took part in the two focus group discussions. All the selected professionals had extensive experience in diabetes treatment and care and provided knowledge on collaboration across healthcare sectors. Moreover, this group of professionals had access to and knowledge about the most vulnerable patients. According to the Pathway Description Programme for the capital Region of Denmark, the most vulnerable patients are treated at the regional out-patients clinics. The home visiting nurses and the diabetes nurses from the out-patient clinic have direct contact with the most vulnerable group of diabetes patients. Thus, the healthcare professionals participating in the FGD were able to provide information about those vulnerable patients that we were not able to recruit for the interviews.

## **Recruitment of study participants**

Recruiting vulnerable citizens and patients turned out to be extremely difficult and time-consuming, as this vulnerable group of both citizens and patients tended to be very hard to reach through the official contacts, recommended by the municipality. It was especially difficult to get in contact with the most vulnerable citizens and patients. Due to limited time available, the number of recruited citizens for the go-along interviews did not fully meet the criteria of the protocol (see appendix 1).

The recruitment of informants was conducted in close collaboration with local authorities and social initiatives in deprived neighbourhoods of Brønshøj-Husum and Valby. Vulnerable citizens attending the semi-structured interviews were recruited through jobcentres in Copenhagen city and local offices in the deprived neighbourhoods in Brønshøj-Husum and Valby. Also, informants were recruited through social network initiatives or on the street through informal conversations if they met some of the recruitment criteria. Vulnerable citizens participating in the go-along interviews were recruited through social network initiatives.

Vulnerable diabetes patients were recruited through general practitioners, home visiting nurses and diabetes nurses working with vulnerable diabetes patients. As this turned out to involve a very slow procedure, patients were further recruited through local, social network initiatives in deprived neighbourhoods in Brønshøj-Husum and Valby helping vulnerable citizens with social and integration issues. A snowball recruitment strategy was used in order to recruit the final informants in the study. Informants nominated, through their social networks, other informants who met the vulnerability criteria and who could contribute to the study.

## **Description of recruitment partners**

During the recruitment process, a network of recruitment partners was established in order to gain access to citizens and patients who met the vulnerability criteria. These partners often worked at offices placed in the deprived neighbourhoods of Brønshøj-Husum and Valby and had daily correspondence with vulnerable citizens living there.

The recruitment partners consist of job centres and social network initiatives including join-in centres and social housing employees. The public job centres offer career counseling to people without a job and are located both in the centre of Copenhagen and in peripheral areas of the city. Informants were recruited in the doorway of the job center by employees from UCPH. The join-in centres are financially supported by the municipality or funded by private organizations and offer a



place for vulnerable citizens to interact with other people and engage in activities, e.g. learning how to sew or ride a bicycle. The join-in centres mainly target people with social or mental disorders. The social housing initiatives and employees are also located in deprived areas providing the citizens living in these neighbourhoods with the possibility of engaging in a variety of activities including food clubs, social events and gender segregated activities in the attempt to improve the social environment. The social housing employees especially focus on improving social and ethnical integration of the citizens in these neighbourhoods. All recruitment partners, including the health professionals, informed potential informants of the study. If they were interested their contact information was written down and employees from UCPH subsequently contacted them in order to arrange an interview.

## **Data analysis**

The semi-structured interviews were analysed according to Malterud's guidelines for systematic text condensation.<sup>12</sup> The transcribed interviews and the reflection notes were read several times and meaningful units were identified and categorized in all interviews. Examples of meaningful units that emerged during the analysis were e.g. *Local Area*, *Physical Activity* and *Contact to Health Care Services*. Afterwards, data was reduced to decontextualized selections of meaningful units and further categorized across the interviews. Initially, three interviews were read and categorized by UC, GMHM and ECK independently and a preliminary consensus on the coding was established. Afterwards, the coding of all interviews was conducted simultaneously by both GMHM and ECK and discrepancies were discussed. Finally, descriptions and concepts were summarized into main findings and these were several times discussed within the research group. Thus, analysis and interpretation has continuously been displayed and discussed in accordance with the standards suggested by Stige et al.<sup>13</sup> Analyses of the semi-structured interviews were conducted, using Nvivo version 10, while the focus group discussions with the healthcare professionals were coded manually, following the same procedure.

Some of the informants with a non-western background did not speak Danish well. When citations from these interviews were included in the report, we edited the word order to make the citation meaningful. The final citations were afterwards reread by the authors to ensure that the original text was adequately expressed in citation.

## **Findings**

The structure of the findings section will follow the three domains set by the D-VA, i.e. the formal domain, the community domain and the vulnerability domain. The data from the focus group discussions with the active citizens, generated and analysed by Steno Diabetes Center is described within the community domain in the report by Steno Diabetes Center.<sup>15</sup> Data from the focus group discussions with healthcare professionals and the semi-structured interviews with vulnerable citizens and patients were generated and analysed by the University of Copenhagen. This will be described in the following subsections. Many of the issues brought up by the informants were common for both patients and citizens at risk, and consequently the citations will alternate between these groups of informants throughout the findings section. When a theme is specific for just one of the groups, this will be clearly indicated.

### **Description of informants**

Table 1 shows the overall characteristics of the 50 informants and illustrates how the social variables listed in the left column are distributed between the two groups of informants. The table shows that the variables to a large extent are equally distributed among all informants though there is an overall preponderance of women, unemployed and informants without children living at home. Likewise, the interviewed groups of patients and citizens have similar distributions of the social variables. However, the interviewed patients comprise more women and are older than the interviewed citizens. In addition, more citizens than patients are unemployed and live without a partner.

**Table 1. Characteristics of the interview informants**

	<b>Patients</b> n (%)	<b>Citizens*</b> n (%)	<b>Total</b> n (%)
<b>Residence</b>			
Brønshøj-Husum	16 (62%)	13 (54%)	29 (58%)
Valby	10 (38%)	11 (46%)	21 (42%)
<b>Sex</b>			
Women	18 (69%)	14 (58%)	32 (64%)
Men	8 (31%)	10 (42%)	18 (36%)
<b>Ethnicity</b>			
Western	12 (46%)	13 (54%)	25 (50%)
Non-western	14 (54%)	11 (46%)	25 (50%)
<b>Age</b>			
35-50	6 (23%)	17 (71%)	23 (46%)
51-65	13 (50%)	7 (29%)	20 (40%)
66+	7 (27%)	0 (0%)	7 (14%)
<b>Employment status</b>			
Student	1 (4%)	2 (8%)	3 (6%)
Employed	4 (15%)	1 (4%)	5 (10%)
Flexjob or early retirement	6 (23%)	2 (8%)	8 (16%)
Retirement	6 (23%)	0 (0%)	6 (12%)
Unemployed	9 (35%)	19 (79%)	28 (56%)
<b>Living with a partner</b>			
Yes	14 (54%)	7 (29%)	21 (42%)
No	12 (46%)	17 (71%)	29 (58%)
<b>Children living at home</b>			
Yes	10 (38%)	9 (38%)	19 (38%)
No	16 (62%)	15 (63%)	31 (62%)
<b>Total (n)</b>	<b>26</b>	<b>24</b>	<b>50</b>

\*Informants from both individual interviews and go along interviews are included

## The Vulnerability Domain

The overall purpose of the vulnerability domain analysis is to determine how vulnerability is locally defined and addressed and how vulnerable individuals are adjusting locally<sup>9</sup>. The criteria for the recruitment of citizens at risk and patients in Copenhagen were based on the results from the RoH analysis for Copenhagen, and as mentioned in the method section, a vulnerable citizen or patient was defined as male gender, older than 45 years, short education, unemployed, BMI >30, non-western background and cohabitation status (living alone).

We experienced throughout the data collection and analysis that there are several degrees of vulnerability. Although all informants met the recruitment criteria the vulnerability of the informants varied a lot. When interviewing the home visiting nurses and diabetes nurses connected to the out-patient clinics it was obvious that they have access to even more vulnerable patients than us. According to the Pathway Description Programme, vulnerable patients who receive care by the health professional in the out-patient clinics or by the home visiting nurses are characterized as individuals who generally lack the capability to take care of their own health – or those who for a shorter period experiences a social or mental crises<sup>14</sup>.

The healthcare professionals themselves characterize their patients as especially vulnerable due to a complex combination of social and physical issues such as: comorbidity, mental illnesses, addiction problems, dementia and language barriers. These patients often suffer from isolation, loneliness and complications due to poorly regulated diabetes. Only a number of the patients participating in this study can be described by this complex set of characteristics. When describing the most vulnerable patients, both informants and healthcare professionals emphasize that there are several issues in their everyday life which affect the prioritization of diabetes or health issues in general among these individuals:

*“The people, who I consider as vulnerable, most often experience diabetes to be the least of their worries. They have so many other problems such as social issues and perhaps another chronic disease. (...) I often find that it is something else than diabetes that are of importance to them in their everyday life.”*

Diabetes nurse CHC

Among citizens at risk, health in general was found to be of lower priority compared to other issues in their everyday life. Some of the issues that contribute to the informants' vulnerability will be described further on.

During the interviews, vulnerability was closely associated with the Danish term “manglende overskud”<sup>b</sup>. We could not find a suitable word for this in English but find the translation, ‘lack of

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<sup>b</sup>The Danish term diverts from the English one, as it concerns both mental and physical reserves of energy

reserves of energy' to be the most suitable. In the following, we will use the Danish designation for the phenomenon.

Due to a range of issues and worries in everyday life, the most vulnerable individuals find that everyday tasks and demands such as self-care are 'just too much'. As a citizen at risk describes, she needs to have her issues solved in order for her to do physical exercise:

*"I tell myself every day that I should go to the gym, but I haven't accomplished that yet. When I have solved some of my issues, I hope I will have the "overskud" to go there"* Female citizen at risk, 50

Another citizen describing the people in her neighbourhood, who are more vulnerable than herself, explains that many have social issues which affect their ability to cope with everyday tasks:

*"There are many socially deprived people in this neighbourhood who have many issues in everyday life, both economic issues and other issues which reduces the "overskud" to take proper care of the children, providing food, and maybe you cannot afford the vegetables necessary"*

Female citizen at risk, 61

In general, it takes a lot of effort for the informants to do physical exercises and they easily find that physical limitations or bad weather restricts them from being active. This was mentioned by most of the informants. Even though many of them would like to have a healthy diet, many find themselves buying food which does not take a lot of time to prepare e.g. microwave food. They do not have the necessary "overskud" to prepare a proper meal for themselves when they feel ill or have emotional down-turns. One citizen has an alcohol problem and eats unhealthy when he is drinking:

*"When I drink, I do not get much to eat. Then I most often end up buying fast food"*

Male citizen at risk, 43

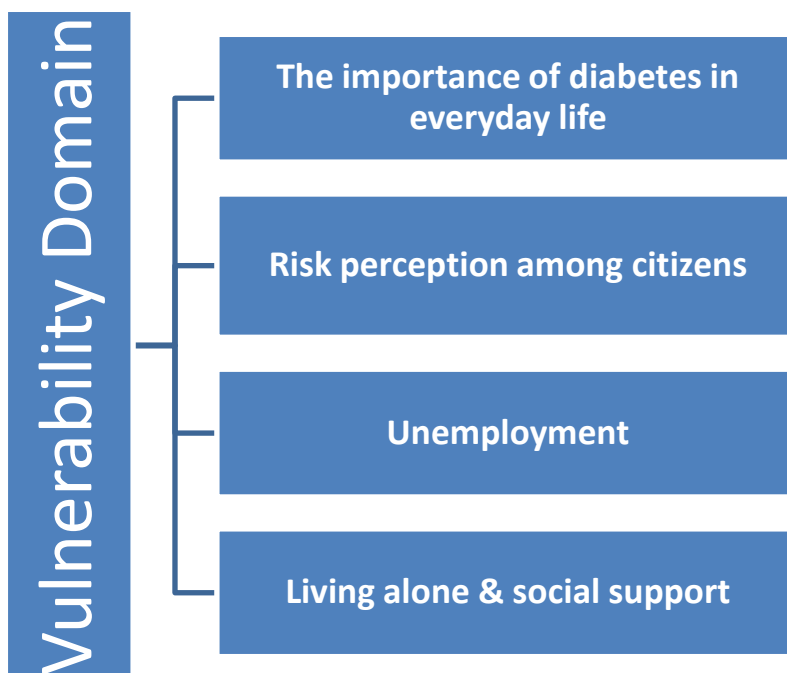
The healthcare professionals further state that management of diabetes has to be as easy as possible for the most vulnerable patients, because they have so many other issue to cope with:

*"If I just talk to her about it. nothing will happen, because she has so many issues to fight with(..) it is of no use, that we tell the patients what they should eat. It has to be as easy and tangible as possible"*

Home visiting nurse

In the following sub-sections, we will elaborate more on the factors and issues, which appear to be the most prevailing issues in the everyday life of the informants, and make them particularly vulnerable to diabetes. This includes a description of how diabetes is perceived in everyday life, of risk perception, unemployment, and living alone, see figure 1.

**Figure 1. Analytical themes.**



### **The importance of diabetes in everyday life**

Throughout the interviews, it was made clear by the patients that diabetes is not a condition that has a great impact on their everyday life. Many of the informants do not give diabetes much thought and do not feel a need to talk about it either. This section will illustrate some of the perspectives provided by the patients and health professionals.

Many of the patients explain that they do not think about their diabetes in their everyday life because they do not feel any symptoms. Some only think about the condition when taking their medicine, when measuring their blood glucoses or during control visits with healthcare professionals. Some have difficulties relating to their diabetes and accepting the diagnosis as they do not feel the effects of it on their body. Many patients do not feel any discomfort or limitations in

their everyday life and therefore the diabetes seems to be less important to them. As a male patient describes:

*“Diabetes has not been on my mind, as I have not yet felt any limitations in my everyday”*

Male patient 66

Several of the patients state that they have only recently been diagnosed with diabetes which might be the reason why they have not experienced any side effects. Others find that their medicine and the regular follow-up visits help stabilize their diabetes and give them a sense of comfort. Only few of the patients have developed complications as a result of their diabetes, but even though they could sense these complications, other chronic diseases seem to be of higher importance than their diabetes. In general, many of the informants suffer from several other chronic diseases and physical disabilities, which seem to influence their everyday life more than their diabetes:

*“It isn’t something I have noticed. To me, type 2 diabetes isn’t something you can sense. And I have so many other chronic diseases. I have 6 different kinds, so how should I be able to tell a difference?”*

Male patient, 72

The issue of discomfort caused by other diseases than diabetes was a recurring theme during the interviews. Many patients explain that diabetes is not on their mind because it does not affect them in the same way as the pains and discomforts caused by other conditions. Some find that diabetes is not a severe condition compared to other diseases. One patient states during an interview that he does not think about his diabetes because he is worried about his heart condition and how he will cope with the next heart attack. Another male patient explains that diabetes is not important as his other illnesses (herniated disc and COPD) have greater impact on his everyday life:

*“To me, diabetes is the least of my worries in my everyday life because I don’t feel it. As I can’t even walk to the nearest bus stop, without getting terrible pains in my back (...), this to me is of much more importance. And when I am sitting here not being able to breath, I am not thinking about how terrible my diabetes is”* Male patient, 72

Several other issues, such as economic problems or major life events also seem to have an effect on the informants’ management of their diabetes:

*“I think about what I am supposed to eat and what I should avoid, and then sometimes it just doesn’t matter. When I am sitting alone and thinking about life: I have lost many close family members the past five years.”* Female patient, 50

This is further emphasized by the healthcare professionals:

*“If you live under bad conditions or basically do not have a home, but instead live in the back of your kids’ restaurant, your diabetes doesn’t play a major role in your everyday life”* Diabetes nurse

Some informants describe that their management of diabetes is affected by their ability to actually sense it. One female patient states during an interview that in order for her to take her diabetes serious she needs to sense the differences in her condition:

*“I might be thinking about diabetes but it isn’t an important part of my life as I can’t sense it. Maybe if I was able to sense the difference when eating a piece of chocolate, but that is not the case and that makes me think that my condition isn’t too bad. On the other hand, when you hear about the potential complications in 10-30 years it makes me consider that maybe I should get my act together”*

Female patient, 50

Later in the interview, she states in order for her to relate to the diabetes she would need to see or sense it because it is too difficult for her at the moment to relate to the diabetes. Another patient did not take his diabetes serious until he felt the consequences of his disease:

*In the beginning I didn’t believe my doctor when he informed me of my diabetes. I didn’t take it serious back then. He gave me some medicine, but I didn’t take it. How old was I? 46 and I thought it was way too early. But suddenly, I started getting heart attacks and then I began taking my diabetes serious. I began taking my medication.* Male patient, 57

Nearly all informants are aware of the consequences of poor management of diabetes. However, it is very different how well they cope with their condition and how severe they perceive it. Some find that thinking of the consequences motivates them to take care of their diabetes, while others have difficulties relating to it. It was especially the informants with non-western background who expressed anxiety when talking about their condition. Many have family members with diabetes and some of them live in other countries and have suffered from serious diabetes complications. One male patient from Egypt explains that he was in the risk zone of developing diabetes for five years, but now after receiving the diagnosis, he is determined to improve his condition, as some of his close relatives have suffered from diabetes:



*“Do you think it will help you now that you have got your diagnosis?”*

*Yes, I do. I have read and heard about it. We are six siblings and four of them are dead; three of them had diabetes and two of them died because of it. My eldest sister had her legs amputated because of her diabetes. So I do know about the complications and how terrible this illness can be, and just the thought of it makes me totally depressed. That is why I feel motivated to do something about it now and change, more than before I was diagnosed, then I often thought: “Well, I am just on the edge, I can allow myself a piece of cake”* Male patient, 66 (non-western background)

In general most of the Danish patients were not able to describe other patients who are more vulnerable than themselves mainly because they do not know any. Patients with non-western background often mention their relatives abroad who suffer severely due to their diabetes. Their relatives are not able to get the same economic and medical support as you get in Denmark:

*“I remember when I heard about my sister’s diabetes; They were under a lot of financial pressure, as it is very expensive to get treatment at a private hospital in Egypt, and they don’t have the same insurance system. It is something that I have not had to struggle with. Thank God. Besides the disease itself, of course. It would have been frustrating having to fight the disease and to think about economic issues.”* Male patient, 66 (non-western background)

**To summarize:** It seems that as long as there are no symptoms, the patients in this study do not react to the disease. For those who have experienced relatives dying from the disease or had severe complications, getting the diagnosis made a difference and motivated them for lifestyle changes. This reaction was primarily told by informants with a non-western background. For those patients with other diseases, had discomforts that were much more present in their everyday life, than was their diabetes. The importance of diabetes in everyday life as well as the management of it was also influenced by social factors and life events.

### **Risks perception among vulnerable citizens**

The citizens at risk of developing diabetes do not give the impression during the interviews that health is a theme that they prefer talking about. They do not feel a need to elaborate on this topic and instead tends to change subject quickly. Also, it varies how much the citizens use the healthcare services. Many say that they put off going to the GP and that their symptoms have to be severe in order for them to contact the healthcare services. This is explained by a female patient during an interview:

*"If I suddenly lost a lot of weight or became extremely thirsty, - then of course I would go for a checkup at the GP. But I would not go without a proper reason."* Female citizen at risk, 50

Primarily citizens who have experienced illness or obesity have reflected on health, risk and lifestyle. Most informants know of diabetes related risk factors and some characterize themselves as being at risk mainly due to their overweight or their genetic background. Others do not see themselves at risk, primarily due to their health behavior or regular health checkups. Some informants find that these health checks at the GP give them a sense of comfort, and therefore, they do not feel that they have to worry about developing diabetes:

*"I have been examined for diabetes and I don't have it. None of the results indicated that I am at risk and my cholesterol levels are just perfect, so I have been informed that it isn't something I should worry about."* Female citizen at risk, 56

Most of the informants do not think about the risk of developing diabetes. Few suggest that maybe they would do more to prevent it if they thought about it in their everyday life; while another citizen states that he would go crazy if he had to think about his risk on top of all other issues:

*"It is not something I think about. If I had to think about that too, I would end up in a mental hospital."* Male citizen at risk, 51

A few of the informants express a sense of ambivalence in relation to the most common risk factor for developing diabetes and other illnesses. During the interviews, one informant mentions that even though you are at risk, it does not necessarily mean you will be the one who gets the disease, because:

*"You know, people who are thin also get heart attacks, even though they exercise and live very healthy"* Female citizen at risk, 50

This ambivalence occurs when discussing difficulties related to change in lifestyle, especially concerning diet. It is hard to make these changes, and both citizens and patients state that they have seen examples of relatives or acquaintances who have had a long life without illness despite having had an unhealthy diet:

*"My old mother, who is more than 90 years old, has not been living a healthy life in any way and despite of this she has become this old. She has always eaten whatever she felt like such as food with high levels of fat and she has completely avoided eating vegetables"* Male patient, 67

Some informants relate unfavourable health behaviour with stress or emotional downturns. Even those who perceive themselves at risk of developing diabetes, sometimes experience that it can be difficult to manage a healthy lifestyle when they are stressed:

*“But even though I know I am at risk, it is difficult for me. If you are for instance stressed or depressed, either you lose weight or you gain weight, because you eat compulsively, you know.”*

Female citizen at risk, 51

Among citizens at risk, some had the opinion that diabetes is not the worst condition you could get. Some call it “a healthy disease” as you can become independent of medication if the diabetes is managed well. Just like the patients, some citizens at risk find they are more motivated to improve their everyday health if they have symptoms or a condition which can be improved. A couple participating in an interview usually kept a quite unhealthy diet until recently when the woman was diagnosed with diabetes. They now find that they have a goal and a reason to improve their life style, as they believe that they can eliminate the diabetes by changing habits:

*“But of course you are at risk, and I would say that diabetes isn’t the worst disease you can get, it might even be the least; but no, it isn’t something I think about.”* Male citizen at risk, 57

**To summarize:** Compared to other chronic diseases, diabetes 2 did not represent a serious health risk among citizens at risk. Somehow, it is perceived as a condition that can be eliminated either by medicine or by lifestyle changes. Also regular health examinations seem to affect the risk perception the informants. Thinking about the risks can be a stressor and these are therefore suppressed due to other issues in everyday life. Finally, many find that changing lifestyle in order to reduce their risk is very difficult.

## **Unemployment**

Throughout the interviews, having a job emerged as being of crucial importance to the informants. The concerns of being unemployed were many and appeared to have a great impact on their everyday life. The informants often returned to this subject during the interview.

Due to the recruiting criteria, the majority of the informants are unemployed. Many are unemployed because of long-term diseases such as cancer, heart problems or physical limitations. Some physical limitations were caused by previous physical labour. The informants have difficulties finding a job

because of their illnesses and for some of them, being old or having a large body size makes it even more difficult. Almost all informants state that they would like to go back to work despite being ill. They experience difficulties when living on transfer income only and they feel that the normal structure of a workday disappears from their everyday life, as they do not have any particular place to go. Therefore, some ends up spending a lot of time at home. Some of the informants also find that having no structure and no specific goals to achieve during the day makes it more difficult to get things done such as physical exercise and errands, which can easily be postponed. Some patients state that a missing structure can have a negative influence on their management of diabetes. One patient emphasizes how a normal workday would make it easier for him to manage his diabetes:

*“If I was working 8-10 hours a day, then things would have been different. If I had a systematic day it would be easier to take care of my diabetes systematically (..) I believe it would have a more positive influence on my illness than now.”* Male patient, 66

All informants state that being unemployed is a challenge to their household economy. This affects some informants more than others. Some find that their scarce economy makes it more difficult to lead a healthier lifestyle. As an example, they find it challenging paying for memberships at the gym, participating in events held by the Diabetes Association, and buying vegetables and specific products containing no sugar. A few citizens at risk state that when having a bad economy, nothing else in their everyday life works well. A citizen at risk explains how being unemployed influences his wellbeing:

*“In my case, if the economy is unstable, then nothing else works. You don’t feel happy; the only thing you feel is being stressed. It permeates you completely. That is probably the worst part of being on government support. It’s the everlasting stress about the economy and the fact that you never have a moment of peace.”* Male citizen at risk, 41

Many of the informants mention that being unemployed has a negative influence on their health. Some feel stressed because of their unemployment and find themselves depressed as they do nothing besides staying at home all day. They emphasize that they think less of their problems when having somewhere to go every day. One citizen at risk states that not having a job is like not having an identity:

*“Being unemployed is a great concern. It is not something I wish for anyone to experience; first of all you don’t have anything to get up to in the morning and secondly, having a job is part of your identity.”*

*When meeting new people, one of the first things someone will ask you is 'where do you work'. It reduces your self-confidence significantly."* Male citizen at risk, 42

**To summarize:** As this section shows a lack of structure and scarce economy have implications on the informants' everyday life. It makes it more difficult for them to get things done and it influences their general well-being. Especially the patients feel that being unemployed makes it more difficult to take proper care of their diabetes which consequently increases their overall vulnerability.

### **Living alone & social support**

Living alone was an indicator of vulnerability in the Rules of Halves Analyses. Due to the recruitment criteria, a high number of informants in the present study live alone, and during the interviews they provide different perspectives on why living alone contributes to their vulnerability.

Some of the informants who do not have families or other close relations nearby to support them experience difficulties being on their own. Some feel very emotionally vulnerable and worry about life and the future, especially when they are sitting home alone. Some have lost close family members, which sometimes influences the patients' ability to take care of their diabetes. As illustrated in a quote used on page 23, a female patient explains that taking care of her diabetes is of no importance when she is thinking about her lost family members. Another patient states that she finds it difficult to take care of her diabetes, because she does not have any relatives left:

*"Do you often think about your diabetes?"*

*Yes, because it is my body, and I have nobody to take care of me. Therefore, I have to be careful. But it is difficult because I'm alone. With my husband, I was happy, but I am not anymore. Being alone is not good."* Female patient, 57 (non-western background)

In general, many of the informants find it very unsatisfying to eat alone and would much rather be together with other people when doing so. As a consequence, they do not bother cooking a proper meal for themselves and instead, they often end up choosing easy solutions such as bread, frozen products or take away. One informant states that he likes to cook but that eating alone reduces his appetite:

*"I like cooking and things like that, but when you're sitting looking at the dinner that you are about to eat, you somehow lose your appetite when you're alone."* Male citizen at risk, 37

Other patients living alone receive support from their family who invites them over for supper. A female patient does not have the energy to cook warm meals for herself, but receives support from her grownup sons who live nearby:

*“I also think it is difficult when you are alone. I rarely cook warm meals, because I don’t feel like it. Instead, I just eat a flat piece of rye bread with butter and cheese. That is primarily what I eat. When I am together with my old son once a week and with my youngest son twice a week, they cook healthy food. (...) It is important for them that I get a proper meal to eat.”* Female patient, 55

In general, most of the informants seem more motivated to participate in social activities, physical exercise classes or attending the gym when they have someone to join them. A couple states during an interview that they would be more motivated to participate in activities if they could go together:

*“If we were to attend, it would have to be together. We do not feel motivated if we are to go by ourselves, also because we do not know anyone there.”* Male citizen at risk, 51

## **Social support**

*“What is important to you in your everyday life?”*

*First of all, my family. My family is the most important thing to me. Absolutely.”* Male citizen, 52

Having a family is of great importance to many of the informants. They value regular interaction with their relatives as well as feeling loved and of importance. When facing difficulties in their everyday life, they often turn to their family or close friends for advice. Some of the informants describe that having family members nearby is essential for their wellbeing. For some, basic requirements such as getting a home cooked meal or being able to get out of bed in the morning can be a struggle in their everyday life, thus having relatives close by makes it less difficult to cope with these issues. Other informants are supported by their families in other ways. A patient with several chronic illnesses describes that he has made a special agreement with his son:

*“I have agreed with my son to send him a smiley in a text-message every morning when I get up, so he knows that I am out of bed. Because I have told him that I am incredibly scared that I will lie one morning unable to get out of bed without being able to tell anyone.”* Male patient, 72

Even though this patient does not see his son very often, being in touch with him every day makes him feel more secure. Some patients state that having a family helps them manage their diabetes. The families support the patients by reminding them of their medication and helping them make

healthier choices. Other patients do not experience the same kind of support at home. They find it very time consuming cooking for their families, because they must prepare an additional healthier meal for themselves apart from the traditional meal which the family still prefers to eat. One patient explains how much it means to him, having a wife to support him:

*"What about your wife, does she support you in regard of taking care of your diabetes?"*

*Yes a lot, it is not because I am a male chauvinist, but she practically does everything at home. She buys groceries, cooks food, and does the dishes and the like. But she also takes good care of me, and is concerned with my illness. And thank God that it is like this, because without her, it would have been very difficult for me to manage my diabetes"* Male patient, 66

**To summarize:** The majority of the informants in the present study live alone. Those who do not have families or other close relations nearby to support them experience difficulties being on their own and cope with minor everyday tasks. Some of the informants describe that having family members nearby is essential for their wellbeing, and it is much more attractive to do e.g. physical activities when they have someone to join them. Also, they describe that it is unsatisfying to eat alone and that this causes them to choose easy solutions instead of cooking. Having social support motivates them in taking care of themselves.

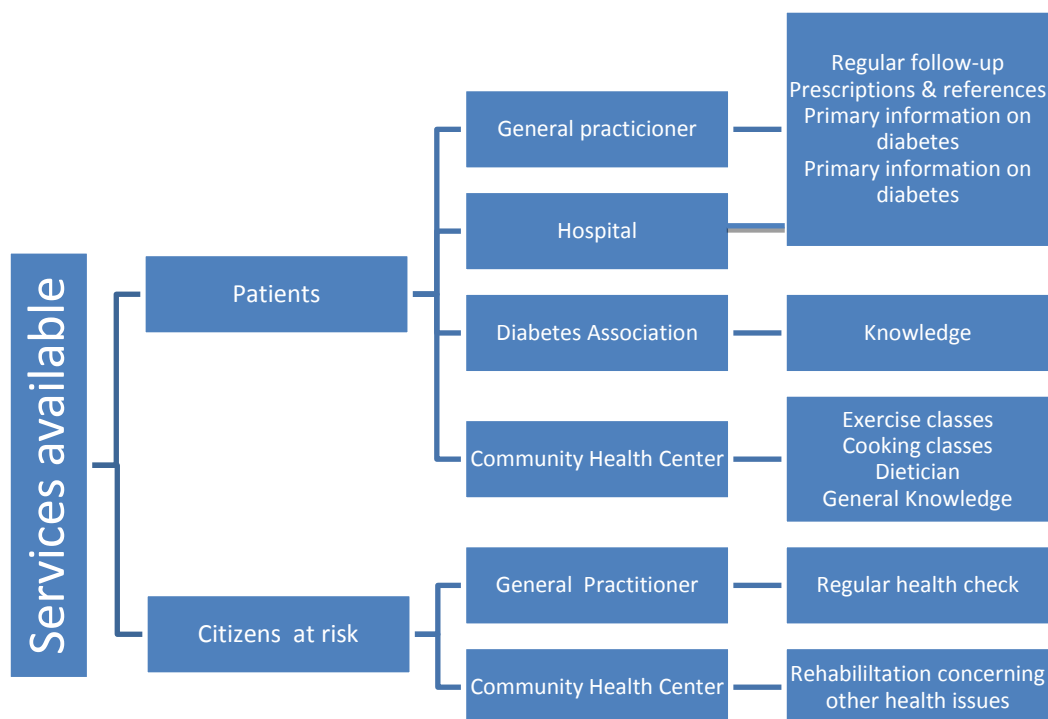
## The Formal Domain

The purpose of the formal domain is to determine if the informants know which services are available and if their use or non-use is a function of their motivation or capability. The Vulnerability Assessment in Copenhagen explores the citizens and patients' perspectives on available services and will not include a mapping of actual existing services. The section will 1) give a brief description of the services available and used (figure 2) and 2) present the barriers and incentives that the informants find influence their use or non-use of the services (figure 3).

## Services Available

The Danish healthcare system provides a range of services which are funded by public taxes. Other services are offered by private or partly private organizations. This section will be based on the services mentioned by our informants and not on the actually services available. Figure 2 is a visualization of the available services mentioned by the informants in terms of their diabetes care. The first column represents the patients and citizens at risk. The second column represents the type of services they use, and the third column contains what the services are used for by the informants.

**Figure 2. The formal domain as described by the informants.**





## Patients

Patients participating in this study primarily receive assistance from their general practitioner (GP), the out-patient clinic at the hospitals, the Diabetes Association and the Community Health Center (CHC). The majority of the patients were diagnosed with diabetes by their GP, whereas others were diagnosed during hospitalization. Most of the patients visit their GP on a regular basis and many go for follow-up visits every third month. They receive information on diabetes from their GP at the time of their diagnosis and apart from this they use the GP when needing prescriptions and references to e.g. the CHC, food specialists ect. It varies how and how much the informants use their GP. It also varies how satisfied they are with their GP, but in general they appreciate their GP if he provides sufficient time during the consultation and listens to them.

Some patients receive care for their diabetes at the out-patient clinics at the hospital. Here they go for regular follow-up visits and receive examinations concerning diabetes complications. Only few patients mention the Diabetes Association. These patients are members of the association and gain information on diabetes by reading the association's cookbook or by calling the hotline.

Most of the patients are referred to the CHC by their GP. Here they attend cooking classes, exercise classes or diabetes specific programs which also include consultations with a dietician. The patients express that the CHC provides them with useful knowledge on how to manage their diabetes. One patient elaborates:

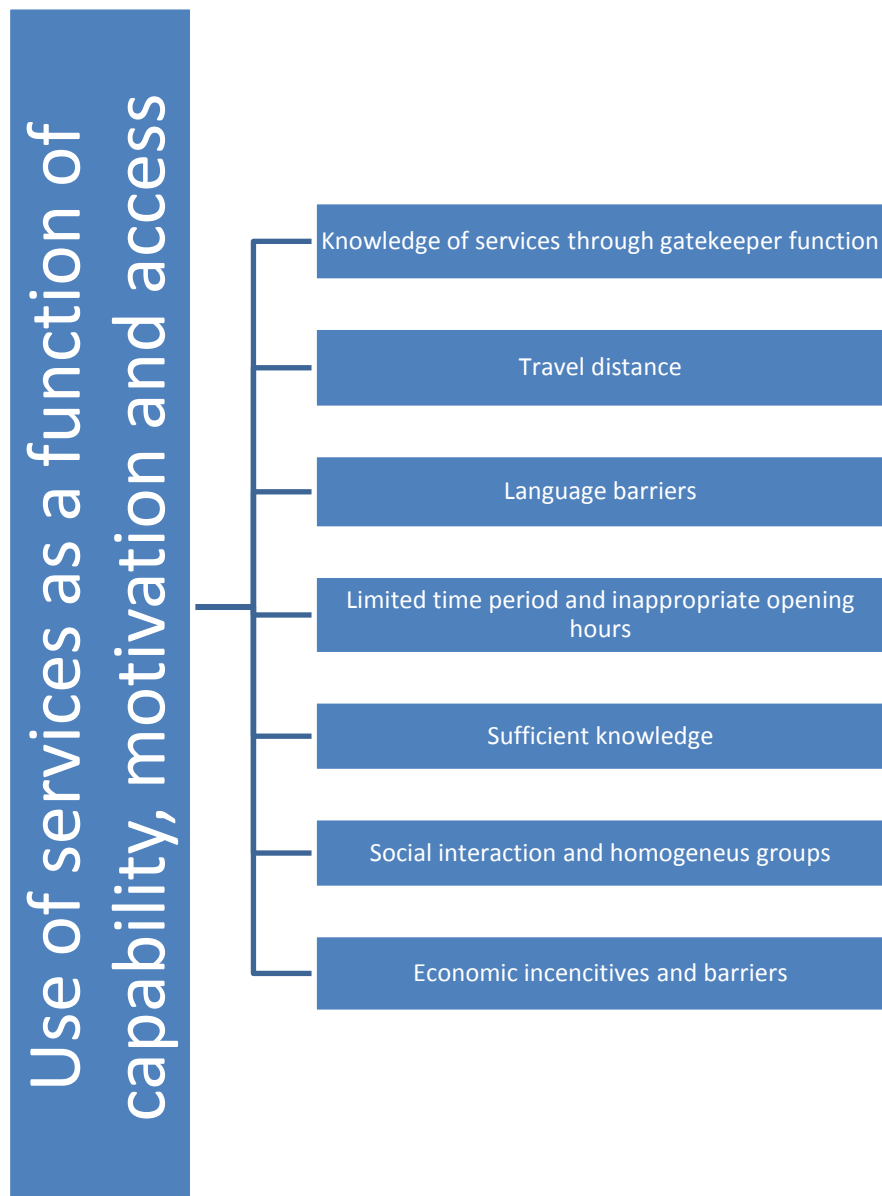
*"I have received information on diabetes from my GP and from the community health center. My GP referred me to the center and I have been very satisfied with the services and assistance they provided to me. I have learned a lot and I have also talked to I dietician and then I have participated in diabetes groups were I have received information on diabetes"* Male, patient, 66

In addition to the services used by the patients, the healthcare professionals mention other services available. The diabetes nurses inform that the hospital has a diabetes program for patients similar to what is offered by the CHC, but almost none of the patients mention being enrolled in a program like this.

## Citizens at risk

Compared to the patients, the citizens at risk do not have the same regular contact with the healthcare system. Some citizens have regular health checks at their GP. Also, the citizens visit their GP if they are in pain or in need of a prescription, but in general they rarely visit their GP. The CHC is not used by many of the citizens at risk, but those who do, have been referred by their GP due to their physical disabilities. The employees from the CHC also provide health checks in the local communities. Barriers and incentives that the informants find influence their use or non-use of the services are presented in figure 3.

Figure 3. Analytical themes.



## **Knowledge of services through gatekeeper**

As a part of the GP's gatekeeping function it is necessary for the citizen to have a GP referral in order to gain access to services available at the hospital as well as the courses offered at the community health center (CHC).

The majority of the citizens at risk had no knowledge of the prevention services and courses provided by the CHC and had neither been informed of them by their GP. The few who knew of the services had been informed through friends, relatives or by their GP in connection with another health issue. Some of the citizens say that their lack of knowledge of these services may be due to the fact that they have not expressed a need for such services or sought the opportunities themselves. Most of the patients had been informed of the CHC by their GP. Few of the patients were also informed during a local information meeting and health check-up in the neighbourhood arranged by the social network initiative and the CHC. The health professionals suggest that a long-term collaboration with these social network initiatives could improve the awareness of the services:

*"We go out there some times and have these health checks. There is a room that we have been allowed to use for the health checks. Through these we have identified few relevant citizens in need. This is great! but if we had at more permanent arrangement.. Then it would be fantastic!"* Nurse from the CHC

The health professionals from the CHC also suggest that further collaboration with general practitioners could improve the access and awareness of the services offered by the CHC. They find that some GPs in the city are not properly aware of the services offered by the CHC and therefore do not refer their patients. Information of the services without a dialog between the GP and the patient may not be sufficient to improve the patient's awareness. A female citizen at risk said during an interview that she had seen information folders lying in the GP's office but in order for her to become fully aware of the opportunities available she would need a personal presentation by the GP:

*"...it makes a difference to have a face to face explanation of the services by the GP. Maybe I have seen the information folders about the services offered by the CHC in the waiting room but I didn't think much about it. I need to talk with the GP about the opportunities"* Female citizen at risk, 55

In addition, the health professionals state that the patients, who haven't had a dialog with their GP when referred to the CHC, do not always understand the purpose and find it difficult to attend the course in the beginning:

*"Sometimes they come here to the center alone, where there hasn't been a dialogue with the doctor about why it is a good idea for them to come here. And then we need to start all over. And they are clearly given a difficult start in this situation because they have no idea about what they are getting themselves into"*

Nurse from the CHC

### **Access through gatekeeper**

The fact that a GP referral is needed to attend the courses relevant for patients and citizens at risk was not expressed directly as an issue by the informants; however, they emphasize the inconvenience of the procedure. They miss the opportunity to going to the CHC independently and they emphasize the importance of the GP's willingness to refer. A female patient expresses the barrier of asking for the referral herself and finds it difficult to get it done:

*"It is not a question about the referral. I just have to call my doctor and let him know that I need one. They are starting up a new course now which I could take part in. I need it. But then there are things in your everyday and you just don't get it done. I want to, but the time flies by. One day takes another"*

Female patient, 60

The health professionals point to the fact that those patients who are not in regular contact with their GP and hospital are the ones not benefitting from the services available for diabetes patients. The only way to get access to a wide range of services offered at the hospital is by having a referral and by showing up:

*"Well, you could say that for us to see them, it requires that they come in by themselves and that they have a referral. There are a lot people out there, who never reaches either their own GP or us"*

Diabetes Nurse

The health professionals agree that this group of patients is particular vulnerable and very difficult to reach. The home-visiting nurses and diabetes nurses explain that these patients are often isolated in their homes without close family relations. The health professionals find no easy way to address the issue, though they call for a coordinator who can take charge of the patient's follow-up care

appointments. Patients too vulnerable to meet for a consultation at the hospital are not offered the same follow-up care opportunities as other patients. They need someone to arrange these appointments for them, and if necessary, that the follow-up care takes place in the patient's own home:

*“when you have an appointment at the outpatient clinic concerning type 2 diabetes, you are enrolled in a the process: you talk to nurses, talk to a doctor, attend a nutritional adviser, are offered different diabetes courses, individual rehabilitation, you talk to a foot therapist, have relevant blood tests taken and you are examined from head to toe by a doctor. But, are you vulnerable and unable to go to the hospital to attend an appointment, then it is absolutely necessary that you have somebody to help you make these appointments. And really, just making a therapist appointment, or being able to go and having your feet examined, can be a real challenge to overcome for a vulnerable citizen. It really takes a lot of support and help (...) if the patient is not able to go to the hospital and have their blood tests done – then the blood tests need to be taken at home. But the vulnerable patients to not get the same full package where all services are a part of a defined procedure.”* Diabetes Nurse

**To summarize:** The majority of the citizens at risk had no knowledge of the prevention services and courses provided by the CHC. The GPs have a decisive role in the vulnerable patients' and citizens' access to healthcare services through thorough information and referral. If the GPs do not fulfill their role adequately the patients have difficulties in seeing potential of the available services. The most vulnerable patients who are not in regular contact with the healthcare services on a regular basis are difficult to reach. They need personal assistance in order for them to get access and profit out of the services available.

### **Travel distance**

Many of the informants do not consider travel distance an issue when visiting their local GP or the CHC. In relation to the CHC, the citizens at risk state that distance would not be an issue if they really needed the services. Many of the informants travel by bus or car when going to the GP or CHC and only a few find this inconvenient even though they need to change busses and the ride often takes more than half an hour. The informants who do consider distance as an issue often have a physical limitation due to illnesses or age related disabilities. Other informants find themselves more motivated to use healthcare facilities if they are placed nearby their home. A patient explains:

*“In order for me to do something positive to diabetes - something that requires an effort - then I need to pull myself together and overcome the primary difficulty of getting out of the door. And then it is of importance to me how far I need to go – if it is on the other side of Amager or if it’s only just 15-20 minutes away. That is of great importance”* Male patient, 66

One citizen at risk suggest that if the facilities were located nearby and if she had the possibility of going there without an appointment then it would be easier for her to get out of the door. This corresponds well with the health professionals’ suggestion on how to reach the most vulnerable groups. They believe that the location of the healthcare facilities is of great importance to the most vulnerable patients. They suggest that small health clinics placed in the communities where people live could improve the access:

*” I believe that if we were able to establish services out in the smaller communities like a clinic where the citizens could come by whenever it suited them then I believe we would be able to reach even more.”* Nurse from CHC

In the neighbourhood, Tingbjerg in Brøndshøj-Husum, the informants are experiencing that the local GPs are closing down their clinics or moving away from the neighbourhood. Some informants find this very frustrating and inconvenient, especially for those who cannot go far due to physical limitations or age:

*“What do people do instead?*

*I guess they will be provided with another GP but given the fact that there isn’t anyone out here, the nearest GP will be located out on Frederikssundsvej. And that is definitely not easy: Then you have to take a bus or two busses when visiting your GP and if you are old and using rolling walkers or a wheelchair then it is definitely not the easy. I feel sorry for them. It is such a shame”* Female, citizen at risk, 61

Based on the statements above travel distance seem to be an issue among those who have physical limitations and those who easily find themselves demotivated.

## Language barriers

50 percent of the informants, both patients and citizens at risk, had a non-western background and therefore spoke Danish as their second language. Some of them spoke Danish almost fluently but a greater part had some difficulties understanding all of the questions during the interviews. Despite this none of them stated that they had trouble understanding their GP or other health professionals. As one citizen from Somalia explains:

*"Yes, I understand. I always go to the GP by myself. But sometimes, if there is something I don't understand, I ask them what it means. Then they explain it to me, so that I understand. But you know, Danish is a very difficult language to learn, especially for someone like me coming from Somalia"*

Male citizen at risk, 39 (non-western background)

Apart from having the health professionals rephrasing information, some informants bring family members along when visiting the GP. They either prefer a family member translating or a translator is not available.

The only limitation mentioned in relation to language difficulties regarded filling out application forms when applying for financial support. This was also commented by the health professionals. Unlike the informants the health professionals experience the language barrier as a major barrier in their daily work. According to them the lack of understanding leads to loss of important information. Most of the health professionals have access to an interpreter in their contact with the patients, but for some of them the use of an interpreter does not fit into their time schedule that often progresses. In these cases they sometimes end up using the patient's children, which the health professionals find very problematic:

*"When the patients need to go to Hvidovre Hospital, the diabetes outpatient clinic, or their GP, or if their diabetes causes them any problem, it all has to be coordinated through the patient's children. And of course, that is a huge problem, and consequently a lot of communication is naturally lost. So there is really some challenges related to home care, there really is."* Home visiting nurse

Other health professionals mention that having an interpreter present during a consultation is very tiresome, both for the health professional and the patient. In the CHC the interpreter is mainly present during the individual interviews but not during team training. The limited time available during the courses can result in superficial and less thorough communication with participants who do not understand much Danish. Those patients are according to the health professionals therefore more vulnerable:

*“Those are the obvious ones, because it is the group, which we find it most difficult to reach, you know, the non-western citizens. It is not always possible to have an interpreter present every time they come. They are there during the individual conversations. But when the patients attend team trainings at which we follow them for a 12 weeks program, it is not possible to communicate thoroughly with them. Sometimes the conversations become very superficial, if they only speak limited Danish. Therefore, I would say that this group is much more difficult to reach and they are more vulnerable than the other groups we work with.”* Senior employee, CHC

The health professionals believe that these vulnerable people with a non-western background often have trouble understanding the severity of their illness and the importance of self-management.

**To summarize:** The health professionals find that language barriers among patients with a non-western background are a severe problem, but this is not mentioned as a problem by the patients themselves.

### **Services offered in a limited time period**

Many of the patients participating in this study find that the services provided by the CHC are very useful, however, many seem discontent with the fact that the services are only offered in a limited time period. Most courses only lasts for 12-weeks and some of the participants find it very challenging to maintain their exercises and healthy diet after completing the courses. As an example one patient is confident that she will stop exercising after completing the 12-week diabetes programme as she does not like to exercise on her own and feels uncomfortable in a regular gym. She hopes she will be able to continue on another course at CHC:

*“Informant: Unfortunately the course only lasts for 3 months.*

*Interviewer: Then what do you think will happen afterwards?*

*Informant: Then I probably won't be doing any exercise.*

*Interviewer: What would it take for you to continue exercising?*

*Informant: The same. At least until I have lost some weight and feel comfortable going to a normal fitness centre. But they also have other courses at the CHC, which I might be lucky enough to attend; those are also three months courses”* Female patient, 55

Other informants also mention the possibility of attending another 12-week course at the CHC, however, they see some barriers: You need a new referral from the GP and the waiting lists are often long. The CHC grant some participants access to the facilities at the CHC without being



enrolled in a course. One patient benefits from this arrangement however he is unable to reach the CHC by himself due to physical limitations and it is only during the 3 months enrolment that it is possible to use the transport services provided by the municipality.

During the focus group discussions the health professionals acknowledge that services offered in a limited time period and the transition to the everyday is a challenge, especially for the most vulnerable, needing extra time during the courses. They suggest a vulnerability-fund which gives the CHC the opportunity of extending the course period for those specifically in need:

*“Sometimes I wonder if the programme could be organized more individually. This way, if we see a progress – if a patient in progress needs an extra month we could give him extra time at the Community Health Center, if we had a vulnerability-fund with e.g. an amount of 100 extra hours available we could use some of these hours on the patient to assure to retention.”* Nurse from CHC

### **Inappropriate opening hours**

Besides the limited time periods for training and education at the CHC both citizens and patients who have been following courses at the CHC or attending other facilities in their community mention the challenge of inappropriate opening hours. Often, the courses do not match well with the informants' everyday life and consequently they are not able to attend the diabetes relevant courses at the CHC. Especially the ones working during the day have difficulties making ends meet, reaching both the classes at the CHC and managing their job at the same time. Some have missed out on parts of their classes – hereby missing out on valuable information:

*“(…) well, now I am still working, so there are some things I haven't been able to attend (…). And then there was a cooking class in here where you attended four classes in order to learn how to make healthy diabetes friendly food. I was able to attend all four times, but unfortunately, I couldn't attend the theory part because of my work. I was not able to come before we had to cook the actual meal.”*  
Male patient, 66

**To summarize:** The informants are worried that the limited time periods at the CHC are too short for them to keep on practicing a healthier lifestyle when finishing the courses. This is also emphasized by the healthcare professionals who request the possibility to grant vulnerable patients with extra hours at the CHC if needed. In addition some informants find that the opening hours at the CHC and other health facilities do not match well with their work life.

## **Sufficient knowledge**

Overall the informants are content with the information available on healthy lifestyle and management of diabetes. If they have any questions they know where and who they should turn to.

Besides being satisfied with the amount of information available, both patients and citizens at risk argue that further information is not needed. They know what is healthy and unhealthy, what to eat and what to avoid. They say that further information through campaigns and lectures is a waste of resources as people are already informed. Many emphasize that they decide for themselves whether they want to adhere or not. A female citizen at risk explains:

*”It doesn’t matter if you organize information lectures or anything like that, it’s of no use, because if people are not interested they will not participate, and I am under the impression that information on healthy food has been provided by the authorities for years, but people decide for themselves if they want to use the information or not”* Female citizen at risk, 55

Other informants say that they only have themselves to blame for not gaining the maximum out of the large amount of available information. Despite the many informants who are satisfied with the information they receive from the health professionals, many find the information can be overwhelming and not always useful. They point, that they themselves are responsible for their lives and their choice of lifestyle:

*”I hear the same story every time: ‘Mind your diet, mind your diet’ and then I say: ‘oh, for fuck’s sake it is my life – of course I know what I am supposed to eat and what I am not allowed to eat’ right?”*  
Female patient, 55

Also several patients blame themselves for not adjusting to the health professionals’ advice and find it very difficult to adhere to the information they receive:

*”I am perfectly aware of what is healthy and what is not an I know what I am supposed to do, but from my perspective there are cliffs between knowledge and action”*  
Female patient, 50

## **Social interaction and homogeneous groups**

Both patients and the few citizens who attend the Community Health Center describe the social interaction with other people as one of the main reasons why they attend and prefer the courses at the health centre compared to other opportunities in the community. During cooking classes and exercise courses they enjoy the group-based exercises and the company of the others attending. This forms a basis for further alliances. Even the short talks with other participants before and after classes are mentioned as a positive outcome:

*“It was nice getting to know the other people and gaining a sort of affiliation – both to the health professionals, who supervised throughout the course but also particularly to the other participants. I enjoy the 15-minutes talk we have before we begin the class. You don’t do that in a normal gym, do you? Male, go-along, 42*

Many of the informants view the community health centre as a substitute for a normal gym and emphasise that the opportunities for social interaction with participants similar to themselves makes the CHC preferable and motivates them to attend. Some patients feel uncomfortable in a normal gym because they feel they do not fit in, either due to their large body size, age or religion. One female patient would not attend a gym because she does not associate herself with the type of people there, wearing designer clothes, while another female patient feels that people stare at her at the gym:

*“My doctor informed me about the CHC, because I wanted to do some exercises but I didn’t like to go to the gym because I was overweight. I have tried - but people stare as if there is something wrong with you” Female patient, 55*

Also, some of the female informants with Muslim background use the facilities at the CHC, because they have the possibility of attending gender segregated classes. This also seems to be a determinant factor for using the facilities in the local neighbourhood including the gym:

*“Do you feel the services (at the CHC) meet your needs?”*

*Yes I wanted to join as I love to participate with other women.. because when you go to the gym there are a lot of men. I do not like that. (...) I do not have much clothes on, because when doing my gymnastics it is difficult to wear a lot of clothes, I am Muslim, so I cannot take my clothes off”*

Female, patient, non-western,40

As an answer to their needs some informants find the services offered by the CHC attractive, as they are able to attend courses with participants similar to themselves e.g. XL-courses, courses for females only or courses available for participants with physical limitations. Employees from the CHC hope that the alliances established during the courses at the CHC will motivate the participants to continue their exercises together once the courses have ended though none of our informants have yet experienced this. The nurse from the CHC elaborates:

*"I think that the most difficult part for them is when they face the change from the group based activities at the center with all the group cohesion and dynamics – and then all of a sudden they are left on their own. They have to manage all by themselves. Few of them find someone to make arrangements with, but after all, it is only a few who have the energy and is capable of establishing new relations." Nurse at CHC*

Even though the majority of the informants using the CHC enjoy the group based activities it is not a need mentioned by everyone. A few citizens mention that they prefer individual guidance when exercising and one patient feels neglected during group exercises. A diabetes nurse also stated during the FGD that the most vulnerable group of patients will not profit from group based activities such as those at the CHC, she further explains why:

*"The group of patients who I visit and who according to the Pathway Programme are defined as vulnerable would not profit from the group based activities – because among those, I see many with dementia, mental illnesses, addiction or other issues that make diabetes a minor issue in their everyday life. I also see all those with other chronic diseases which have major impact on their life and therefore they do not have the ability to manage their diabetes as well. Diabetes means so little to them and they can't cope with it. So, this is what I mean when I say that these vulnerable patients will not have any benefit from group based activities". Diabetes nurse*

**To summarize:** Social interaction with other participants similar to themselves is an important motive for joining the activities at the CHCs. The alliances established during the courses make the participants adhere to the exercise classes but still, as soon as the course ends at the CHC, the participants do not seem to continue exercising. According to the healthcare professionals the most vulnerable patients would not profit from group based activities because they struggle with so many other problems.

## **Economic incentives and barriers**

In general, paying for health services is not perceived as a challenge by the patients as most of their medical expenses are paid through the government taxes. All of the patients are covered by the public health insurance and some have taken on extra private health insurances. Some also receive extra financial support if they have several chronic illnesses making the medical /pharmaceutical expenses more affordable. Still, some patients, particularly those without private health insurances, mention economic barriers in relation to their diabetes care. These patients experience difficulties when paying for their pharmaceutical products as it makes their everyday expenses seem even more challenging. For this reason one patient has chosen to buy a generic product, which from his point of view does not have same effect as the original product prescribed by the GP:

*“I received one kind of medicine, which turned out to be too expensive so could not afford that. So now I use another kind of medicine which is supposed to be same, right? But it is difficult for me, because the effect is not the best” Male patient, 59*

One patient with non-western background state that they she has difficulties when applying for additional economic support as she can't fill out the application forms. The healthcare professionals are aware of this challenge and try to help their patients even though it is not a part of their job description; As a health professional explains:

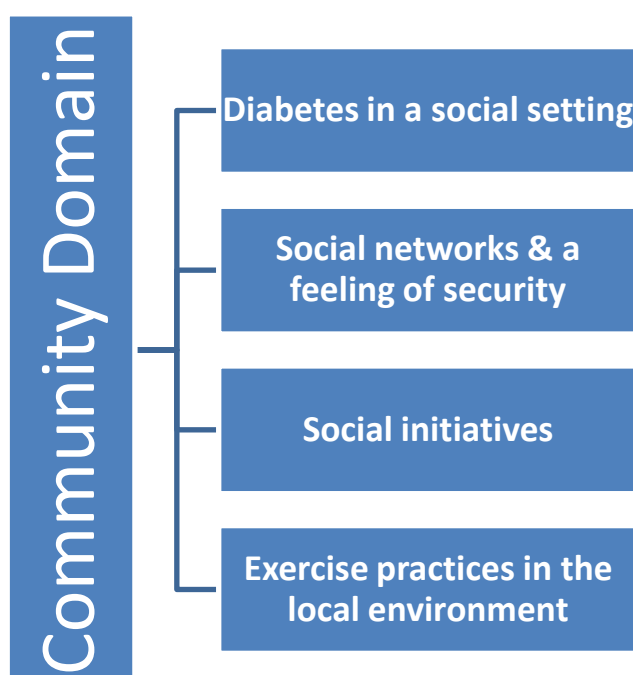
*“some of our patients also face problems when applying for financial support for test sticks and similar stuff which they are entitled according to §100 so they can receive support every month. Of course I try to help by reading through the many papers and filling out the thing in Danish, which I even as a Danish person have difficulties understanding” Diabetes nurse*

It is the health professionals' experience that besides them the patients do not have many other places to go when they need help for this.

## The Community Domain

The purpose of the community domain is to determine if there are non-governmental organisations to mediate or if there are other local systems of support. Also, the aim is to determine if there are local models of understanding and addressing a problem. As this domain is thoroughly analysed by the Steno Diabetes Center the following section focuses on only those perspectives that were most important for the social and health related wellbeing in the areas.

Figure 4. Analytical themes



### Diabetes in a social setting

Some patients find it very difficult to manage their diabetes when participating in social activities with friends and family. Some say that they find it difficult to resist and avoid an unhealthy diet when socialising with others although they normally cook healthy meals for themselves at home and would never drink alcohol or eat cake on their own. Patients with both western and non-western background state that food is often an essential part of social gatherings and that these are often not compatible with diabetics' diet. Several of the patients do not want their hosts to take special care of them by cooking separate diabetic friendly meals. They do not want to stand out by eating something different from everyone else and thereby draw attention to themselves and their

diabetes. In addition, they find that the diabetic friendly food is often less appetising compared to the meals others are eating:

*"I attend many social gatherings in which food is involved (...) I don't want to distinguish myself from the social settings I am in. I don't feel like flashing that I have a disease and cannot eat specific items. I don't want to lead other people's attention to my special needs regarding food and so on.. Because I feel it draws the focus away from the purpose of the social gathering"* Male Patient, 67

### **Talking about diabetes and other health issues**

Most of the patients and citizens at risk find it unnecessary to talk about diabetes and other health issues with people in their peripheral social environment. If they have a need for this, they talk to their partner or close relatives. Also, health in general is not a topic which many of the informants find interesting to talk about. According to the informants, talking about health issues like diabetes is not the custom. It only concerns oneself and it is not of interest to others. Several states that health issues are not pleasant to talk about and they do not want to be looked on as person who complains or talks about his/ her illnesses. Though most informants argue that they do not feel diabetes is something to be ashamed of, they do not wish to draw attention to themselves or their diabetes:

*"I do not tell people that I have many health problems.. Because I must admit that I do like giving the impression, that I am a healthy and well-functioning person when I am with other people. If someone ask then of cause I do not mind talking about it by answering their questions. But in my social life – diabetes does not take up any space. We do not meet up to talk about sickness"* Male Patient, 67

Many of the patients also explain that they do not feel a need to talk to others about their health or diabetes partly because they are not affected by their disease and therefore do not give it much thought. Some find that talking about their diabetes does not help them, but only makes them feel worse off:

*"I do not feel a need. I do not feel affected by the diabetes and therefore I do not feel a need to sit and discuss with others in some kind of association or other gatherings where you share experiences: I do not have a need for that."* Male patient, 72

Very few informants describe a need to talk about their diabetes and share their thoughts with other diabetes patients. However, not all of them know where to find a support group. Two male patients

believe that exchanging advice and thoughts on diabetes with people they feel comfortable with would help them in their everyday management of diabetes and they seek for opportunities like this.

*“‘Diabetes Clubs’ I would call them. We do not have anything like that, I have not come across any, where people with diabetes could come and have a chat. That is what I need!”* Male patient, 59

A small group of female informants with non-western background also describe a need to talk about health issues and diabetes. Though this group of patients feels that their needs are met as they can meet up with other women at the facilities offered by the join-in centers. Here they are able to talk and exchange advice on everyday issues including diabetes:

*“Do you like coming here at ‘Kontakten’?”*

*Yes, I am very happy about it. Some people talk about diabetes. Some asks me about my problems and that is very good for me.”* Female patient, 38

**To summarize:** Some patients find it very difficult to manage their diabetes when participating in social activities with friends and family. They do not want to stand out by eating something else than others and they do not want their host to take care of their special needs. It is not common to talk about illness, including their diabetes, and for some talking about it even makes them feel uncomfortable. Others do not like to give the impression that they have a disease. Only some of the informants feel a need to talk about their diabetes with others, but not everyone knows where to find an opportunity to do so.

## **Social networks & a feeling of security**

The informants have good as well as unpleasant things to say about their neighborhood; still many give the impression that they are proud and fond of living there. According to the informants, most people do not know their neighbours well. However, they greet each other when they meet in the streets making them feel part of a community. Few informants have a good relationship with their neighbours and help one another by keeping an eye on each other’s flats. Some also receive support from their neighbours at times when they are not able to manage daily errands themselves. Having this support is of great importance and gives them a fundamental feeling of safety. A female citizen explains why the support from neighbours is of importance to her:



*“It makes me feel less isolated and gives me a fundamental feeling of comfort. If I have a problem someone will help me If I am away, my neighbors will make sure that no one breaks into my house (..) also it is nice to have someone to talk to during the summer”* Female citizen, 55

It is primarily the informants with non-western background who describe social activities that take place in their neighbourhood, and many of them have moved to the area because they have friends and family living there. Informants of Danish origin also describe that the people in their neighbourhood with non-western background meet up more often and use the out-door facilities e.g. meeting up and doing barbeques on the lawns. Several informants describe this as admirable. One citizen at risk elaborates:

*”Back in the days, all neighbours from the apartment spent time together on the lawn and had a nice time with their children. We do not do that anymore. I think that it is very admirable that the foreigners are so good at sticking together.”* Female citizen at risk, 55

Many of the women with non-western background also describe social gatherings where they visit each other on turn A few of the informants believe that the areas lack benches or other seating areas for people to gather, but in general most of the informants enjoy the surroundings of their neighborhood.

Due to previous criminal incidents not all informants feel entirely safe in their neighbourhood. Some informants mention specific areas, which they attempt to avoid because they feel unsafe or uncomfortable. These are specific places where either young troubled kids hang out or where alcoholics sit all day. Some female informants state that they feel unsafe going out after nightfall and therefore attempt to avoid this. One citizen drives to another part of the city if she needs to go shopping after nightfall. A patient describes this feeling of unsafeness during an interview:

*”In the evening after ten o’clock I stay at home and my kids do too. May things have happened in this area and more safety is needed”* Female patient, 58 (non-western)

Other informants are worried about their young boys getting into trouble. For this reason, some have considered moving away from the area (see also ref 15). Despite these concerns, most of the informants feel safe walking around in their neighbourhood. The informants living in the area of Tingbjerg in Brønshøj-Husum state that the area has been unsafe for several years but much has changed and a lot has been done to reduce the amount of crime in the area. The presence of the police also makes the informants feel more secure. Many of them are tired of the communities’ bad

reputation' and want people from the outside to notice the good things happening there too (see also ref.15)

**To summarize:** According to the informants, most people do not know their neighbours well. However, they greet each other when they meet in the streets making them feel part of a community. Few informants have a good relationship with their neighbours and receive support when manage daily errands themselves. Having this support is of great importance and gives them a fundamental feeling of safety. Many informants do not feel that there are activities in the neighbourhood, which meet their interests. This goes especially for men and some of the informants of Danish origin.

### **Social initiatives**

During the interviews, the informants describe that various social initiatives and activities take place in their neighbourhoods and that these have a positive impact on their everyday. These are often arranged by the social housing employees or initiated indirectly by public funds e.g. join-in centres. Examples mentioned are food clubs, women's clubs, or free legal aid. The informants, and especially women with non-western background, find that these initiatives meet their needs, as they provide a place for them to meet up and talk about everyday issues (including issues concerning diabetes). A wide range of activities are organised such as gymnastics, walks, communal cooking and information meetings about neighbourhood criminality, society or health. Sometimes volunteers or health counsellors attend the meetings and provide health check-ups free of charge. The women find that these activities give them purpose in their everyday; hereby they avoid sitting at home alone without anything to do.

*"It is a really good place. We have the opportunity to meet up with each other, and sometimes a health counsellor comes and provides health check-ups. Also on Fridays, volunteers are there making coffee – then women arrive with their children and sit there talking together, which is nice. I feel like this is our second home. If for instance you do not have family here, this is a place to meet up with others."*

Female, go-along interview, 47

A woman of Danish origin also appreciates a social initiative organized by a non-profit organisation at which she receives individual and emotional support from a mentor. This mentor also supports her during meetings with the social services:

*"I actually have many brothers and family... But funny enough, it is not always them who help me. Even though I can talk to my family, I prefer having the woman from Frelsens Hær to help me. It is*

*easier, because she not that close... and she also supports me if I need assistance during meetings with the job centre” Female citizen at risk, 50*

### **Social initiatives do not meet all groups**

Several male informants and informants of Danish origin do not find the many social initiatives and activities offered in their neighbourhood appealing, as they often are organized specifically to women and children with non-western background. Many informants do not feel that there are activities in the neighbourhood, which meet their interests.

*”There are many activities arranged for women with non-western background and for women with young children; however, these are groups, which I do not in any way fit into. So, there are not any activities for me to take part in.” Female Citizen at risk, 55*

Some informants would like more activities to be available to men, as few initiatives organize activities specifically to male citizens:

*”In Tingbjerg, we have completely forgotten the men. All projects are targeting women and problematic children” Male, go-along interview, 48*

Others describe, that they miss the activities, which were organized years back and which focused on Danish traditions. Few of the informants state that they have tried to attend the organized activities, but found that it was difficult to be included in the existing groups of participants and did not feel welcome:

*”I do not feel a part of the group there, and if you come and just have to sit there by yourself at a long table, then it doesn’t really matter” Female citizen at risk, 56*

### **Possibilities in the physical environment**

Almost all informants describe the green areas near their neighbourhood and they all find that these make the neighbourhood a nice place to live in. The green areas make it attractive for the informants to spend time outdoors. Informants from Brønshøj-Husum describe the marsh nearby, while informants from Valby are fond of the parks, cemetery and green lawns. Having these green areas nearby give them the possibilities to meet up and socialise or perform physical activity. Many spend time there walking or running together with friends or family members.

Very few of the informants do not have green areas close to their neighbourhood. These informants mention that the absence of green areas near their neighbourhood has a negative effect on their willingness to exercise outdoors. One citizen state that running around in the streets of Copenhagen is just like smoking five cigarettes, while a patient mentions that if he lived nearby a forest it might improve his desire for walking:

*"I will never be one of those people running in streets of the city.. And running around the lakes in the city Center is suppose be really unhealthy. I have heard that it corresponds to smoking 5 cigarettes. But if was out in the Woods or somewhere similar then I would enjoy running there. But yeah, I will never go jogging in the center of the city"* male citizen at risk, 41

Within the neighbourhoods, there is a wide range of opportunities to perform physical activity. Some of the social housing initiatives in the deprived neighbourhoods have established gym facilities free of charge, which is important to many of the informants. There are also possibilities for women to exercise without the presence of men. The social housing initiatives organize exercise classes where people can learn how to swim or cycle. Some of the informants also use the regular city gyms outside the neighbourhoods, though several informants think paying for memberships at the gyms is too expensive. In general, many informants use the local facilities instead because these are free of charge:

*"There are all kinds of machines and it's all for free. I believe that it is very good for us (...) I cannot pay for at fitness membership for myself, because then I will not be able to buy food for my daughter. That is why I really appreciate that I can go for free"* Female citizen, go-along, 37

### **Exercise practices in the local environment**

According to the informants, people living in Brønshøj-Husum and Valby do a wide range of physical activities. There are people who enjoy outdoor activities like cycling, running, and swimming, while others prefer exercising indoor e.g. in a gym. However, even though both patients and citizens at risk mention that they see other people running in the neighbourhood, almost none of them run themselves, especially not the patients. When asking the informants what kind of activities they prefer most of them state that they enjoy going for walks. They walk in their local neighborhood either alone or in smaller groups. In general most of the informants like exercising together with other people, but some of them prefer to do it alone. Many of the informants have physical limitations due to a life with hard labour or other illnesses. These functional limitations prevent them from doing other kinds of hard physical exercise like e.g. running:

*“you have to run, but I cannot walk that fast (..) because I have osteoarthritis and my heart beats very fast and that is why I walk, but do not run”* Female patient, 55

**To summarize:** Almost all informants describe the green areas near their neighbourhood and they all find that these make the neighbourhood a nice place to live in. This gives them possibilities of meeting up and doing physical and social activities together. Only few like to do more vigorous exercise, mainly due to physical limitations. Training facilities in the local area are sometimes used and it is important that they are free of charge.

## **Strengths and limitations**

As mentioned in the method section the recruitment procedure caused considerable effort, as the official contacts recommended by the municipality did not provide adequate access to the vulnerable study population. In order to recruit informants who would fulfill the recruitment criteria we established alternative contact among local social network initiatives and individuals, but despite this effort only few of the informants (both among citizens at risk and among patients) represent the most vulnerable. However, we find that the focus group discussions with the healthcare professionals did provide valuable information about the most vulnerable patients. Especially the home visiting nurses and the diabetes nurses from the out-patient clinics had an extensive knowledge and based on this material, we have been able to elaborate on the living conditions and experiences faced by this group of patients in Copenhagen.

The present Vulnerability analysis does not follow the global Vulnerability Assessment tool (D-VA) in every detail as some topics and questions were not relevant in a Danish context and other issues seemed more obvious to investigate for Copenhagen. Also, some of the issues in the D-VA have been addressed in the RoH analysis and consequently, more focus was directed to in-depth interviews on the perceptions and experiences of the vulnerable study population. We did, however, develop all thematic interview guides in close collaboration with UCL (David Napier and Anna-Maria Volkmann) and the analysis cover all relevant aspects of the global vulnerability filters. The in-depth interviews provide a detailed material on social, environmental and structural determinants for developing type 2 diabetes among vulnerable citizens in the city – as well as on how vulnerable groups perceive and use the municipal and regional healthcare services.

## **Conclusion**

The overall objectives of the Vulnerability Assessment are to gain in-depth information on what attributes the most to vulnerability seen from the perspectives of vulnerable diabetes patients and citizens at risk. In Copenhagen, we focussed on how everyday life influences the perceptions and experiences of health risks and illness among fifty vulnerable patients and citizens at risk in the city. We aimed at investigating how the local environment and practices influence individual practices and behavior, and how the management of diabetes is influenced by social factors. Also, the analysis addressed how the vulnerable population perceived and experienced the availability of the

healthcare services in their local community. These questions were analyzed within the three domains defined in UCL's Vulnerability Assessment Tool, i.e. the Formal domain, the Community domain and the Vulnerability domain.

The purpose of the *Vulnerability domain* is to determine how vulnerability is locally defined and addressed and how vulnerable individuals are adjusting.

The criteria for the recruitment of citizens at risk and patients in Copenhagen were based on the results from the RoH analysis for Copenhagen, defining a vulnerable citizen or patient as male gender, older than 45 years, short education, unemployed, BMI >30, non-western background and cohabitation status (living alone). We experienced throughout the data collection and analysis that there are several degrees of vulnerability. The healthcare professionals, who had an extensive knowledge about the most vulnerable patients, characterized their patients as vulnerable due to a complex combination of social and physical issues, often suffering from isolation, loneliness and complications due to their poorly regulated diabetes. Even though only some of the patients participating in this study could be described by this complex set of characteristics, they had all experienced a range of problems in their everyday life which affect the prioritization of diabetes or health issues in general. Vulnerability was closely associated with the Danish term "manglende overskud", in English 'lack of reserves of energy'. Due to a range of issues and worries in everyday life, such as comorbidity, unemployment, economic problems, major life events and loneliness, management of diabetes and healthy lifestyle practice could be 'just too much'.

Among the vulnerable patients diabetes was not on their mind, mainly because they did not feel any symptoms but also because of pain and discomfort caused by other diseases. Some found that diabetes is not a severe condition compared to other diseases. As long as there were no symptoms, the patients in this study did not react to the disease. The importance of diabetes in everyday life as well as the management of it was also influenced by social factors and life events.

Vulnerable citizens were not prone to talk about health issues and they did not give diabetes much thought. Compared to other chronic diseases, diabetes 2 did not represent a serious health risk among citizens at risk. Somehow, it was perceived as a condition that could be eliminated either by medicine or by lifestyle changes. Also regular health checks seemed to affect the risk perception among the citizens, i.e. as soon as a health check showed that everything was normal, health risks were not further considered. Thinking about the risk could be a stressor and these thoughts were

therefore suppressed due to other issues in everyday life. In addition, many found that changing lifestyle in order to reduce their risk was very difficult. When discussing difficulties related to change in lifestyle some informants expressed an ambivalence, because they had seen examples of relatives or acquaintances who have had a long life without illness despite having had an unhealthy diet.

Among the informants unemployment was a very important factor that attributed to their overall vulnerability. The lack of structure and a scarce economy had major implications on the informants' everyday life and also influenced overall wellbeing including their management of diabetes. Those who did not have family or other close relations nearby to support them experienced difficulties being on their own, and found it more difficult to cope with small everyday tasks. Cooking proper meals and participating in social and physical activities were not found enjoyable when being on their own. Therefore many informants avoided these activities which attributed to their vulnerability. In addition, many of the informants who lived alone were emotionally vulnerable. Both informants and health professionals emphasized how important it is that lifestyle changes and self-care management are as tangible and easy as possible.

The purpose of the *Formal domain* is to determine which services are available according to the informants and if their use or non-use is a function of their motivation or capability.

Patients participating in this study primarily received assistance from their GP, the out-patient clinic at the hospitals, the Diabetes Association and the Community Health Center (CHC). Compared to the patients the citizens at risk did not have the same regular contact with the healthcare system. The majority of the citizens at risk had no knowledge of the prevention services and courses provided by the CHC. The GPs had a decisive role in the vulnerable patients' and citizens' access to healthcare services through information and referral. The most vulnerable patients who were not in contact with the healthcare services on a regular basis were difficult to reach and they needed personal assistance in order to get access and benefit out of the services available.

Information on healthy lifestyle was appreciated by the informants but they also stated that they did not need more lectures or knowledge. It was not lack of knowledge that made lifestyle changes difficult. Many of the informants viewed the community health centre as a substitute for a normal gym and emphasised that the opportunities for social interaction with participants similar to



themselves made the CHC preferable and motivated them to attend. For the most vulnerable patients, group based activities may not be a solution as they do not profit from it.

The informants were worried that the limited time periods at the CHC were too short for them to keep on practicing a healthier lifestyle when finishing the courses. They found it difficult to keep up the activities by themselves. The health professionals suggested the possibility to grant vulnerable patients with extra hours at the CHC if needed. In addition some informants found that the opening hours at the CHC and other health facilities did not match well with their work life. Travel distances to healthcare facilities also seemed to be a barrier for those who have physical limitations.

Some patients with non-western background had difficulties applying for financial support for their diabetes medicine because they did not understand the application forms. Some mentioned economic challenges when paying for their medicine, but most of the informants had not experienced major economic problems in relation to their diabetes. Most patients with Danish origin were not able to describe other patients who suffered more from diabetes than themselves, but patients with non-western background often mentioned relatives abroad who suffered severely because of their diabetes. In relation to this they emphasized the differences in medical and financial support between Denmark and their country of origin.

The purpose of the *Community domain* is to determine if there are non-governmental organizations to mediate or if there are other local systems of support. Also, the aim is to determine if there are local models of understanding and addressing a problem. This domain was thoroughly analyzed by the Steno Diabetes Center and consequently only those perspectives that were most important for the social and health related wellbeing of the informants were included in this analysis.

Almost all informants enjoyed the green areas near their neighbourhood which gave them the possibilities to meet up and socialise, or go for walks. However, the informants described that it is primarily the citizens with non-western background who meet up and use the outdoor facilities. Due to physical limitations only few liked to do more vigorous exercise. Gym facilities in the local neighbourhood were sometimes used and it was important that they were free of charge.

According to the informants, most people do not know their neighbours well. However, greeting each other when they meet in the streets made them feel part of a community. Some also described to receive support from neighbours at times when they were not able to manage daily errands

themselves. Many female informants with non-western background found that the social network initiatives provided them with a purpose in their everyday as they had a place to go and talk to other women about everyday issues instead of staying home alone. However, many male informants and informants with Danish origin found that the social activities organized in their neighbourhood did not meet their interests and they therefore feel left out.

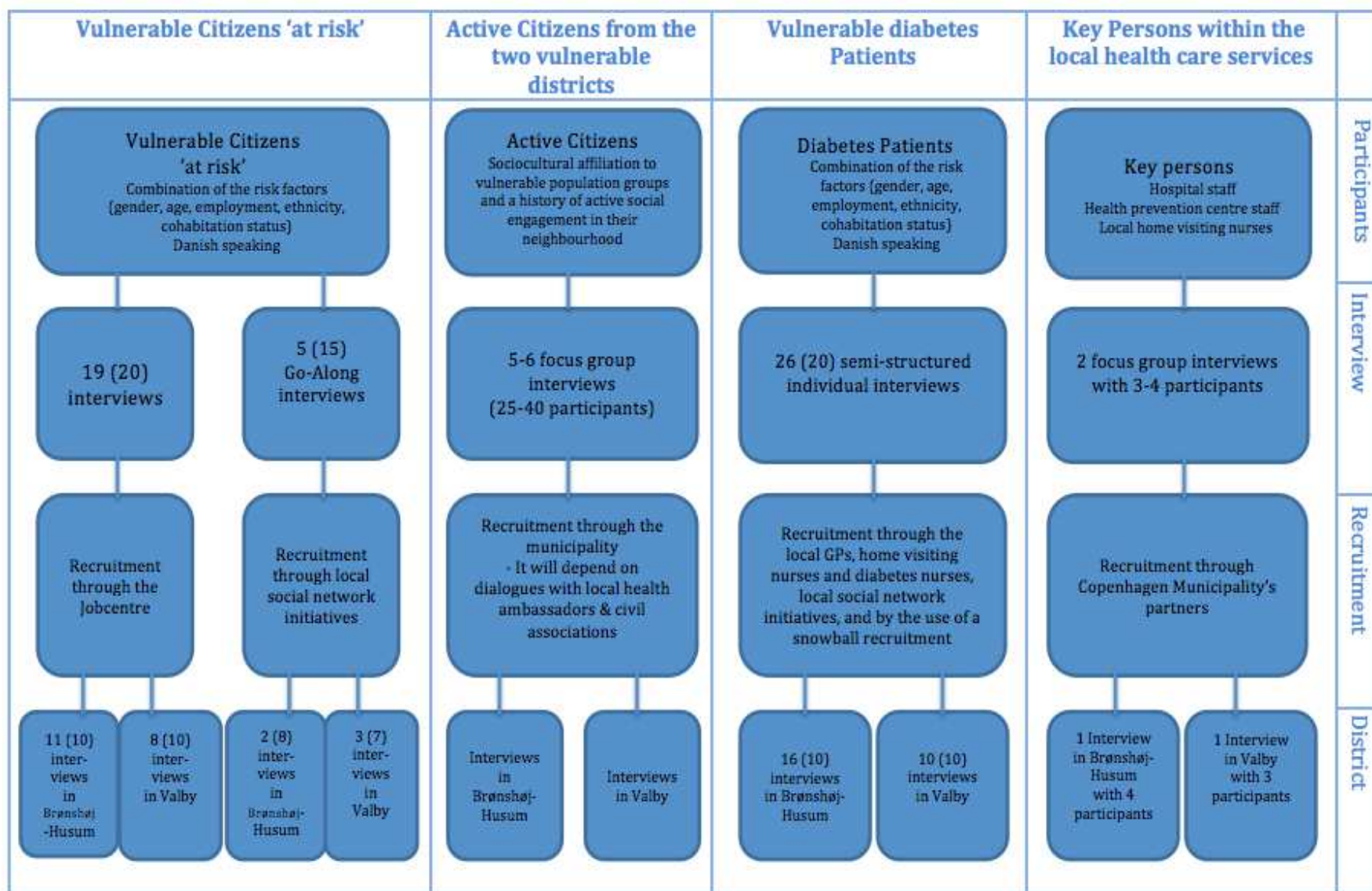
Managing diabetes and keeping the prescribed diet is difficult when participating in social activities with friends and family. It is not common to talk about illness and some feel uncomfortable talking about their diabetes as they do not want to draw negative attention to themselves. Only few felt that they have the need to share their experiences with other diabetes patients. Some of them did not know where to find such opportunities, while several female patients with non-western background had this need met at the social network initiatives.

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## Appendix 1: Flowchart



## Appendix 2: Letters of information

### Information Letter

#### Dear Informant

The purpose of the survey is to find out how the citizens of Brønshøj-Husum and Valby experience the area in which they live and how it's affecting their daily health. The results are meant for a report to help the council to a better understanding, of how the progression of type 2 diabetes in the city can be stopped and how the handling of the disease can be improved. We will be interviewing both citizens with and without diabetes.

The interview will be recorded on tape and your name and personal contact info will be erased so you won't be recognized. At any time you can withdraw from the survey in which case all recordings will be erased.

Novo Nordisk is one of our partners, so even though the survey is not about a certain product, we are still obliged to pass on information about any side effects mentioned during the interview. Considering the patients' health all information about side effects will be registered and processed at Novo Nordisk. If relevant the information will be passed on to the National Board of Health in which case your name and contact info will be erased from the material.

By my signature I consent that I have read, understood and accepted the above information

---

Signature and date

If you have any questions you are more than welcome to contact us by phone:

0045 XX XX XX XX or 0045 XX XX XX XX.

## **Permission for contact**

If you, during the interview, have shared information about side effects from using a Novo Nordisk product; do you allow that we obtain your contact information so that Novo Nordisk can contact you in case there is a need for further information about certain side effects?

1) Yes

2) No

If you do not want to share your contact information, so that Novo Nordisk can contact you directly; are we allowed to contact you on behalf of Novo Nordisk concerning further information?

1) Yes

2) No

Even if you do not want to be contacted about further information on side effects you can still participate in this interview.

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Signature and date

## Appendix 3: Questions not included in the questionnaires

Domain	Number	Questions not included in questionnaires	Argumentation*
FORMAL DOMAIN (F)	F1.2	<b>Do you have health insurance?</b>	All citizens are covered by the Danish national health insurance in DK. Though we have included the questions: if the diabetes related expenses are a challenge and whether these expenses have an influence on the everyday management of diabetes (PI)
	F1.4	<b>Has your household /family received any kind of assistance because of <u>your</u> diabetes?</b>	Several questions in the questionnaire (PI) address the different kinds of assistance received because of diabetes. Additionally included a question concerning whether they received any other kinds of assistance e.g. from the municipality, because of their diabetes.
	F1.5	<b>Has your household /family received any kind of assistance because of <u>their</u> diabetes?</b>	Several questions in the questionnaire (PI) address the different kinds of assistance received because of diabetes. Additionally we included a question concerning whether they received any other kinds of assistance e.g. from the municipality, because of their diabetes.
	F2.1	<b>Did the assistance you received for your diabetes have a lasting effect on your diabetes symptoms?</b>	We added the question: Did the assistance you received attend your needs? (PI)
	F2.2	<b>Did the assistance you received for your diabetes have a lasting effect on your overall sense of wellbeing?</b>	We added the question: Did the assistance you received attend your needs? (PI)
	F3.2	<b>Do you think that your diabetes needs will be met in the future?</b>	We added the question: Did the assistance you received attend your needs? (PI)
	F4.1	<b>Do you know any other people (NOT in your household/family) Who received assistance with their diabetes?</b>	We do ask: Do you know anyone else who has diabetes (PI)? And In your opinion, who do you think suffers most from having diabetes? Why, how? (PI)
	F5.2	<b>What is the most useful information that you have received about you diabetes?</b>	We added the question: Does the information about diabetes provided to you by the health professionals make sense to you? (PI)



			And Do you use this knowledge in your everyday life? How? (PI)
COMMUNITY DOMAIN (C)	C1.1	<b>Do you feel like you are a part of a community?</b>	Will be covered in Steno's FGD
	C1.3	<b>Where you live, do people get together to grow food?</b>	This question is not relevant in a Danish context as the majority of the Danish population living in Copenhagen buy groceries instead of growing them.
	C2.1	<b>In your community, are there any traditions that promote cooperation?</b>	We do ask: Is it normal for people to help each other in this area? How? (GAI/CI)
	C2.3	<b>In your community, would you say that people follow a traditional lifestyle?</b>	We do ask whether they have any family traditions regarding their everyday diet. (PI/GAI/CI)
	C3.6	<b>Do you grow your own food?</b>	This question is not relevant in a Danish context as the majority of the Danish population living in Copenhagen buy groceries instead of growing them.
	C4.1	<b>In your neighbourhood, do people commonly have access to free drinking water?</b>	This question is not relevant in a Danish context as all citizens in Denmark have access to clean drinking water from the water tap in their homes with a very low price pr. Gallon.
	C5.4	<b>Do you enjoy these activities?</b>	We added the question: Could you imagine doing any of these activities in this area? Why/why not? (PI/GAI/CI) We do not specifically ask to the enjoyment of these activities, though enjoyment could potentially be an answer to the above question.
	C5.5	<b>Do you think of yourself as a physically active person?</b>	We do ask: Could you imagine doing any of these activities in this area? Why/why not? Anywhere else? What should be different in order for you to be active in this area? (PI/GAI/CI)
VULNERABILITY DOMAIN (V)	V.1.1	<b>Please explain you understanding of diabetes?</b>	We do ask: Who has provided you with information about diabetes? Do you feel your questions have been answered? (PI)
	V1.5	<b>In your opinion, what do you think is the most problematic symptom of diabetes?</b>	We do ask: Do you feel that you can manage your diabetes yourself? What makes the management difficult? What helps? (PI)

	V2.4	<b>In comparison to other people in your community, do you feel financially secure?</b>	We do ask: Do you have any economic challenges, which have an impact one the daily management of your diabetes? (PI)
	V2.5	<b>Do you feel that your basic needs in life are taken care of?</b>	We interpreted these <i>basic needs</i> as access to food, water and shelter. According to this definition all participants in this study have these needs met.
	V4.5	<b>Do you feel confident about your future?</b>	We do ask: Has having diabetes changed your outlook on life? (PI)

- PI= Patient interviews, GAI= Go-along interviews, CI= Citizen interviews



**DIABETES VULNERABILITY  
ASSESSMENT TOOL:  
MODIFIABLE RISK FACTORS  
IN URBAN AREAS**

A. David Napier

**Novo Nordisk - Cities Changing Diabetes**

## Modifiable Risk Factors for Diabetes in Urban Areas: Diabetes Vulnerability Assessment Tool

A. David Napier (*Principal Investigator*)

*Professor of Medical Anthropology; Director, Science, Medicine, and Society Network*

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*Medical Anthropologist; Health Psychologist*

## SUMMARY

Given the complexity of the challenge posed by the rapidly increasing disease burden of diabetes in urban settings, a multidisciplinary approach to understanding its drivers is called for. Building on cross-disciplinary skill sets, we focus on vulnerability and modifiable risk factor assessments with a site-specific *Diabetes Vulnerability Assessment (D-VA)* instrument.

### THE D-VA:

- Is a statistically integrated, **qualitative** research instrument.
- Builds on **existing quantitative data**.
- **Identifies** and verifies the **presence of diabetes-specific risk factors**.
- **Integrates** new qualitative findings with pre-existing qualitative ones.
- **Uncovers new data** inaccessible to quantitative research alone.

The D-VA is the first fully integrated rapid assessment instrument approved by the United Nations for the assessment of various vulnerable populations in differing social settings. The assessment instrument examines the experience of health and illness in individuals with diabetes through three domains: the *Formal Domain*; the *Social Domain*, and the *Vulnerability Domain*.

By conducting a D-VA it is possible to capture the complexity of the conditions that have an impact on disease development and progression in diabetes, as well as the conditions under which any preventative measures may be implemented. These include the social, cultural and environmental frameworks that enhance or, conversely, limit optimal health outcomes. The D-VA is a locally sustainable intervention tool because ideally it creates new and builds upon existing links to communities and stakeholders. Furthermore, it has been developed in such a way that its structural features are replicable in other settings, yielding an ever-growing global data pool for vulnerability factors in diabetes.

The DV-A has two additional long-term outcomes:

- First, quantitative and qualitative data can be collected and integrated for applying an existing evidence base to national policies and local practices; and
- Second, local teams can be established with the added potential for carrying out ongoing work in the future.

## RATIONALE

There is a good knowledge base regarding the impact of biomedical and some socio-economic risk factors for diabetes. What has not yet been comprehensively examined is how cultural and wider social components mediate the experience of diabetes (and its precursor) in urban settings, especially regarding the diagnostic process and long-term care provision.

While small-scale qualitative studies have been able to offer some valuable insights into individual illness experience, they are often perceived as anecdotal and lack cross-validation with larger quantitative data sets. There is an urgent need for supplementing quantitative data with qualitative data to maximize the impact of findings: only then can long-term improvements be achieved and sustained policy change effected.

Because the drivers of clinical non-adherence are, as is well established, often beyond the capacity of certain vulnerable individuals to change, understanding the local 'capacity thresholds' of behaviours allows us to focus on what is potentially modifiable. As a foundation for future interventions, we establish who can change behaviours and under what circumstance individuals with diabetes are able, and motivated, to do so.

Thus, this D-VA is guided by three fundamental research questions:

- A) What are the **social risk factors**<sup>1</sup> in urban diabetes? Which are modifiable?
- B) What are the **cultural determinants** of urban diabetes? Which are modifiable?
- C) Who is **most vulnerable** to suffer because of these risk factors and cultural determinants of diabetes? How can they become less vulnerable?

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<sup>1</sup>We differentiate between social risk factors and cultural determinants. A known social risk factor for diabetes is, for example, living alone; while a cultural determinant of diabetes might be living in a culture that values large body size (as, for example, is the case with some populations in Nigeria).

## PARTICIPANT RECRUITMENT AND DATA COLLECTION

The main aim of the vulnerability assessment is to identify and explore the characteristics of vulnerable groups in a given CCD site. Thus, participant recruitment is a critical aspect of conducting an academically rigorous Vulnerability Assessment. For the D-VA, we explicitly select interview participants based on their potential to inform us about some of the most salient issues in the experience of urban diabetes; in other words, we do not randomly sample participants.

Instead, we recruit participants by applying so-called *case filters* to a pre-existing quantitative data set. These case filters are particular characteristics (e.g., high BMI, living alone, living in a community without access to health insurance) that 'flag' individuals to be contacted for further investigation. In some CCD sites, case filters are generated through statistical means. In others, where this is not possible due to lack of available data, the global and local academic teams agree upon case filters for recruitment based on preliminary research and experience.

In vulnerability assessments, a set of case filters is called a *case definition*. We expect around ten case definitions for each site that will be fully explored through ethnographic interviews. It is standard practice to conduct 15-30 interviews for each case definition. This number has been shown elsewhere to allow for good generalizations to be made about each case definition, but is not a fixed figure. The actual number of interviews will vary significantly from site to site - depending on local needs and possibilities - producing locally unique information as well as global continuities.

## DATA ANALYSIS AND RESULTS

Conducting a vulnerability assessment creates a repository of detailed 'stories' derived from interviews that are grouped according to their respective case definitions. The analysis of the D-VA interviews yields a set of locally valid *vulnerability indicators* (characteristics that make individuals vulnerable to diabetes and to suffering from its complications) and *vulnerability cases* (individual cases that represent broadly the experiences of significant numbers of individuals grouped by specific vulnerability indicators).

The PI and a multidisciplinary team of leading experts based at University College London, UK, will carry out the overall analysis of the global CCD vulnerability indicators and vulnerability cases. Local findings will be made available to the local academic teams, so they can conduct a site-relevant analysis of the D-VA data depending on specific research paradigms, established needs and possibilities. Thus, local results will enable each CCD site to tailor interventions to specific needs.

A comprehensive baseline report will integrate the D-VA findings with the quantitative data that provided case filters as the starting point of the qualitative assessment. This brings together both research streams of the CCD program, and creates a multi-faceted, comprehensive overview of urban diabetes in each partner city, and around the globe.

## D-VA VARIANTS

Because all CCD sites have different quantitative data sets available upon which the D-VA will be based, two variants of the instrument will be used in the course of this project:

- 1) The D-VA, as described above
- 2) The D-VA **Rapid Assessment tool** (D-VA.RA)

The latter allows for qualitative data collection alongside quantitative data collection.

The D-VA.RA approach will be used for example in Mexico City, and will be described in detail in a separate document.

### NOTA BENE:

- The D-VA is NOT meant to be a comparative study between several research sites.
- Rather, D-VA findings are of cumulative value = Local assessments have validity in their own right, and are conducted with local needs and requirements in mind.
- Together, local findings generate a global pool of knowledge that may well be 'larger than the sum of its parts'.
- There is no expectation of exact comparability between sites. The D-VA is not subject to though statistical principles, though statistical evaluation of some aspects of D-VA findings at a later point is absolutely possible.
- The main feat of the D-VA lies in skilled and careful analysis and interpretation of findings, which will be mindful of local variance while aiming to be of global relevance.

### The D-VA Consists of the Following Core Phases (Simplified Overview):

- 1) **Design of a site-specific D-VA**  
: (Vulnerability 'filters' have been agreed upon by the research team for ALL CCD sites)
- 2) **Training of local investigators**  
: (fieldworkers and community liaisons, using techniques developed specifically for the D-VA)
- 3) **Conduct of the site-specific D-VA**  
: (incl. vulnerability assessment, focus groups, interviews etc)
- 4) **Analysis of collected data and cross-validation** with existing quantitative data (Feedback of qualitative data and super-imposition of new data onto quantitative data)
- 5) **Recommendations** for a strategy to modify risk factors for vulnerability in urban diabetes.

### The D-VA.RA Consists of the Following Core Phases:

- 1) **Design of a site-specific D-VA**  
: (Vulnerability 'filters' have been agreed upon by the research team for ALL CCD sites)
- 2) **Begin quantitative data collection**  
: (e.g. household surveys, population assessment)
- 3) **Simultaneous training of local investigators** (fieldworkers and community liaisons, using techniques developed specifically for the D-VA)
- 4) **Conduct of the site-specific D-VA.RA**  
: As soon as first results come in from quantitative survey, D-VA.RA fieldwork begins (Conduct vulnerability assessment, focus groups, interviews etc)
- 5) **Analysis of collected data and cross-validation** with existing quantitative data (Feedback of qualitative data and super-imposition of new data onto quantitative data)
- 6) **Recommendations** for a strategy to modify risk factors for vulnerability in urban diabetes.

## DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)

### (F1) NATURE OF ASSISTANCE



(F1.1) **Have you received any kind of assistance since having been diagnosed with diabetes?**

YES

NO

(F1.1) If yes, what kind(s) of assistance have you received?

(F1.1) If yes, who provided that assistance?

(F1.1) If yes, when were you first offered assistance because of your diabetes?

(F1.1) If yes, how long did the assistance last?

(F1.1) If no, do you know why you have not received any assistance?



(F1.2) **Do you have health insurance?**

YES

NO

(F1.2) If yes, does your health insurance cover your diabetes-related expenses completely?

(F1.2) If no, why do you not have health insurance?

(F1.2) If no, do you know if health insurance is available where you live?

(F1.2) If no, how did you/do you pay for the assistance you received with your diabetes?



(F1.3) **Do you know of any other kinds of assistance you could get for your diabetes?**

YES

NO

(F1.3) If yes, what keeps you from accessing them?



(F1.4) **Has your household/family received any kind of assistance because of your diabetes?**

YES

NO

(F1.4) If yes, what kind(s) of assistance did they receive?

(F1.4) If no, please explain  
(F1.4) If no, what kind of assistance do you think need?



(F1.5) **Has anybody in your household/family received assistance for their diabetes?**

YES

NO

(F1.5) If yes, what kind(s) of assistance did they receive?

(F1.5) If no, is that because you are the only person with diabetes in your household?

**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F2) DURATION OF EFFECT/IMPACT**



**(F2.1) Did the assistance you received for your diabetes have a lasting effect on your diabetes symptoms?**

YES

NO

(F2.1) If yes, please explain

(F2.1) If no, please explain



**(F2.2) Did the assistance you received for your diabetes have a lasting effect on your overall sense of wellbeing?**

YES

NO

(F2.2) If yes, please explain

(F2.2) If no, please explain

**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F3) NEEDS MET**



**(F3.1) Did the assistance you received for your diabetes meet your needs?**

YES

NO

(F3.1) If yes, please explain

(F3.1) If no, please explain



**(F3.2) Do you think that your diabetes needs will be met in the future?**

YES

NO

(F3.2) If yes, please explain

(F3.2) If no, please explain



**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F4) EQUALITY OF ACCESS**



**(F4.1) Do you know any other people (NOT in your household/family) who received assistance with their diabetes?**

YES

NO

(F4.1) If yes, how does that compare to the assistance you received?

(F4.1) How did they benefit from the assistance they received?



**(F4.2) In general, do you think that there is good assistance for people with diabetes available where you live?**

YES

NO

(F4.2) If yes, please explain

(F4.2) If no, please explain

**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F5) HEALTH COMMUNICATION**



**(F5.1) Has someone explained diabetes to you?**

YES

NO

(F5.1) If yes, who has given you the most useful information about diabetes?

(F5.1) If no, have you tried to find information about your diabetes on your own?

(F5.1) If no, have you been able to find satisfactory information about your diabetes on your own?



**(F5.2) What is the most useful information that you have received about your diabetes?**

?

**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F6) PROVIDERS OF ASSISTANCE**



**(F6.1) Where you live, are there any non-governmental organisations that help people with diabetes?**

YES

NO

(F6.1) If no, why do you think that is?

(F6.1) If yes, what kind?

(F6.1) If yes, do you go there or use their services?

(F6.1) If not, why not?

(F6.1) If yes, what kind of services do you use?



**(F6.2) Where you live, is there anyone else you can think of that helps people with diabetes?**

YES

NO

(F6.2) If yes, who are they?

(F6.2) If yes, have you used their services?

(F6.2) If yes, please explain

(F6.2) If no, why do you think that is?



**(F6.3) Do you have a designated healthcare provider?**

YES

NO

(F6.3) If yes, please explain

**DIABETES VULNERABILITY ASSESSMENT – FORMAL DOMAIN (F)**  
**(F7) GENERAL**



**(F7.1) What kind of assistance would you like to have for your diabetes?**

?

**DIABETES VULNERABILITY ASSESSMENT – COMMUNITY DOMAIN (C)**

**(C1) COMMUNITY**



**(C1.1) Do you feel like you are part of a community?**

YES

NO

(C1.1) If yes, can you describe your community?

(C1.1) If no, please explain



**(C1.2) Were you born in the neighbourhood you live in?**

YES

NO

(C1.2) If no, please explain



**(C1.3) Where you live, do people get together to grow food?**

YES

NO

(C1.3) If yes, do you participate in any of such activities?

(C1.3) If yes, please explain

(C1.3) If no, please explain



**(C1.4) Where you live, do people get together to exercise?**

YES

NO

(C1.4) If yes, do you participate in any of such activities?

(C1.4) If yes, please explain



**(C1.5) Where you live, do people get together to help one another live with diabetes?**

YES

NO

(C1.5) If yes, do you participate in any of such activities?

(C1.5) If yes, please explain



**(C1.6) Are there any other ways not mentioned above in which people where you live help each another?**

YES

NO

(C1.6) If yes, do you participate in any of such activities?

(C1.6) If yes, please explain



**(C1.7) Do you think more could be done to improve community organisation for people with diabetes?**

YES

NO

(C1.7) If yes, what do you think should be done to improve community organisation for people with diabetes?

## DIABETES VULNERABILITY ASSESSMENT – COMMUNITY DOMAIN (C)

### (C2) CUSTOMS AND TRADITIONS



(C2.1) In your community, are there any traditions that promote cooperation?

YES

NO

(C2.1) If yes, please explain

(C2.1) If yes, are these cooperations short- or long term?

(C2.1) If yes, are these cooperations restricted to the place where you live?



(C2.2) In your community, are there any customs or traditions that have an impact on how people eat?

YES

NO

(C2.2) If yes, please explain



(C2.3) In your community, would you say that people follow a traditional lifestyle?

YES

NO

(C2.3) If yes, please explain

(C1.3) If no, please explain



(C2.4) Do you think that your community's customs and traditions are changing?

YES

NO

(C2.4) If yes, please explain



(C2.5) In your community, who do people traditionally go to for advice with their health concerns?



(C2.6) Has this changed in the recent past?

YES

NO

(C2.6) If yes, please explain



(C2.7) Where do you go to for advice with your health concerns?



**DIABETES VULNERABILITY ASSESSMENT – COMMUNITY DOMAIN (C)**

**(C3) NUTRITION**



(C3.1) In your community, what would you say is the main food that people eat on a work day?



(C3.2) What would you say is the main food that you and your family eat on a work day?



(C3.3) In your community, what would you say is the main food that people eat for a celebration?



(C3.4) What would you say is the main food that you and your family eat for a celebration?



(C3.6) Do you grow your own food?

YES

NO

(C3.6) If yes, why?

(C3.6) If no, why?

(C3.6) If yes, how much of your own food do you normally eat?



(C3.7) Where in your neighbourhood do people most often buy groceries?



(C3.8) Where in your neighbourhood do you most often buy groceries?



(C3.9) Where in your neighbourhood go people most often to eat?





(C3.10) Where in your neighbourhood do you go most often to eat?

?



(C3.11) In your community, how often do people eat outside of their homes in a week?

?



(C3.12) How often do you eat outside of your home in a week?

?



(C3.13) In your household, who prepares the food?

?

## DIABETES VULNERABILITY ASSESSMENT – COMMUNITY DOMAIN (C) (C4) INFRASTRUCTURE



(C4.1) In your neighbourhood, do people commonly have access to free drinking water?

YES

NO

(C4.1) If yes, have they access to drinking water at home (from tap?)

(C4.1) If no, what do people commonly drink when they are thirsty?



(C4.2) In your neighbourhood, do people commonly work closely to where they live?

YES

NO

(C4.2) If yes, how do you get to where you work?

(C4.2) If no, how far do you travel to get to where you work?

(C4.2) How do you travel get to work?



(C4.3) Do you like where you live?

YES

NO

(C4.3) If yes, please explain

(C4.3) If no, please explain

**DIABETES VULNERABILITY ASSESSMENT – COMMUNITY DOMAIN (C)**

**(C5) EXERCISE**



**(C5.1) Are there public areas in your neighbourhood where people can play football, tennis etc or go walking and running in a park, for example?**

YES

NO

(C5.1) If yes, please explain

(C5.1) If yes, are they used often?

(C5.1) If yes, please explain

(C5.1) If yes, do you use them yourself?

(C5.1) If no, why not?



**(C5.2) What kinds of physical activities do people usually do in your neighbourhood?**

?



**(C5.3) What kinds of physical activities do you do?**

?



**(C5.4) Do you enjoy these activities?**

YES

NO

(C5.4) If yes, please explain

(C5.4) If no, please explain



**(C5.5) Do you think of yourself as a physically active person?**

YES

NO

(C5.5) If yes, please explain

(C5.5) If no, please explain

**DIABETES VULNERABILITY ASSESSMENT – VULNERABILITY DOMAIN (V)**  
(V1) ILLNESS UNDERSTANDING/INTERPRETATION



(V1.1) Please explain your understanding of diabetes



(V1.2) In your opinion, who do you think is most likely to get diabetes?



(V1.3) In your opinion, what makes people develop diabetes?



(V1.4) In your opinion, who do you think suffers most from having diabetes?



(V1.5) In your opinion, what do you think is the most problematic symptom of diabetes?



(V1.6) In your opinion, how do you think diabetes could be prevented?





**DIABETES VULNERABILITY ASSESSMENT – VULNERABILITY DOMAIN (V)**  
**(V2) STANDARD VULNERABILITY INDICATORS**



**(V2.1) Are you currently employed?**

YES

NO

(V2.1) If yes, is your work long-term?

(V2.1) If yes, do you receive any workplace benefits?

(V2.1) What kind of workplace benefits do you receive?

(V2.1) If no, please explain

(V2.1) If no, do you receive any government benefits?

(V2.1) What kind of government benefits do you receive?



**(V2.2) Do you live alone?**

YES

NO

(V2.2) If no, please describe who you live with



**(V2.3) Are you responsible for somebody else's care?**

YES

NO

(V2.3) If yes, does that person also have diabetes?



**(V2.4) In comparison to other people in your community, do you feel financially secure?**

YES

NO

(V2.4) If yes, please explain

(V2.4) If no, please explain



(V2.5) Do you feel that your basic needs in life taken care of?

YES

NO

(V2.5) If yes, please explain

(V2.5) If no, please explain



(V2.6) Do you feel you are able to manage your diabetes symptoms?

YES

NO

(V2.6) If yes, please explain

(V2.6) If no, please explain  
(V2.6) If no, what would help you to manage better on your own?



(V2.7) Can you afford your diabetes care?

YES

NO

(V2.7) If no, please explain

## DIABETES VULNERABILITY ASSESSMENT – VULNERABILITY DOMAIN (V) (V3) SAFETY



(V3.1) Is your neighbourhood a safe place to live?

YES

NO

(V3.1) If yes, please explain

(V3.1) If no, please explain



(V3.2) Where you live, do people exercise alone?

YES

NO

(V3.2) If yes, would it be safe for you to do so?  
(V3.2) Please explain

(V3.2) If no, please explain

**DIABETES VULNERABILITY ASSESSMENT – VULNERABILITY DOMAIN (V)**  
**(V4) TRUST AND AGENCY**



(V4.1) What people do you trust for general health advice?



(V4.2) Can you tell me who you trust most/least with your diabetes care?



(V4.3) Has having diabetes changed your outlook on life?

YES

NO

(V4.3) If yes, please explain

(V4.3) If no, please explain



(V4.4) Has having diabetes changed your enjoyment of life?

YES

NO

(V4.4) If yes, please explain

(V4.4) If no, please explain



(V4.5) Do you feel confident about your future?



**DIABETES VULNERABILITY ASSESSMENT – VULNERABILITY DOMAIN (V)**  
**(V5) OTHER CONCERNS**



**(V5.1) Are there other people you know who you think are suffering from diabetes and are living without care?**

YES

NO

(V5.1) If yes, who are they?



**(V5.2) Is there anything else you would like to share with me at this point about your experience with diabetes?**

?

THANK YOU VERY MUCH