

# Domains of (cognitive) functioning underlying the 'Dementia Scale for individuals with Intellectual Disabilities' (DSVH) (Maaskant & Hoekman, 2011)

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# Psychologie Faculteit der Sociale Wetenschappen



# Domains of (cognitive) functioning underlying the 'Dementia Scale for individuals with Intellectual Disabilities' (DSVH) (Maaskant & Hoekman, 2011)

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#### Acknowledgements

In the past year, I examined the DSVH (Maaskant & Hoekman, 2011) to determine whether domains of (cognitive) functioning could be identified. In doing so, I have gained insight into the different factors that are involved in the preparation of a research project. Additionally, I have learned how to perform and interpret a Multiple Correspondence Analysis and how it can be a useful tool for analyzing categorical data. I could not have done this alone and I would like to thank those who have helped me.

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Minke van den Berg

Almere, 19 September 2021

#### Abstract

The life expectancy of individuals with intellectual disabilities is increasing. Clinicians of organizations that provide personalized care to individuals with intellectual disabilities experience complicating factors in the diagnostic process of dementia classification. Identifying domains of (cognitive) functioning underlying the 'Dementia Scale for individuals with Intellectual Disabilities' (DSVH) could aid these organizations in the development of personalized care guidelines for individuals with intellectual disabilities and dementia. The aim of this pilot study was to identify potential domains of (cognitive) functioning underlying the DSVH. It was hypothesized that domains regarding mood, aggression, appetite, loss of interest, functional decline (reduced self-care skills), cognitive decline, personality, speech, maladaptive behaviours, disorientation, confusion, environmental awareness, and motor skills would be found. A Multiple Correspondence Analysis was employed to visualize the relationship between different active variables in a sample consisting of 50 participants (n = 50). Domains regarding the presence of forgetfulness, an increase in negative mood, decline in motor skills, decline in orientation in time, decline in responses to stimuli, and a decline in characteristic behaviour were found. The results found in this study suggest that those domains of (cognitive) functioning might be underlying the DSVH, that could be uncovered when the analysis is performed on a sufficiently large and diverse sample in future studies.

Keywords: intellectual disabilities, dementia, dementia classification, domains of functioning

#### Layman's abstract

The life expectancy of individuals with intellectual disabilities is increasing. Clinicians of organizations that provide personalized care to individuals with intellectual disabilities experience complicating factors in the diagnostic process of dementia classification. The 'Dementia Scale for individuals with Intellectual Disabilities' (DSVH) is a psychodiagnostic instrument that is used by the clinicians of these organizations to classify individuals with intellectual disabilities with dementia.

Identifying domains of (cognitive) functioning that could be underlying the (DSVH), could aid these organizations in the development of personalized care guidelines for individuals with intellectual disabilities and dementia. The aim of this pilot study was to identify potential domains of (cognitive) functioning underlying the DSVH. It was expected to identify domains regarding mood, aggression, appetite, loss of interest, functional decline (reduced self-care skills), cognitive decline, personality, speech, maladaptive behaviours, disorientation, confusion, environmental awareness, and motor skills.

A statistical analysis was performed that can be used to detect underlying structures in datasets. This analysis displays the data in 'clouds' of points in a coordinate system. These 'clouds' of

points are interpreted as domains. Domains regarding the presence of forgetfulness, an increase in negative mood, decline in motor skills, decline in orientation in time, decline in responses to stimuli, and a decline in characteristic behaviour were found. These results suggest that those domains of (cognitive) functioning might be underlying the DSVH. The domains could be uncovered when the analysis is performed on a sufficiently large and diverse sample in future studies.

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The life expectancy of individuals with intellectual disabilities is increasing and with this the number of age related diseases among this population and the challenges in the care for elderly individuals with intellectual disabilities (Meeusen-van de Kerkhoff & Maaskant, 2004; Meeusen & Geus, 2005; Strydom, Chan, King, Hassiotis, & Livingston, 2013). One of these age-related diseases is dementia (Strydom et al., 2013; Devshi et al., 2015). There are limited studies available that investigate the prevalence of dementia symptoms in individuals with intellectual disabilities. This makes it difficult to estimate the exact prevalence of dementia in individuals with intellectual disabilities (Devshi et al., 2015). However, Strydom, Hassiotis, King, and Livingston (2009) found that the incidence of dementia in their research sample was up to five times higher than that for the general population as well as a downward shift in age-associated risk of developing dementia in individuals with intellectual disabilities. This suggested that dementia seems to occur at a younger age in individuals with intellectual disabilities and that they have a shorter survival period (Devshi et al., 2015; Strydom et al., 2013).

According to the 'National Guideline for Dementia Screening' by Meeusen and Geus (2005), individuals with intellectual disabilities need to be screened for dementia. They state that performing a premorbid measurement of the level of cognitive functioning in individuals with intellectual disabilities can help detect future differences in their level of cognitive functioning. Establishing a baseline measurement is also important for determining the source of the changes in the cognitive functioning of individuals with intellectual disabilities (Meeusen & Geus, 2005). In addition to assessment of the level of cognitive functioning, the level of self-sustainability and the behavioural functioning also need to be determined (Meeusen & Geus, 2005). Individuals with severe intellectual disabilities and individuals with Down Syndrome (DS) have to be screened for dementia from 40-years and older. Furthermore, Meeusen and Geus (2005) suggest that individuals with mild or moderate intellectual disabilities have to be screened for dementia from 50-years and older. Every year a repeated measurement needs to be performed.

Maaskant and Geus (2005) suggest the use of the behavioural assessment scale 'Dementia Scale for individuals with Intellectual Disabilities (DSVH)' (Maaskant & Hoekman, 2011), complementary to traditional test material, to help determine whether symptoms can be attributed to dementia or to other causes for functional and cognitive decline (related to vision, hearing, pain, hypothyroidism, depression, medication or sleep) (Maaskant & Hoekman, 2011). The DSVH (Maaskant & Hoekman, 2011) is based on the 'Dementia Scale for Down's Syndrome' (DSDS) by Gedye (1995). The differential diagnostic items and the test items of the DSDS had been translated and adjusted slightly (Maaskant & Hoekman, 2011). The DSVH consists of a total of 60 items that cover different cognitive and physical functions that are affected by dementia (Maaskant &

Hoekman, 2011). Additionally, the DSVH (Maaskant & Hoekman, 2011) helps clinicians determine whether it is justified to classify an individual with intellectual disabilities with dementia and if so, which dementia phase (the first, second, third, or fourth phase).

However, clinicians of organizations that provide personalized care to individuals with intellectual disabilities experience complicating factors in the process of classifying individuals with intellectual disabilities with dementia. Individuals with intellectual disabilities have limited cognitive capacities (and sometimes additional physical limitations). This can make it difficult to determine cognitive decline. Additionally, clinicians have indicated that the classification process is complex, because various differential diagnoses have to be taken into account. Additionally, different (neuro)psychological tests have to be conducted in order to achieve a thorough classification (Meeusen & Geus, 2005). Clinicians also experience complications in the development and implementation process of care guidelines, once an individual with intellectual disabilities has been classified with dementia.

The DSVH (Maaskant & Hoekman, 2011) does not provide scores related to domains of (cognitive) functioning in its current form. Clinicians would be able to develop specialized care guidelines for individuals with intellectual disabilities based on specific domains of (cognitive) functioning, if these domains were to be identified. The purpose of this pilot study is to examine the DSVH (Maaskant & Hoekman, 2011) and determine whether it can be divided into domains of (cognitive) functioning. In order to assess this, exploratory hypotheses regarding the potential domains of (cognitive) functioning are formulated based on dementia questionnaires for individuals with intellectual disabilities, behavioural assessment scales for screening dementia in individuals with intellectual disabilities, and scientific literature on the manifestations of dementia in individuals with intellectual disabilities. Different studies have been conducted on domains of (cognitive) functioning or clusters of symptoms found in individuals with intellectual disabilities who have been classified with dementia. It is hypothesized that the following domains of (cognitive) functioning will be found when assessing the DSVH (Maaskant & Hoekman, 2011): mood, aggression, appetite, loss of interest, functional decline (reduced self-care skills), cognitive decline, personality, speech, maladaptive behaviours, disorientation, confusion, environmental awareness, and motor skills (Cooper, 1997; Deb, Hare, Prior, & Bhaumik, 2007; De Vreese et al., 2015; Devshi et al., 2015; Fonseca et al., 2019; McKenzie, Metcalfe, & Murray, 2018; Zeilinger, Stiehl, & Weber, 2013).

#### Methods

#### **Design and ethics**

This cross-sectional pilot study has a correlational research design. The purpose of this pilot study is to examine the DSVH (Maaskant & Hoekman, 2011) and determine if it can be divided into

domains of (cognitive) functioning. Additionally, this study is the first phase of an extensive study by Prinsenstichting. The aim of the extensive study is, in addition to the domains of (cognitive) functioning, to determine potential strengths and weaknesses profiles in relation to (cognitive) functioning. The domains of (cognitive) functioning and strengths and weaknesses profiles will be used to develop a score form that could be implemented in the classification process alongside the DSVH (Maaskant & Hoekman, 2011). Additionally, the domains and profiles will be used to develop care guidelines for individuals with intellectual disabilities.

Prinsenstichting is an organization which provides individuals with intellectual disabilities with personalized care to help improve their quality of life (Prinsenstichting, n.d.). The research sample consists of 50 participants (n = 50) who are currently receiving different kinds of individual care from Prinsenstichting. A psychodiagnostic assistant of Prinsenstichting was appointed to the registration of the responses of these participants on the DSVH items (Maaskant & Hoekman, 2011) in an Excel file. Each participant received a personal code. Furthermore, all of the personal information was removed from the Excel file to ensure that no personal information could be traced back to an individual in the dataset. Because of this, the Committee Ethics Psychology had deemed it unnecessary to review this pilot study for ethical approval, because no personal information could be accessed by the researcher. Additionally, the relatives of the participants did not have to sign informed consent forms due to the absence of personal information being shared.

#### **Participants**

The research sample consists of 50 participants. The participants have been selected by a psychodiagnostic assistant of Prinsenstichting. There were no exclusion criteria, but the participants had to meet two inclusion criteria in the selection process. The first inclusion criterion was that the DSVH (Maaskant & Hoekman, 2011) measurement was available for each participant. The second inclusion criterion was that based on the DSVH (Maaskant & Hoekman, 2011), from which a score is calculated that helps clinicians determine whether an individual can be classified with dementia, a conclusion was reached on whether or not the participant could be classified with dementia. The sample thus consisted of both participants with a dementia classifications and participants who did not receive a dementia classification. The psychodiagnostic assistant was able to select 50 participants who met the two inclusion criteria. Data regarding age range and gender within the sample have been lost due to a miscommunication in the process of the data collection and transfer.

Clinicians perform repeated measurements on their clients in order to determine (indications of) cognitive decline. Therefore, the most recent (Maaskant & Hoekman, 2011) measurement of each participant was used for the dataset. All of the participants within the sample have an intellectual disability that varies in severity. Additionally, a number of participants have a physical disability such

as problems related to vision, hearing, or motor skills in addition to their intellectual disability.

#### Measures

The DSVH (Maaskant & Hoekman, 2011) is a questionnaire that is used by clinicians to determine whether an individual with intellectual disabilities could be classified with dementia. It consists of eight demographic items and 60 items regarding dementia symptoms. The responses on the DSVH (Maaskant & Hoekman, 2011) can be used by clinicians to calculate a score that gives an indication of whether a dementia classification is plausible. In addition to the classification, it also provides a dementia phase indication (the first, second, third, or fourth phase of dementia). The items can be scored as absent (symptoms are absent, because they are related to the intellectual or physical disability), inapplicable (symptoms could be developed in a later phase, but are currently not present), present (symptoms are present), and characteristic (symptoms are present, but the symptoms are characteristic for the intellectual or physical disability of the individual who is being assessed). The responses on the DSVH (Maaskant & Hoekman, 2011) items had been divided into two categories. Absent, inapplicable, and characteristic were labeled as 'absent' with the assigned code 0. Present has been labeled 'present' with the assigned code 1. The responses on the items regarding the demographic characteristics with unknown responses or unknown information were labeled with the code 'NB', which stands for unknown.

The DSVH (Maaskant & Hoekman, 2011) consists of eight demographic items (regarding the presence of Down Syndrome, hearing impairment, epilepsy, innate heart defect, cataract, and hypothyroidism) and 60 items regarding potential dementia symptoms. Items 1 through 20 cover the first phase of dementia. Dementia is a plausible classification if eight or more items of item 1 through 20 (differential diagnoses items not included) are scored as 'present'. Items 21 through 40 cover the second phase of dementia. Dementia is a plausible classification providing that ten or more items of item 1 through 40 are scored as 'present' (differential diagnoses items not included). There are indications for the second phase of dementia if seventeen or more items of item 1 through 40 are scored as 'present'. Item 41 through 55 cover the third phase of dementia. The third phase of dementia can be considered providing that the criteria for the second phase are met. Additionally, seven or more items of item 41 through 55 are scored as 'present'. Items 56 through 60 cover the fourth phase of dementia. There are indications for the fourth phase of dementia if the criteria for the third phase have been met, and at least three of item 56 through 60 are scored as 'present' (of which are two of items 57, 59 or 60). Each one of the 60 items have been assigned a shorter code label consisting of a maximum of four words.

#### Procedure

An Excel file was composed that corresponded with the eight demographic items and the 60

items of the DSVH (Maaskant & Hoekman, 2011). This Excel file was sent to Prinsenstichting. A psychodiagnostic assistant of Prinsenstichting reported the responses of 50 participants to the demographic items and the DSVH (Maaskant & Hoekman, 2011) items in the Excel file. The Excel file was transferred back once all of the responses were collected.

#### Statistical analyses

A Multiple Correspondence Analysis (MCA) was performed to explore the hypothesis whether domains of (cognitive) functioning regarding mood, aggression, appetite, loss of interest, functional decline (reduced self-care skills), cognitive decline, personality, speech, maladaptive behaviours, disorientation, confusion, environmental awareness, and motor skills can be found when assessing the DSVH (Maaskant & Hoekman, 2011).

A Multiple Correspondence Analysis is an analysis technique for nominal categorical data that can be used to detect underlying structures in a dataset. The Multiple Correspondence Analysis represents datasets as 'clouds' of points in a multidimensional Euclidean space, this means that it describes each variable by locating them in a lower-dimensional space. The results are usually interpreted on the basis of the relative positions of the variables (points) and the distribution of their categories along the dimensions (axes) (Costa, Santos, Cunha, Cotter, & Sousa, 2013). A Multiple Correspondence Analysis is a useful analysis for exploratory studies due to its lack of assumptions regarding the distribution of variables. Additionally, its descriptive powers allow for the examination of simultaneous interactions of variables and their direct links (Di Franco, 2016).

The DSVH (Maaskant & Hoekman, 2011) has an inter-rater reliability of .81 %. Furthermore, the DSVH (Maaskant & Hoekman, 2011) has a test sensitivity of .96 % and a test specificity of .86 %. The data within a Multiple Correspondence Analysis is divided into supplementary variables and active variables. The active variables in the analysis contribute directly to the formation of factors and the supplementary variables, also known as illustrative variables, do not contribute to the creation of factors. However, supplementary variables are useful. Supplementary variables improve the interpretation of the factors, because they also have positions along the factorial axes (Di Franco, 2016). The eight demographic DSVH (Maaskant & Hoekman, 2011) items were labeled as supplementary variables in this pilot study. The 60 DSVH (Maaskant & Hoekman, 2011) items were labeled as active variables.

Di Franco (2016) stated that anomalous cases or low-frequency categories should be removed from the dataset, because a lack of variation in the responses to items could lead to distorted interpretations of the data. The variation in the responses to the items was assessed with the use of the statistical program RStudio (Ripley, 2001). RStudio (Ripley, 2001) was used to create frequency tables and bar plots of the responses to each item. A criterion of five or more responses

was applied. Items with five responses or less (for either the 'present' or 'absent' category) were removed from the analysis. This has led to removal of supplementary variables (item) 5 and 9 and the removal of the active variables (item) 21, 23, 41, 47, 49, 50, 51, 53, 54, 56, 58, and 60. The remaining six supplementary variables and 48 active variables were analyzed.

A significance level of  $\alpha$  =.05 was used. The statistical analysis was performed with the use of the statistical program RStudio (Ripley, 2001) with the software packages FactoMineR and factoextra. The Multiple Correspondence Analysis was performed on a sample that consisted of 50 participants. Di Franco (2016) stated that a Multiple Correspondence Analysis should be performed on a sufficiently large sample with at least 20 cases per single active category (of each variable). This pilot study contains 48 active dichotomous variables (each having a 'present' and 'absent' category). This means that a sufficiently large sample would consist of 1920 participants. The results had to be interpreted in a cautious matter, because the research sample consisted of merely 50 participants.

An estimate of the stability of the solution was made before the factors. A Multiple Correspondence Analysis shows the amount of inertia that is reproduced by all of the identified dimensions (Di Franco, 2016). To assess the stability of the solution, a scree test criterion was applied to determine how many components (dimensions) would be retained for the analysis. The scree test criterion was performed by creating a scree plot in RStudios (Ripley, 2001). A scree plot shows a line plot of the eigenvalues of the components in the analysis (Lewith, Jonas, & Walach, 2010). Based on the 'elbow' of the scree test criterion (point of inflection) and the proportion of variance accounted for, a two dimensional solution was deemed the most appropriate.

The contributions of each active variable and their coordinate values were used to determine how much influence each active variable and their categories have had in determining the two components (dimensions) in the solution. The interpretation of the contributions of each active variable and its coordinate values was done with the use of the square cosine. The square cosine (goodness of fit) allows the researcher to estimate the contribution that is made by a component (dimension) to the reproduction of the dispersion of each active category. The square cosine is expressed by a number (proportion) that varies between 0 and 1. A category is not well represented on the component (dimension) if the contribution is low. If the contribution is high, the researcher can analyze the role in the formation of the axis (dimension) on which the category was well represented (Di Franco, 2016).

#### **Results**

#### **Assumptions**

There are no assumption requirements that need to be met when performing a Multiple Correspondence Analysis (Costa, Santos, Cunha, Cotter, & Sousa, 2013). The characteristics of the

participants within the sample are shown in Table 2. A two dimensional Multiple Correspondence

 Table 2

 Clinical, physical, and cognitive characterization

	Count
Clinical characteristics	
Severity intellectual disability  Mild	2
Moderate	7
Severe	9
Profound	2
Unknown	30
Down Syndrome	30
Yes	16
No	34
Physical characteristics	34
Hearing impairment	
Yes	23
No	27
Epilepsy	27
Yes	17
No	33
Innate heart disease	33
Yes	5
No	29
Unknown	16
Cataract	
Yes	12
No	29
Unknown	16
Hypothyroidism	
Yes	6
No	30
Unknown	14
Cognitive characteristics	
Dementia classification	
Yes	27
No	23
Dementia phase	-
First phase	14
Second phase	10
Third phase	3
Fourth phase	0

Analysis solution was deemed to be the most suitable based on the scree test criterion. The first principal axis (dimension 1) explained 24.6 % of the principal inertia (total variance) and the second principal axis explained 8.8 % of the principal inertia (total variance), hence 33.4 % in total. Each of the remaining 33 principal axes explained less than 7.05 % which suggested that a two dimensional Multiple Correspondence Analysis solution provides a decent approximation of the data.

Additionally, a lower dimensional solution, like a two dimensional solution, can be plotted more easily that allows for more concise interpretation (Richards & van der Ark, 2013). However, this analysis consisted of 48 active variables (of which each has two categories) and 6 supplementary variables. This lead to large 'clouds' of points distributed along the two axes. This made it difficult to interpret the exact positions and contributions of each active variable. Because of this, the interpretation of the contributions and the relative position of each variable was analyzed with the use of the square cosine. The square cosine is expressed by a proportion that varies between 0 and 1 (Di Franco, 2016).

#### **Multiple Correspondence Analysis**

The contributions of variables, and coordinate values of categories, allow for consideration of how much influence each variable or category has had in determining a certain factor (Di Franco, 2016). The largest contributions and the smallest p-values were used to determine which variables have had the biggest contribution to each dimension. The active variables with the largest contribution and the smallest p-values were used to determine which variables have had the biggest contribution to each dimension. The active variables with the largest contribution and the supplementary variables with the strongest link to each dimension were plotted separately once they were identified. Table 3 (Appendix B3) and Table 5 (Appendix C5) display the contributions of the variables to the formation of the first and second dimension, respectively. These tables include both the active and supplementary variables included in the analyses, which are ranked from most to least related to the dimension. Table 4 (Appendix B4) and Table 6 (Appendix C6) show the coordinate values of the categories for each variable on the first and second dimension, where a larger value means a stronger link with that dimension (meaning that the category is more likely to be true when a person scores high on that dimension). As mentioned previously, supplementary variables have no influence on the formation of the components of the analysis, but plotting them in the analysis does provide insight on how these supplementary variables are linked to the first and second dimension.

#### Dimension 1

Table 4 shows the categories with the largest contributions to the first dimension. The contributions of all variables (and their categories) to the first dimension can be found in Appendix B.

The variable 'Dementia' (item 10) and the variable 'Dementia phase indication' (item 11) are supplementary variables. The remaining variables are active variables. The 'present' category of each active variable (which contributed the most to the definition of the first dimension) had the strongest link to the first dimension. Additionally, the category 'present' of the supplementary variable 'Dementia' (item 10) is most strongly linked to the first dimension. The same is true for the category 'inapplicable' of the supplementary variable 'Dementia phase indication' (item 11).

Table 4

MCA contribution categories along axis (dimension) 1

	NACA disease a	
	MCA dimension 1	
	Estimate of coordinate	<i>p</i> -value
Dementia_10_yes	.41	< .001
Item.48. Decline.Reaction.Pers.Stim_1	.43	< .001
Item.43. Needing.Guidance.Dressed.Forget_1	.44	< .001
Item.44. Guidance.Eating.Forget_1	.49	< .001
Item.19. Forget.dressing_1	.37	< .001
Item.01. Forget.routine_1	.31	< .001
Item.57. Guidance.Eating.Meals_1	.41	< .001
Item.24. Not.Know.Household.Object_1	.41	< .001
Item.16. Decline.Alert.Eye.Contact_1	.30	< .001
Item.33. More.Fearful_1	.30	< .001
Item.20. Not.Remem.Seq.Actions_1	.32	< .001
Item.11. Increase.Irritability_1	.29	< .001
Item.34. Scarcity.Charac.Actions_1	.33	< .001
Item.13. Loss.Interest.Charac1	.29	< .001
Item.55. Seizures_1	.48	< .001
Item.14. Less.Capab.Keep.Occup_1	.30	< .001
Item.17. Slowing.Movements_1	.29	< .001
Item.40. Loss.Fine.Motor.Skills_1	.31	< .001
Dementia phase indication_11_inapplicable	.78	< .001
Item.15. Less.Intered.Act.Others_1	.33	< .001
Item.42. Does.Not.Recog.Forgot_1	.37	< .001
Item.03. Forget.Names.Words_1	.36	< .001
Item.52. Freq.Incontinent.Urine_1	.34	< .001
Item.07. Does.Not.Under.Verbal_1	.28	< .001
Item.46. Has.Trouble.Find.Places_1	.38	< .001
Item.29. Less.Init.Speaking_1	.27	< .001
Item.08. Decline.Spatial.Orien_1	.31	< .001
Item.25. Does.Not.Remem.Events_1	.24	< .001

#### **Dimension 2**

Table 6 shows the categories with the largest contributions to the second dimension. The contributions of all variables (and their categories) to the second dimension can be found in Appendix C. The category 'present' of the active variables item 45, item 26, item 22, and item 5 are most strongly linked to the second dimension. The category 'absent' of the active variables item 29 and item 9 are most strongly linked to the second dimension.

Table 6

MCA contribution categories along axis (dimension) 2

	MCA dimension 1		
	Estimate of coordinate	<i>p</i> -value	
Item.45. Decr.Awar.Day.Night_1	.31	< .001	
Item.26. Refer.Past.Event.Recent_1	.29	< .001	
Item.29. Less.Init.Speaking_0	.21	< .001	
Item.09. Less.Init.Start.Speaking_0	.20	< .001	
Item.22. Need.Reassur.Supervisor_1	.15	< .001	
Item.05. Change.Sense.Time_1	.17	< .001	

#### Further exploration of variables with the largest contributions

The categories of the variables with the largest contribution and the supplementary variables with the strongest link to each dimension were plotted separately to further explore their relationships to the dimensions. Each point in the plot represents an individual within the sample and also shows its position relative to the two dimensions. The 'absent' category is represented in the colour black and the 'present' category is represented in the colour red. A dimension distinguishes categories well if the confidence ellipses of the categories show no overlap on that dimension.

Additionally, a dimension cannot be used to discriminate between the two categories if the ellipses show overlap (this means that the categories have the same positions on the axis (dimension) or if they have the same value on that dimension). An example for both dimensions is given. The variable with the strongest link to the first dimension is shown in Figure 1. The variables with the strongest link to the second dimension is shown in Figure 2. The Figures of all the variables with the strongest links to the dimensions can be found in Appendix D.

Figure 1 (Appendix D1) shows the categories (and their confidence ellipses) of the active variable 'Reduced responses to individuals or stimuli' (item 48). This variable has the strongest link to the first dimension. From Figure 1 it becomes clear that the first dimension (horizontal axis) distinguishes best between the 'present' and 'absent' categories, because the confidence ellipses of the two categories show no overlap on this dimension. The categories do show overlap on the

second dimension (vertical axis). This means that the second dimension cannot be used to discriminate between the categories.

**Figure 1**Active variable 'Reduced responses to individuals or stimuli' (item 48)

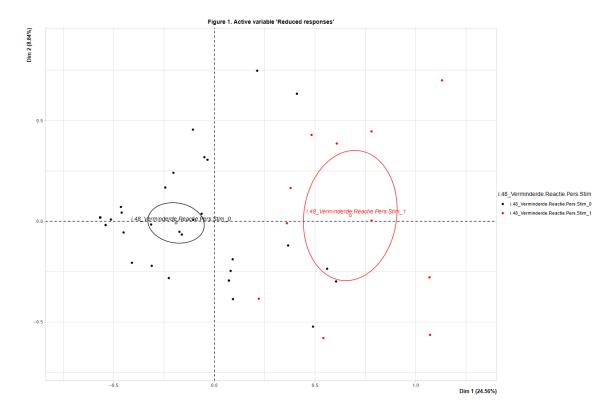
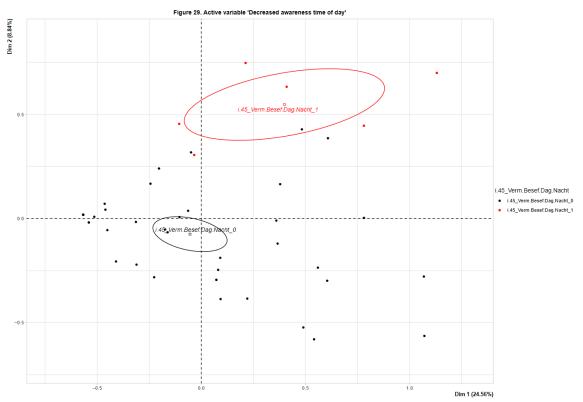


Figure 2 (Appendix D29) shows that the second dimension (vertical axis) discriminates best between the two categories, because little overlap is seen between the ellipses of the active variable 'Decreased awareness of daytime and nighttime and does not show proper response to time of day' (item 45). The first dimension (horizontal axis) does not sufficiently discriminate between the two categories, because overlap can be seen between the confidence ellipses on this dimension.

**Figure 2**Active variable 'Decreased awareness of daytime and nighttime and does not show proper response to time of day' (item 45)



A Multiple Correspondence Analysis was performed to explore potential underlying domains of the DSVH (Maaskant & Hoekman, 2011). As mentioned previously, the variables (and their categories) with the largest contribution (both active and supplementary) were plotted separately to further explore their relationships to the dimensions. This was done to determine whether the dimensions discriminate sufficiently between the categories of the variables. The variables for which the dimensions did not discriminate sufficiently are not used to interpret the potential domains.

The first dimension does not sufficiently discriminate between the categories ('present' and 'absent') of the following active variables: 'Less initiative to speak (includes sign language)' (item 29), 'Shows decline in spatial orientation' (item 8), 'Does not remember events from the same day or the previous day' (item 25), and the supplementary variable 'Dementia phase indication'. The second dimension does not sufficiently discriminate between the categories ('present' and 'absent') of the active variable 'Changes in sense of time (e.g. wakes up at nighttime)' (item 5). The variables with the strongest link to the dimensions and for which the dimensions discriminated sufficiently between the categories, were used to interpret potential underlying domains.

The active variables can be divided into clusters based on content similarities (e.g. variables

regarding different aspects of forgetfulness). A cluster of active variables with content similarities is called a domain. In some cases, the essence of a dimension can be captured in a single overarching domain that covers the content of the active variables with the strongest link to that dimension. In this pilot study, the essence of the first and second dimension cannot be captured in two overarching domains.

However, the active variables within one dimension (of which the categories have the strongest link to that dimension) were divided into clusters based on content similarities and the description of each item (variable) in the DSVH manual (Maaskant & Hoekman, 2011). These clusters were interpreted as domains of (cognitive functioning). The categories ('present' or 'absent') of each active variable were also taken into account. For example, a cluster of active variables with content similarities regarding forgetfulness could be identified in relation to the first dimension. The category 'present', of these active variables, had the strongest link to the first dimension. Therefore, a domain regarding the presence of forgetfulness could be identified in relation to the first dimension.

Domains regarding the presence of forgetfulness, an increase in negative mood, a decline in motor skills, a decline in responses to stimuli, a decline in characteristic were identified in relation to the first dimension based on the content similarities of the items and the description of the items (variables) in the DSVH manual (Maaskant & Hoekman, 2011). However, the active variables ('Is less interested in the activities of others' (item 15), 'Has seizures' (item 55), 'Less capable of keeping oneself occupied' (item 14), and 'Is frequently incontinent for urine (not on purpose)' (item 52) could not be clustered and thus were assigned to a domain named 'other'. The supplementary variable 'Dementia' (item 10) has not been assigned to one of the domains, but it was taken into account when interpreting the domains. The category 'present' of the supplementary variable 'Dementia' (item 10) had the strongest link with the first dimension. This means that the presence of dementia symptoms, is strongly related to the first dimension.

Domains regarding a decline in orientation in time and the absence of speech related complications were found in relation to the second dimension based on the content similarities of the items and the description of the items (variables) in the DSVH manual (Maaskant & Hoekman, 2011). The active variable 'Needing reassurance that supervisor is nearby and seems to be uneasy when left alone' (item 22) could not be clustered and was therefore assigned to a domain named 'other'.

#### **Discussion**

Organizations that provide personalized care to individuals with intellectual disabilities experience complicating factors in the diagnostic process of dementia classification. Identifying domains of (cognitive) functioning underlying the DSVH (Maaskant & Hoekman, 2011) could aid

these organizations in the development of personalized care guidelines for individuals with intellectual disabilities and dementia. The aim of this pilot study was to identify potential domains of (cognitive) functioning underlying the DSVH (Maaskant & Hoekman, 2011). It was hypothesized that domains regarding mood, aggression, appetite, loss of interest, functional decline (reduced self-care skills), cognitive decline, personality, speech, maladaptive behaviours, disorientation, confusion, environmental awareness, and motor skills would be found.

#### Domains found in relation to the first and second dimension

A domain regarding the presence of forgetfulness was found in relation to the first dimension. This domain was in line with the hypothesized cognitive decline domain. Memory decline is the most commonly met criterion when individuals with intellectual disabilities are screened for dementia, therefore, it was expected to uncover a domain regarding the presence of forgetfulness (Strydom et al., 2010). Additionally, a domain regarding an increase in negative mood (presence of negative mood) was found in relation to the first dimension. This is in line with the hypothesized (negative) mood domain. Emotional changes like a low mood are often found in (the early phases of) dementia in individuals with intellectual disabilities and it was expected to uncover a domain regarding an increase in negative mood (Strydom et al., 2010). Furthermore, a domain regarding a decline in motor skills was found in relation to the first dimension. This domain is in line with the hypothesized domain regarding decline in motor skills, that is used in the Alzheimer's Functional Assessment Tool (AFAST) (De Vreese et al., 2015). In relation to the second dimension, a domain regarding a decline in orientation in time was found. This is in line with the hypothesized domain regarding disorientation, because this domain has been used in other questionnaires that are developed to assess potential dementia symptoms (Zeilinger et al., 2013).

#### Hypothesized domains that were not found

It was hypothesized that a domain regarding the presence of speech related complications would be found based on literature (Cooper, 1997). Contrary to this hypothesized domain, a domain regarding the absence of speech related complications was found in relation to the second dimension. Furthermore, it was hypothesized that, domains regarding the loss of interest, confusion, aggression, appetite, functional decline (reduced self-care skills), personality, maladaptive behaviours, and environmental awareness would be found. No domains have been identified that are in line with these hypothesized domains. This pilot study was performed on a small sample. The lack of representation of the hypothesized domains could be the result of sampling fluctuations as a result of the small sample. Additionally, the differential diagnoses DSVH (Maaskant & Hoekman, 2011) items regarding vision, hearing, pain, depression, medication, sleep, and hypothyroidism were not used as active variables in the analysis which could be an explanation for the absence of the

remaining hypothesized domains.

#### Additional domains that were found

Two additional domains were found that were not in line with the hypothesized domains based on literature and questionnaires. An additional domain regarding the presence of a decline in responses to stimuli was found in relation to the first dimension. Furthermore, an additional domain regarding the presence of a decline in characteristic behaviour was found in relation to the first dimension. An explanation for these domains not being in line with the hypothesized domains, could be participants suffering from complications as a result from a differential diagnosis. The DSVH manual (Maaskant & Hoekman, 2011) provides additional information about each item. The active variables (items) regarding a decline in responses to stimuli and a decline in characteristic behaviour are related to the differential diagnoses. For example, the presence of a decline in responses to stimuli could be the result of a participant suffering from vision related complications. Additionally, a Multiple Correspondence Analysis detects differences in responses between individuals and uses this to uncover potential underlying domains. The sample consisted of both participants with and without a dementia classification. This could be a potential explanation for the domains that were found, because it is possible that the analysis uncovered differences between these two groups rather than the individual differences.

#### Limitations

The results need to be interpreted in a cautious manner as a result of complicating factors in this study. A sufficiently large sample for the purpose of a Multiple Correspondence Analysis should consists of at least 20 cases per single active category of each variable (Di Franco, 2016). A sample consisting of 1920 participants would have been sufficient for this study, but the sample consisted of merely 50 participants. Additionally, information regarding the age and gender of the participants in the sample had been lost in the data transfer process. Not being able to control for the variables age and gender lessens the validity and plausibility of the interpretation. Furthermore, differential diagnoses have not been used for the analysis. Differential diagnoses items are not used to calculate the scores used for dementia classification, because they reduce the validity of the dementia classification. The differential diagnoses have also not been used for the analysis for the purpose of data reduction. Not being able to control for the differential diagnoses lessens the validity and plausibility of the interpretation. These limitations make it impossible to generalize the findings to the general population of individuals with intellectual disabilities.

#### **Future research**

Propositions have been identified that could be taken into account in future studies. The research sample size was insufficient for a Multiple Correspondence Analysis. Organizations that

provide personalized care to individuals with intellectual disabilities could collaborate to facilitate in organizing a sufficiently large and diverse sample. It is important that the variation in gender and age within the sample is known. Additionally, the sample of this pilot study consisted of both participants with and without a dementia classification. In future studies, samples should only consist of participants who have received a dementia classification. A Multiple Correspondence Analysis uses differences in responses between individuals within a research sample to uncover potential underlying domains. The domains found in the data could partly be the result of the differences between the participants with and without a dementia classification within the sample. A Multiple Correspondence Analysis might produce different results when performed on a research sample consisting of only participants who have received a dementia classification.

#### Conclusion

This pilot study was performed for the purpose of developing new tools and care guidelines for individuals with intellectual disabilities and to help improve the quality of life for this aging population. A Multiple Correspondence Analysis was used to explore potential domains of (cognitive) functioning underlying the DSVH (Maaskant & Hoekman, 2011). Indications of such domains have been found in this study, but the evidence is too ambiguous to make a substantiated conclusion. However, it can be concluded that a Multiple Correspondence Analysis could be a useful tool to further explore potential domains of (cognitive) functioning underlying the DSVH (Maaskant & Hoekman, 2011), because it enables the visualization of different relationships between groups of behavioural and structural factors. The results found in this pilot study suggest that domains of (cognitive) functioning might be underlying the DSVH (Maaskant & Hoekman, 2011) that might be uncovered when the analysis is performed on a sufficiently large and diverse sample.

#### References

- Cooper, S.A. (1997). Psychiatric symptoms of dementia among elderly people with learning disabilities. *International journal of geriatric psychiatry*, *12*(6), 662-666.
- Costa, P. S., Santos, N. C., Cunha, P., Cotter, J., & Sousa, N. (2013). The use of multiple correspondence analysis to explore associations between categories of qualitative variables in healthy ageing. *Journal of Aging Research*, 2013. doi:10.1155/2013/302163
- Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007). Dementia screening questionnaire for individuals with intellectual disabilities. *The British Journal of Psychiatry*, 190(5), 440-444.

- De Vreese, L. P., Gomiero, T., Uberti, M., De Bastiani, E., Weger, E., Mantesso, U., & Marangoni, A.

  (2015). Functional abilities and cognitive decline in adult and aging intellectual disabilities.

  Psychometric validation of an Italian version of the Alzheimer's Functional Assessment Tool

  (AFAST): Analysis of its clinical significance with linear statistics and artificial neural networks.

  Journal of Intellectual Disability Research, 59(4), 370-384.
- Devshi, R., Shaw, S., Elliott-King, J., Hogervorst, E., Hiremath, A., Velayudhan, L., Kumar, S., Baillon, S., & Bandelow, S. (2015). Prevalence of behavioural and psychological symptoms of dementia in individuals with learning disabilities. *Diagnostics*, *5*(4), 564-576.
- Di Franco, G. (2016). Multiple correspondence analysis: one only or several techniques?. *Quality & Quantity*, *50*(3), 1299-1315.
- Fonseca, L. M., Haddad, G. G., Mattar, G. P., Oliveira, M. C. D., Simon, S. S., Guilhoto, L. M., Busatto, G. F., Zaman, S., Holland, A. J., Hoexter, M. Q., & Bottino, C. M. (2019). The validity and reliability of the CAMDEX-DS for assessing dementia in adults with Down syndrome in Brazil.

  \*Brazilian Journal of Psychiatry, 41(3), 225-233.\*
- Gedye, A. (1995). *Manual for dementia scale for Down Syndrom*. Vancouver, BC: Gedye Research and Consulting.
- Lewith, G. T., Jonas, W. B., & Walach, H. (2010). *Clinical research in complementary therapies e-book:*\*Principles, problems and solutions. Elsevier Health Sciences.
- Maaskant, M. & Hoekman, J. (2011). *Dementieschaal voor mensen met een verstandelijke handicap* (DSVH): Handleiding. Bohn Stafleu van Loghum.
- McKenzie, K., Metcalfe, D., & Murray, G. (2018). A review of measures used in the screening, assessment and diagnosis of dementia in people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 725-742.
- Meeusen, R. & Geus, R. (2005). *Dementie in beeld: Landelijke richtlijnen voor het vaststellen van dementie bij mensen met een verstandelijk beperking* [brochure]. Retrieved from

- https://www.kennispleingehandicaptensector.nl/gehandicaptensector/media/documents/Thema's/Eigen%20regie/dementie-in-beeld-gehandicaptenzorg.pdf
- Meeusen-van de Kerkhof, R., & M.A. Maaskant (2004). Levensloop en veroudering. In: M. Kersten, & D. Flikweert (Eds.) Onderzoek over grenzen (IASSID-congresbundel, pp. 64-76). Utrecht: NGBZ en LKNG/NIZW
- Prinsenstichting (n.d.). Over ons. Retrieved from https://www.prinsenstichting.nl/over-ons/
- Richards, G., & van der Ark, L. A. (2013). Dimensions of cultural consumption among tourists:

  Multiple correspondence analysis. *Tourism Management*, *37*, 71-76.
- Ripley, B. D. (2001). The R project in statistical computing. *MSOR Connections. The newsletter of the LTSN Maths, Stats & OR Network, 1*(1), 23-25.
- Strydom, A., Hassiotis, A., King, M., & Livingston, G. (2009). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychological medicine*, *39*(1), 13-21.
- Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Sinnema, M., & Maaskant, M. (2010). Dementia in older adults with intellectual disabilities-epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), 96-110.
- Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Research in developmental disabilities*, *34*(6), 1881-1885.
- Zeilinger, E. L., Stiehl, K. A., & Weber, G. (2013). A systematic review on assessment instruments for dementia in persons with intellectual disabilities. *Research in developmental disabilities*, 34(11), 3962-3977.

## Appendix

## Appendix A. Overview of the clusters of symptoms found in studies

### Table A1

Overview clusters of symptoms found in literature

Literature	Clusters of symptoms	
Devshi <i>et al.</i> (2015)	Mood	
	Agression	
	Sleep	
	Eating	
	Loss of interest	
	Inefficient thought	
Cooper (1997)	Sleep	
	Concentration	
	Personality	
	Speech	
	Appetite	
	Mood	
	Loss of interests	
	Maladaptive behaviours	
	Forgetfulness	
	Confusion	
	Reduced self care skills	
	Disorientation	
	Loss of skills	

Table A2Overview domains found in questionnaires

Questionnaires	Domains
DSQIID	Deficits in memory and confusion
	Apathy and insecurity  Confusion and sleep
CAMDEX-DS	Highest level of functioning
	Functional and cognitive decline Current mental health
	Current physical health
AFAST	Use of bathroom
	Motor skills and walking
	Bathing skills
	Dressing skills
	Personal and oral hygiene
	Use of sanitary products
-	Environmental awareness

Appendix B. Contributions of the categories and variables to the first dimension Table B3

MCA contribution variables along axis (dimension) 1

	MCA dimension	<u>1_</u>	
	$R^2$	<i>p</i> -value	
Dementia phase indication_11	.84	<.001	
Dementia_10	.67	<.001	
Item.48. Decline.Reaction.Pers.Stim	.52	<.001	
Item.43. Needing.Guidance.Dressed.Forget	.51	<.001	
Item 44. Guidance.Eating.Forget	.46	<.001	
Item.19. Forget.dressing	.43	<.001	
Item.01. Forget.routine	.39	<.001	
Item.57. Guidance.Eating.Meals	.37	<.001	
Item.24. Not.Know.Household.Object	.37	<.001	
Item.16. Decline.Alert.Eye.Contact	.37	<.001	
Item.33. More.Fearful	.36	<.001	
Item.20. Not.Remem.Seq.Actions	.35	<.001	
Item.11. Increase.Irritability	.35	<.001	
Item.34. Scarcity.Charac.Actions	.35	<.001	
Item.13. Loss.Interest.Charac.	.34	<.001	
Item.55. Seizures	.33	<.001	
Item.14. Less.Capab.Keep.Occup	.33	<.001	
Item.17. Slowing.Movements	.32	<.001	
Item.40. Loss.Fine.Motor.Skills	.31	<.001	
Item.15. Less.Intered.Act.Others	.31	<.001	
Item.42. Does.Not.Recog.Forgot	.30	<.001	
Item.03. Forget.Names.Words	.30	<.001	
Item.52. Freq.Incontinent.Urine	.30	<.001	
Item.07. Does.Not.Under.Verbal	.28	<.001	
Item.46. Has.Trouble.Find.Places	.24	<.001	
Item.29. Less.Init.Speaking	.22	<.001	
Item.08. Decline.Spatial.Orien	.22	<.001	
Item.25. Does.Not.Remem.Events	.20	<.001	
Item.06. Mistake.Time.Activity	.20	.001	
Item.39. Unintent.Incontinent.Stool	.20	.001	
Item.22. Reassurance.Alone.Supervisor	.18	.002	
Item.35. Hitting.Others.Objects	.18	.002	
Item.30. Speech.Slower.Unintell	.18	.002	
Item.04. Forget.Names.Acquaint	.18	.003	
tem.27. Repeat.Simple.Movement	.17	.003	
Item.32. Sadness	.17	.003	
Item.59. Always.Incontinent	.17	.003	
Item.37. Losing.Balance	.16	.004	
Item.02. Losing.Object	.15	.005	

Item.36. Disturbed.Depth.Perception	.14	.007	
Item.38. Movements.Slow.Clumsy	.12	.013	
Item.31. Mumbles	.12	.014	
Item.09. Less.Init.Start.Speaking	.11	.020	
Item.05. Change.Sense.Time	.11	.020	
Item.18. Incon.Urine	.11	.025	
Item.26. Refer.Past.Event.Recent	.09	.032	
Item.45. Decr.Awar.Day.Night	.09	.036	
Downsyndrome_01	.08	.040	

 Table B4

 MCA contribution categories along axis (dimension) 1

West contribution categories along axis (aimen	MCA dimension 1	
	Estimate of coordinate	<i>p</i> -value
Dementia_10_yes	.41	<.001
Item.48. Decline.Reaction.Pers.Stim_1	.43	< .001
Item.43. Needing.Guidance.Dressed.Forget_1	.44	< .001
Item.44. Guidance.Eating.Forget_1	.49	< .001
Item.19. Forget.dressing_1	.37	< .001
Item.01. Forget.routine_1	.31	< .001
Item.57. Guidance.Eating.Meals_1	.41	< .001
Item.24. Not.Know.Household.Object_1	.41	< .001
Item.16. Decline.Alert.Eye.Contact_1	.30	< .001
Item.33. More.Fearful_1	.30	< .001
Item.20. Not.Remem.Seq.Actions_1	.32	< .001
Item.11. Increase.Irritability_1	.29	< .001
Item.34. Scarcity.Charac.Actions_1	.33	< .001
Item.13. Loss.Interest.Charac_1	.29	< .001
Item.55. Seizures_1	.48	< .001
Item.14. Less.Capab.Keep.Occup_1	.30	< .001
Item.17. Slowing.Movements_1	.29	< .001
Item.40. Loss.Fine.Motor.Skills_1	.31	< .001
Dementia phase indication_11_inapplicable	.78	< .001
Item.15. Less.Intered.Act.Others_1	.33	< .001
Item.42. Does.Not.Recog.Forgot_1	.37	< .001
Item.03. Forget.Names.Words_1	.36	< .001
Item.52. Freq.Incontinent.Urine_1	.34	< .001
Item.07. Does.Not.Under.Verbal_1	.28	< .001
Item.46. Has.Trouble.Find.Places_1	.38	< .001
Item.29. Less.Init.Speaking_1	.27	< .001
Item.08. Decline.Spatial.Orien_1	.31	< .001
Item.25. Does.Not.Remem.Events_1	.24	< .001
Item.06. Mistake.Time.Activity_1	.24	.001
Item.39. Unintent.Incontinent.Stool_1	.29	.001
Dementia phase indication_11_phase 3	.12	.002
Item.22. Reassurance. Alone. Supervisor_1	.22	.002
Item.35. Hitting.Others.Objects_1	.23	.002
Item.30. Speech.Slower.Unintell_1	.23	.002
Item.04. Forget.Names.Acquaint_1	.26	.002
Item.27. Repeat.Simple.Movement_1	.28	.003
Item.32. Sadness_1	.24	.003
Item.59. Always.Incontinent_1	.31	.003
Item.37. Losing.Balance_1	.23	.004
Item.02. Losing.Object_1	.24	.004
Item.36. Disturbed.Depth.Perception_1	.29	.006

Item.38. Movements.Slow.Clumsy 1	.23	.013
Item.31. Mumbles 1	.19	.014
Item.09. Less.Init.Start.Speaking_1	.21	.019
Item.05. Change.Sense.Time_1	.20	.020
Item.18. Incon.Urine_1	.16	.025
Item.26. Refer.Past.Event.Recent_1	.23	.032
Severity.Intellectual.Disability_04_unknown	.31	.033
Item.45. Decr.Awar.Day.Night _1	.23	.036
DownSyndrome_1_yes	.16	.040
DownSyndrome_1_no	16	.040
Item.45. Decr.Awar.Day.Night_0	23	.036
Item.26. Refer.Past.Event.Recent_0	23	.032
Item.18. Incon.Urine_0	16	.025
Item.05. Change.Sense.Time_0	20	.020
Item.09. Less.Init.Start.Speaking_0	21	.020
Item.31. Mumbles_0	19	.014
Item.38. Movements.Slow.Clumsy_0	23	.013
Item.36. Disturbed.Depth.Perception_0	30	.007
Item.02. Losing.Object_0	24	.005
Item.37. Losing.Balance_0	23	.004
Item.59. Always.Incontinent_0	31	.003
Item.32. Sadness_0	24	.003
Item.27. Repeat.Simple.Movement_0	28	.003
Item.04. Forget.Names.Acquaint_0	26	.002
Item.30. Speech.Slower.Unintell_0	23	.002
Item.35. Hitting.Others.Objects_0	23	.002
Item.22. Reassurance.Alone.Supervisor_0	22	.002
Item.39. Unintent.Incontinent.Stool_0	29	.001
Item.06. Mistake.Time.Activity_0	24	.001
Item.25. Does.Not.Remem.Events_0	24	< .001
Item.08. Decline.Spatial.Orien_0	31	< .001
Item.29. Less.Init.Speaking_0	27	< .001
Item.46. Has.Trouble.Find.Places_0	38	< .001
Item.07. Does.Not.Under.Verbal_0	28	< .001
Item.52. Freq.Incontinent.Urine_0	34	< .001
Item.03. Forget.Names.Words_0	36	< .001
Item.42. Does.Not.Recog.Forgot_0	37	< .001
Item.15. Less.Intered.Act.Others_0	33	< .001
Item.40. Loss.Fine.Motor.Skills_0	31	< .001
Item.17. Slowing.Movements_0	29	< .001
Item.14. Less.Capab.Keep.Occup_0	30	< .001
Item.55. Seizures_0	48	< .001
Item.13. Loss.Interest.Charac_0	29	< .001
Item.34. Scarcity.Charac.Actions_0	33	< .001
Item.11. Increase.Irritability_0	29	< .001
Item.20. Not.Remem.Seq.Actions_0	32	< .001

Item.33. More.Fearful_0	30	< .001	
Item.16. Decline.Alert.Eye.Contact_0	30	< .001	
Item.24. Not.Know.Household.Object_0	41	< .001	
Item.57. Guidance.Eating.Meals_0	41	< .001	
Item.01. Forget.routine_0	31	< .001	
Item.19. Forget.dressing_0	37	< .001	
Item.44. Guidance.Eating.Forget_0	49	< .001	
Item.43. Needing.Guidance.Dressed.Forget_0	44	< .001	
Item.48. Decline.Reaction.Pers.Stim_0	43	< .001	
Dementia phase indication_11_phase 1	76	< .001	
Dementia_10_no	41	< .001	

Appendix C. Contributions of the categories and variables to the second dimension Table C5

MCA contribution variables along axis (dimension) 2

	MCA dimension 2		
	$R^2$	<i>p</i> -value	
Item.45. Decr.Awar.Day.Night	.46	<.001	
Item.26. Refer.Past.Event.Recent	.41	<.001	
Item.29. Less.Init.Speaking	.35	<.001	
Item.09. Less.Init.Start.Speaking	.25	<.001	
Item.22. Need.Reassur.Supervisor	.25	<.001	
Item.05. Change.Sense.Time	.23	<.001	
Item.13. Loss.Interest.Charac	.20	.001	
Item.27. Repeat.Simple.Movement	.18	.002	
Item.15. Less.Intered.Act.Others	.17	.003	
Item.57. Guidance.Eating.Meals	.15	.005	
Item.25. Does.Not.Remem.Events	.13	.012	
Item.39. Unintent.Incontinent.Stool	.11	.017	
Item.40. Loss.Fine.Motor.Skills	.11	.018	
Item.03. Forget.Names.Words	.11	.022	
Item.04. Forget.Names.Acquaint	.10	.026	
Item.36. Disturbed.Depth.Perception	.10	.028	
Item.17. Slowing.Movements	.08	.048	
Item.01. Forget.routine	.08	.050	

 MCA contribution categories along axis (dimension) 2

men continuation categories along and fam.	MCA dimension 2	
	Estimate of coordinate	<i>p</i> -value
Item.45.Decr.Awar.Day.Night_1	.31	< .001
Item.26. Refer.Past.Event.Recent_1	.29	< .001
Item.29. Less.Init.Speaking_0	.21	< .001
Item.09. Less.Init.Start.Speaking_0	.20	< .001
Item.22. Need.Reassur.Supervisor_1	.15	< .001
Item.05. Change.Sense.Time_1	.17	< .001
Item.13. Loss.Interest.Charac_0	.14	.001
Item.27. Repeat.Simple.Movement_1	.17	.002
Item.15. Less.Intered.Act.Others_0	.15	.003
Item.57. Guidance.Eating.Meals_1	.16	.005
Item.25. Does.Not.Remem.Events_1	.11	.012
Item.39. Unintent.Incontinent.Stool_0	.13	.017
Item.40. Loss.Fine.Motor.Skills_0	.11	.018
Item.03. Forget.Names.Words_0	.13	.022
Item.04. Forget.Names.Acquaint_1	.12	.026
Item.36. Disturbed.Depth.Perception_0	.14	.028
Item.17. Slowing.Movements_0	.85	.050
Item.01. Forget.routine_1	.08	.050
Item.01. Forget.routine_0	08	.050
Item.17. Slowing.Movements_1	09	.048
Hypothyroidism_8_unknown	15	.033
Item.36. Disturbed.Depth.Perception_1	14	.028
Item.04. Forget.Names.Acquaint_0	12	.026
Item.03. Forget.Names.Words_1	13	.022
Item.40. Loss.Fine.Motor.Skills_1	11	.018
Item.39. Unintent.Incontinent.Stool_1	13	.017
Item.25. Does.Not.Remem.Events_0	11	.012
Item.57. Guidance.Eating.Meals_0	16	.005
Item.15. Less.Intered.Act.Others_1	15	.003
Item.27. Repeat.Simple.Movement_0	17	.002
Item.13. Loss.Interest.Charac_1	14	.001
Item.05. Change.Sense.Time_0	17	< .001
Item.22. Need.Reassur.Supervisor_0	15	< .001
Item.09. Less.Init.Start.Speaking_1	20	< .001
Item.29. Less.Init.Speaking _1	21	< .001
Item.26. Refer.Past.Event.Recent_0	29	< .001
Item.45. Decr.Awar.Day.Night_0	31	< .001

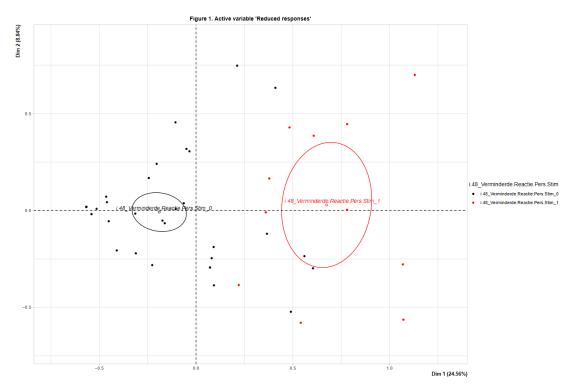
#### Appendix D. Figures of variables with strongest links to the first and second dimension

Each point in the plot represents an individual within the sample and shows its position relative to the two dimensions. The first dimension is represented on the horizontal axis. The second dimension is represented on the vertical axis. The 'absent' category (with corresponding code 0) is represented in the colour black. The 'present' category (with corresponding code 1) is represented in the colour red. A dimension distinguishes categories well if the confidence ellipses of the categories show no overlap on that dimension. Additionally, a dimension cannot be used to discriminate between the two categories if the ellipses show overlap (this means that the categories have the same positions on the axis (dimension) or if they have the same value on that dimension).

Dimension 1

Figure D1

Active variable 'Reduced responses to individuals or stimuli' (item 48)



From Figure D1 it becomes clear, when looking at the confidence ellipses of the two categories for the active variable 'Reduced responses to individuals or stimuli' (item 48) that they show no overlap on the first dimension. This means that this dimension distinguishes these categories best. Both of the ellipses show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between the two categories.

Figure D2

Active variable 'Needing guidance when getting dressed due to forgetfulness' (item 43)

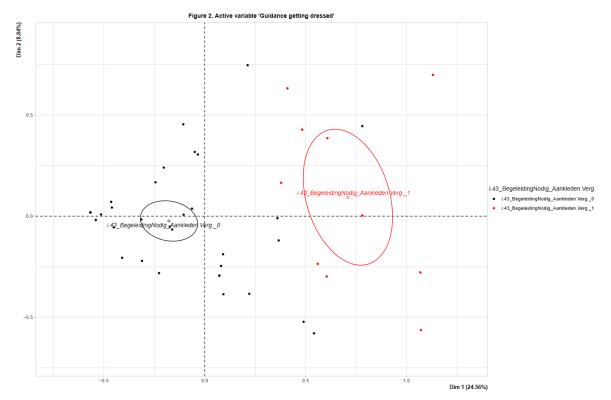
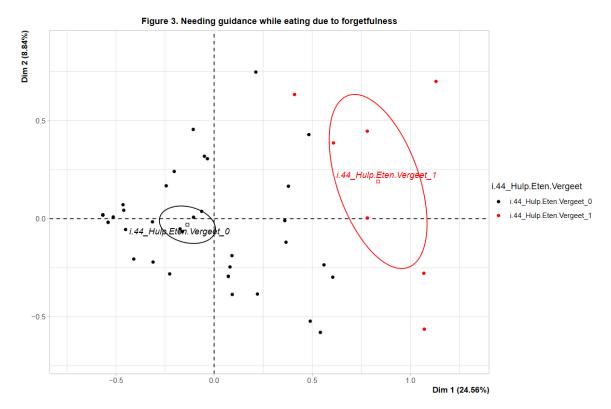


Figure D2 shows that the confidence ellipses of the categories for the active variable 'Needing guidance when getting dressed due to forgetfulness' (item 43) have no overlap on the first dimension. This means that this dimension distinguishes both categories best. Both of the ellipses show overlap on the second dimension. Because of this, the second dimension cannot be used to discriminate between these two categories of this variable.

Figure D3

Active variable 'Needing guidance while eating due to forgetfulness' (item 44)



From Figure D3 it becomes clear that the confidence ellipses of the two categories of the active variable 'Needing guidance while eating due to forgetfulness' (item 44) show no overlap on the first dimension. This means that the first dimension distinguishes these categories best. Both of the ellipses do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between the two categories.

Figure D4

Active variable 'Decline in dressing skills (no compulsory behavior)' (item 19)

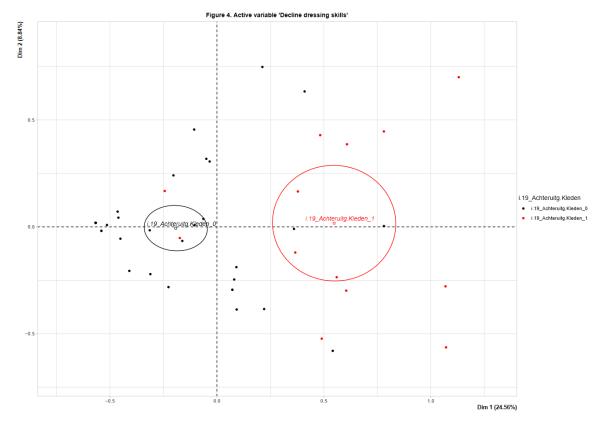


Figure D4 shows that the two confidence ellipses of the active variable 'Decline in dressing skills (no compulsory behavior)' (item 19) show no overlap on the first dimension. This means that this dimension distinguishes these categories best. Both of the confidence ellipses show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D5

Active variable 'Forgetting what he is doing while performing routine related actions' (item 1)

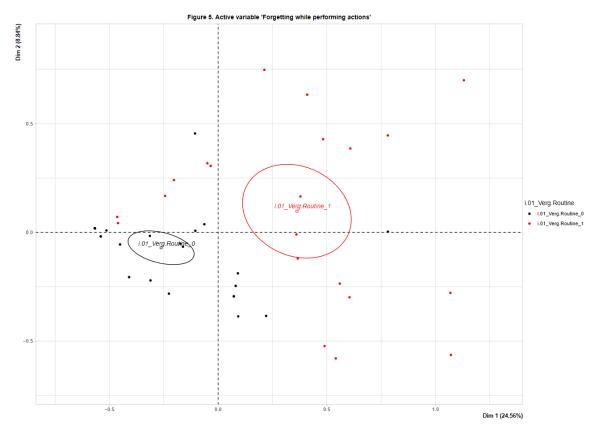
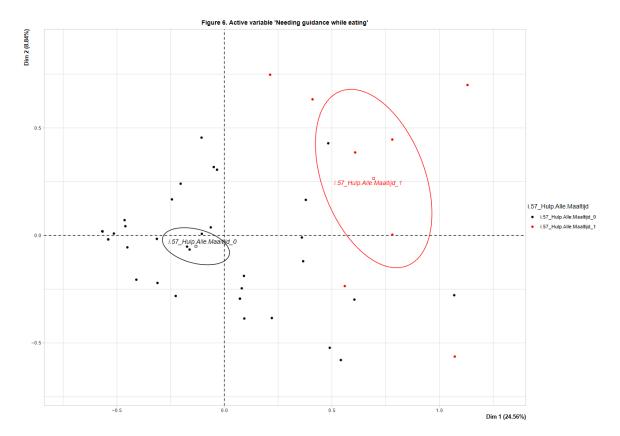


Figure D5 shows that the ellipses of the two confidence ellipses of the active variable 'Forgetting what he is doing while performing routine related actions' (item 1) have no overlap on the first dimension. This means that this dimension distinguishes these categories best. Both of the confidence ellipses show some overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D6

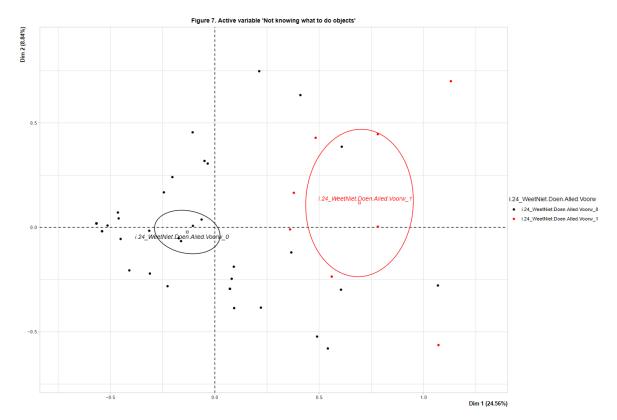
Active variable 'Needing guidance while eating' (item 57)



As seen in Figure D6, the two ellipses of the active variable 'Needing guidance while eating'
(item 57) have no overlap on the first dimension. This means that the first dimension distinguishes
these categories best. Both of the confidence ellipses do show overlap on the second dimension. This
means that the second dimension cannot be used to discriminate between these categories.

Figure D7

Active variable 'Not knowing what to do with household objects' (item 24)



From Figure D7 it becomes clear that the two ellipses of the active variable 'Not knowing what to do with household objects' (item 24) have no overlap on the first dimension. This means that the first dimension distinguishes these categories best. Additionally, both of the confidence ellipses do show overlap on the second dimension. This means that this dimension cannot be used to discriminate between these categories.

Figure D8

Active variable 'Decline alertness and less eye contact' (item 16)

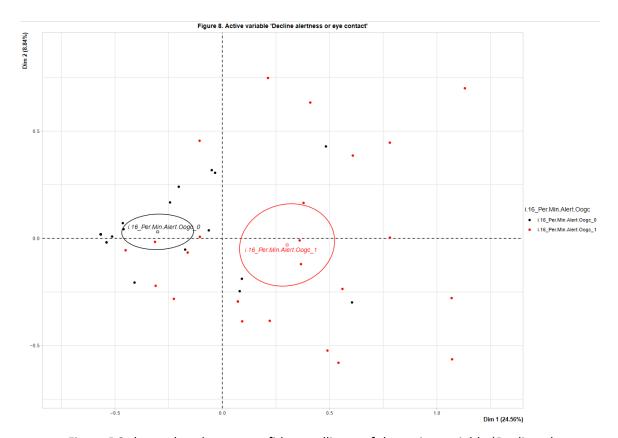
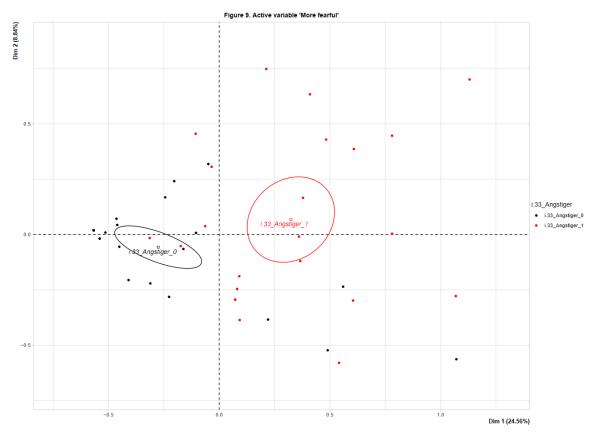


Figure D8 shows that the two confidence ellipses of the active variable 'Decline alertness and less eye contact' (item 16) have no overlap on the first dimension. This means that the first dimension distinguishes these categories best. Additionally, both of the confidence ellipses of these categories do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D9

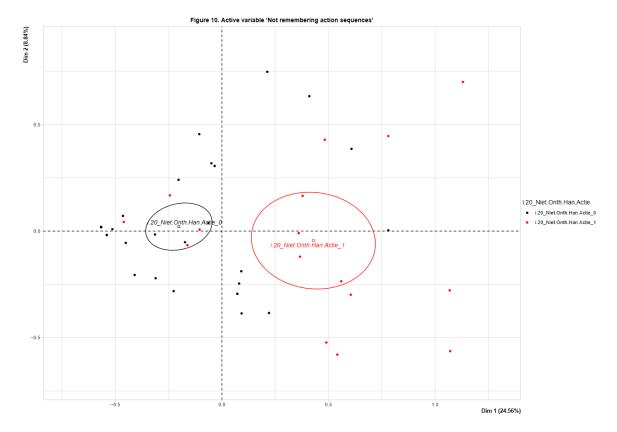
Active variable 'More fearful' (item 33)



From Figure D9 it becomes clear, when looking at the confidence ellipses of the two categories for the active variable 'More fearful' (item 33), that they show no overlap on the first dimension. This means that the first dimension distinguishes these categories best. However, both of the ellipses do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these two categories.

Figure D10

Active variable 'Not remembering sequences of actions to perform action properly' (item 20)



As seen in Figure D10, the two ellipses of the active variable 'Not remembering sequences of actions to perform action properly' (item 20) have no overlap on the first dimension. This means that this dimension distinguishes these categories best. Both of the confidence ellipses do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D11

Active variable 'Increase irritability and more easily agitated' (item 11)

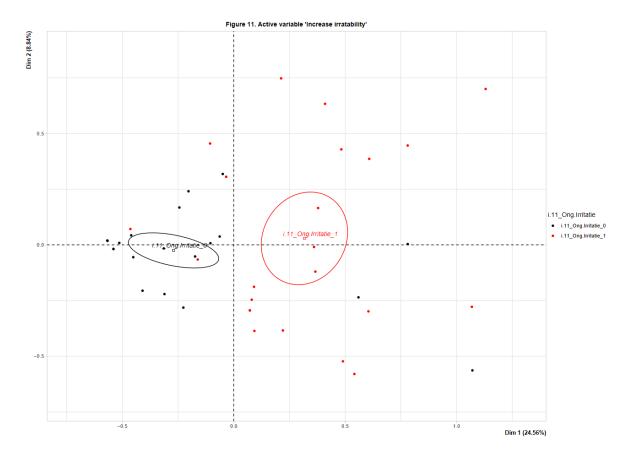
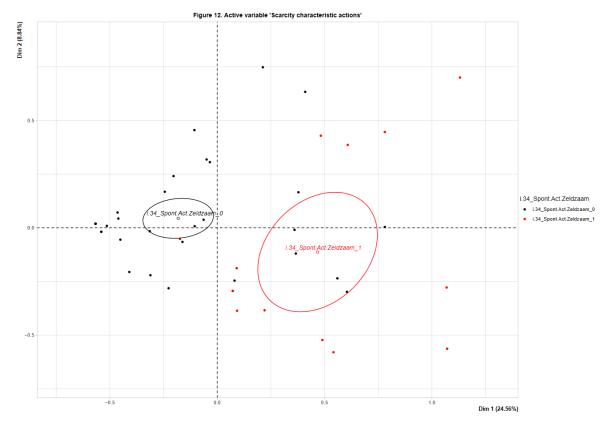


Figure D11 shows that the two confidence ellipses of the active variable 'Increase irritability and more easily agitated' (item 11) have no overlap on the first dimension. This means that the first dimension distinguishes these categories best. Additionally, both of the confidence ellipses of the categories do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D12

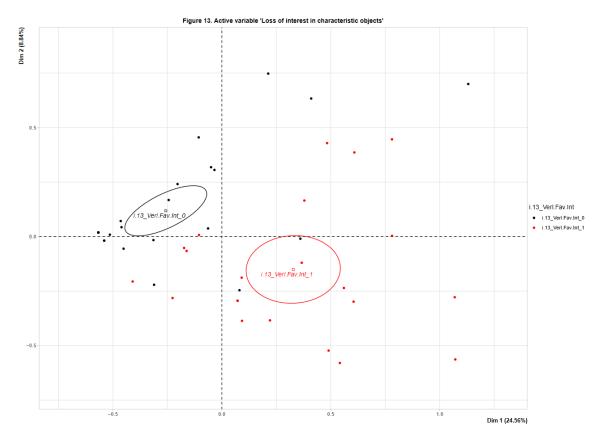
Active variable 'Scarcity characteristic actions' (item 34)



From Figure D12 it becomes clear that the two ellipses of the active variable 'Scarcity characteristic actions' (item 34) show no overlap on the first dimension. This means that the first dimension distinguishes these categories best. However, the two categories do show overlap on the second dimension. Because of this, second dimension cannot be used to discriminate between the two categories.

Figure D13

Active variable 'Loss of interest in characteristic objects, handwork, or events' (item 13)



As seen in Figure D13, the two confidence ellipses of the active variable 'Loss of interest in characteristic objects, handwork, or events' (item 13) have no overlap on the first and second dimension. This means that both dimensions can be used to discriminate between these categories.

Figure D14

Active variable 'Has seizures' (item 55)

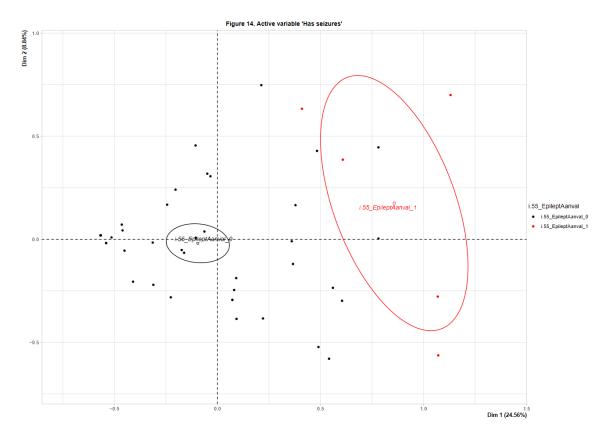
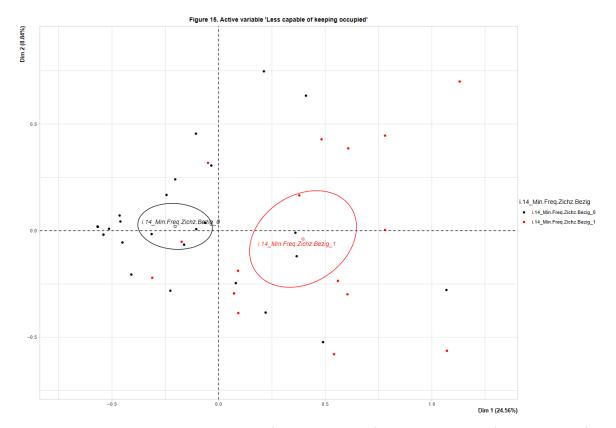


Figure D14 shows that the two ellipses of the active variable 'Has seizures' (item 55) have no overlap on the first dimension. The first dimension, therefore, distinguishes these categories best. Additionally, both of the confidence ellipses of these categories do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these categories.

Figure D15

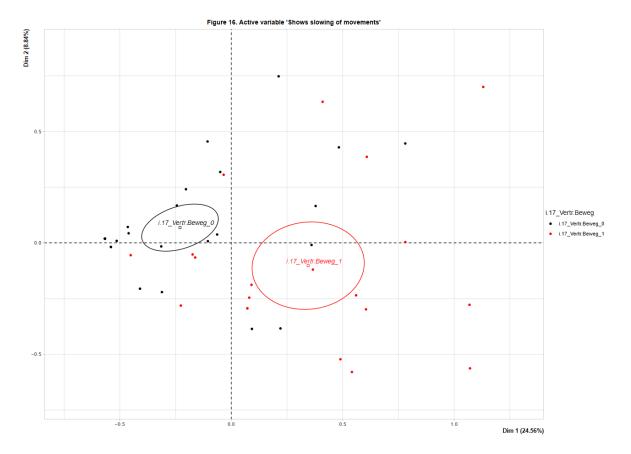
Active variable 'Less capable of keeping oneself occupied' (item 14)



As seen in Figure D15, the two confidence ellipses of the active variable 'Less capable of keeping oneself occupied' (item 14) have no overlap on both dimension. Additionally, the confidence ellipses do show overlap on the second dimension. Because of this, the first dimension can be used to discriminate between the two categories and the second dimension cannot.

Figure D16

Active variable 'Shows slowing of movements' (item 17)



From Figure D16 it becomes clear that the confidence ellipses of the active variable 'Shows slowing of movements' (item 17) do not overlap on the first dimension. This means that the first dimension discriminates sufficiently between the two categories. The categories, however, do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between the two.

Figure D17

Active variable 'Loss of fine motor skills' (item 40)

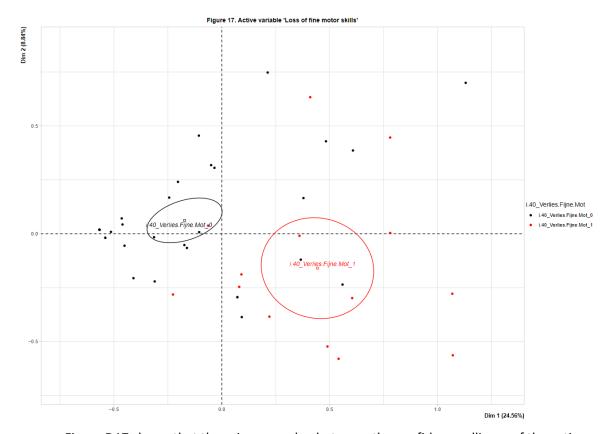
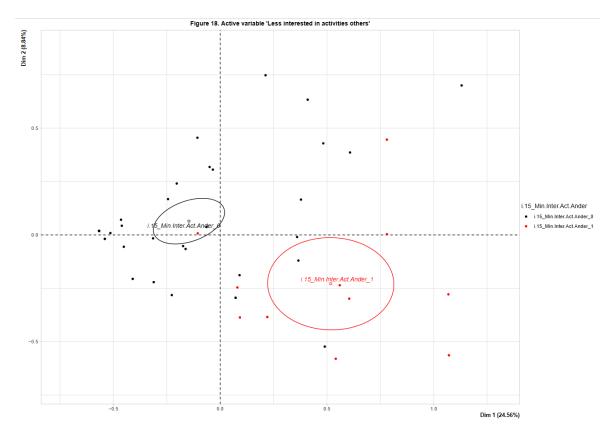


Figure D17 shows that there is no overlap between the confidence ellipses of the active variable 'Loss of fine motor skills' (item 40) on the first dimension. Because of this, the first dimension can be used to discriminate between the two categories. The confidence intervals do show some overlap on the second dimension. This means that this dimension cannot be used to discriminate between the two categories.

Figure D18

Active variable 'Is less interested in the activities of others' (item 15)



As seen in Figure D18, the confidence ellipses of the active variable 'Is less interested in the activities of others' (item 15) do not overlap on the first dimension. This means that it can be used to discriminate between the two categories. The confidence intervals show some overlap on the second dimension. This means that the second dimension cannot sufficiently discriminate between the two categories.

Figure D19

Active variable 'Does not recognize family or friends or has forgotten their names' (item 42)

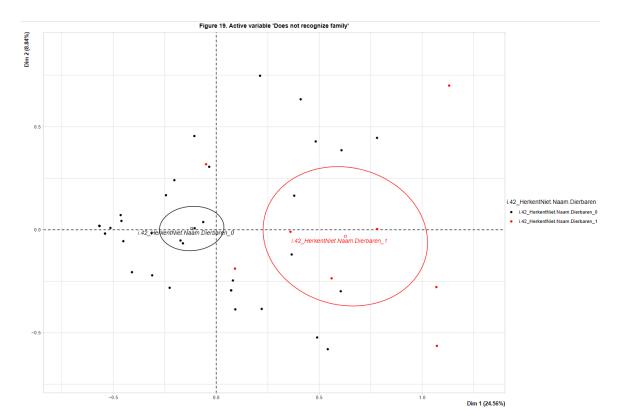
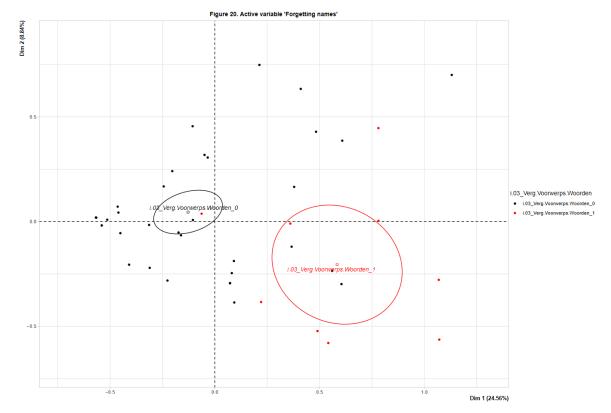


Figure D19 shows that the confidence ellipses of the active variable 'Does not recognize family or friends or has forgotten their names' (item 42) do not show overlap on the first dimension. The confidence intervals do show overlap on the second dimension. This means that the first dimension discriminates sufficiently between the two categories and the second dimension does not.

Figure D20

Active variable 'Forgetting names and names of objects/ not remembering words' (item 3)



From Figure D20 it becomes clear that the two ellipses of the active variable 'Forgetting names and names of objects/ not remembering words' (item 3) show no overlap on the first dimension. This means that the first dimension distinguishes these categories best. Both of the categories do show some overlap on the second dimension. Therefore, the second dimension does not discriminate sufficiently between the two categories.

Figure D21

Active variable 'Is frequently incontinent for urine (not on purpose)' (item 52)

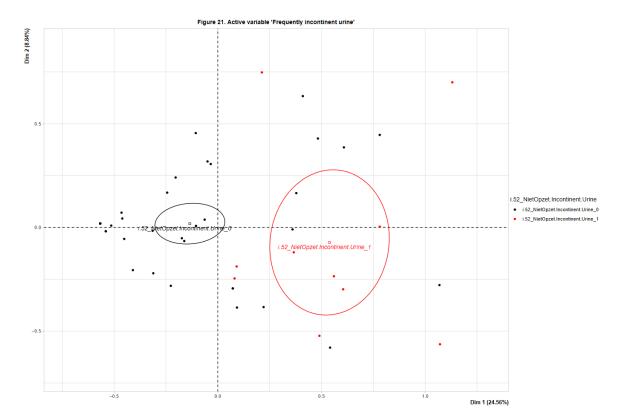
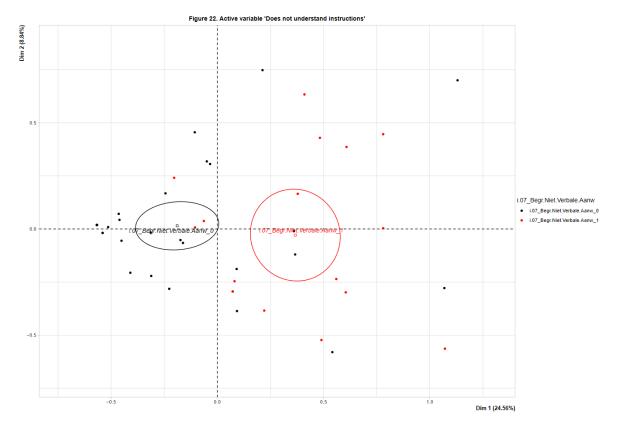


Figure D21 shows that the two confidence ellipses of the active variable 'Is frequently incontinent for urine (not on purpose)' (item 52) show no overlap on the first dimension. This means that the first dimension distinguishes the two categories best. The two confidence ellipses do show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between the two categories.

Figure D22

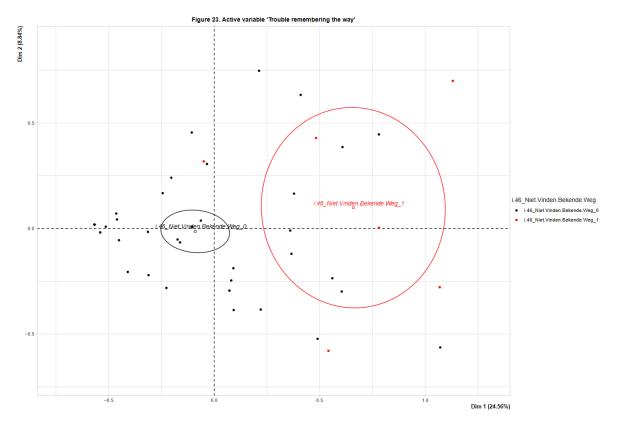
Active variable 'Does not understand verbal instructions (that used to be understood)' (item 7)



From Figure D22 it becomes clear that the first dimension distinguishes best between the two categories of the active variable 'Does not understand verbal instructions (that used to be understood)' (item 7), because the confidence ellipses of the categories do not overlap on this dimension. The categories do show overlap on the second dimension. This means that this dimension cannot be used to discriminate between the two categories.

Figure D23

Active variable 'Has trouble remembering the way (to familiar places) or needs to receive help to get there' (item 46)



As seen in Figure D23, the confidence ellipses of the active variable 'Has trouble remembering the way (to familiar places) or needs to receive help to get there' (item 46) do not overlap on the first dimension. The first dimension distinguishes best between the two categories. The ellipses do show overlap on the second dimension. This means that the second dimension does not discriminate sufficiently between the two categories.

Figure D24

Active variable 'Less initiative to speak (includes sign language)' (item 29)

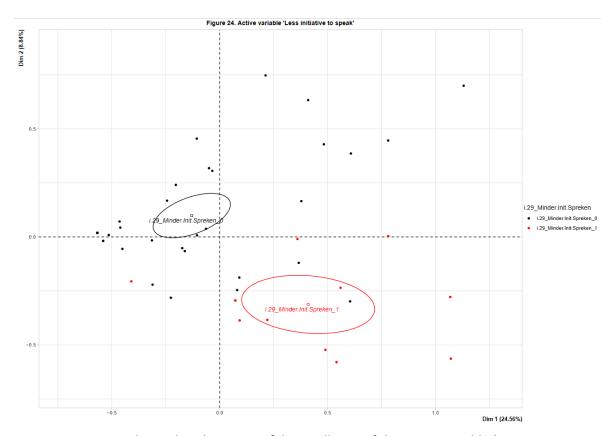
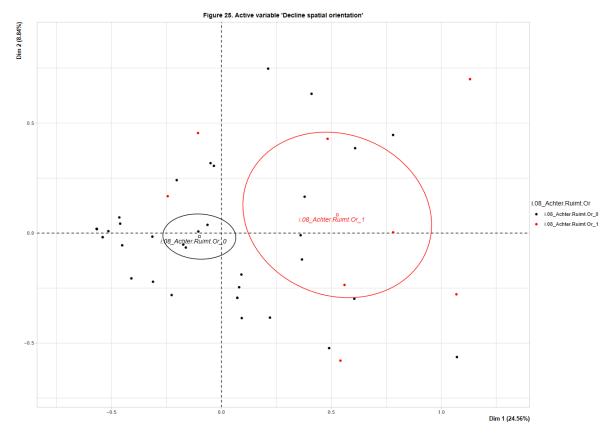


Figure D24 shows that the two confidence ellipses of the active variable 'Less initiative to speak (includes sign language)' (item 29) do not overlap on either one of the dimensions. This means that both of the dimensions can be used to discriminate between the two categories.

Figure D25

Active variable 'Shows decline in spatial orientation' (item 8)



It becomes clear, when looking at Figure D25, that the confidence ellipses of active variable 'Shows decline in spatial orientation' (item 8) that the first dimension distinguishes best, because the ellipses do not show overlap on the first dimension. The ellipses do show overlap on the second dimension. This means that the second dimension does not discriminate sufficiently between the two categories.

Figure D26

Active variable 'Does not remember events from the same day or the previous day' (item 25)

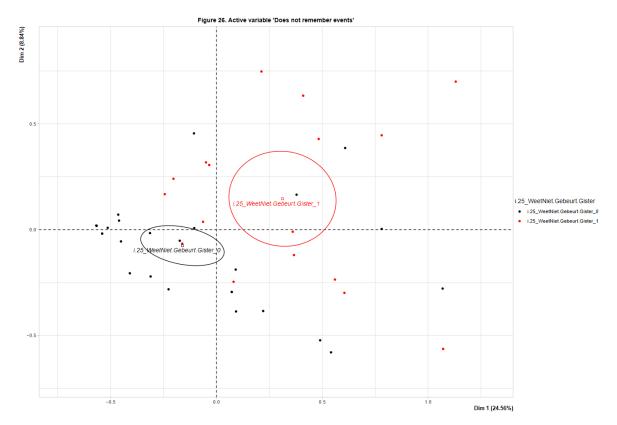
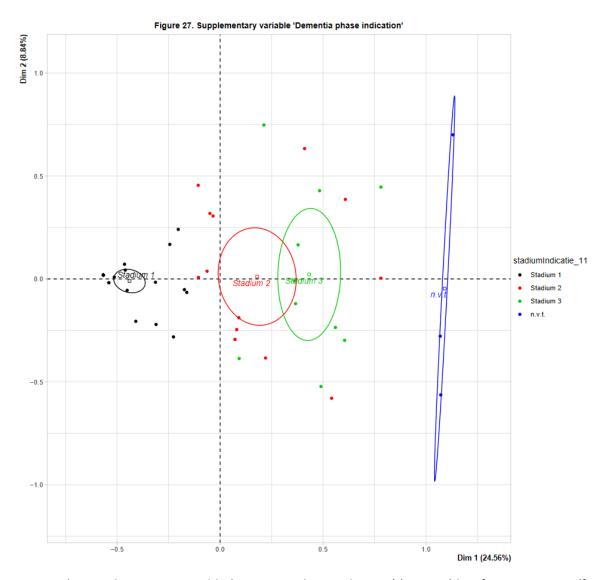


Figure D26 shows that the confidence ellipses of the active variable 'Does not remember events from the same day or the previous day' (item 25) do not overlap on the first dimension. This means that the first dimension distinguishes best between the two categories. The ellipses do show some overlap on the second dimension. Because of this, the second dimension cannot be used to discriminate between the two categories.

Figure D27

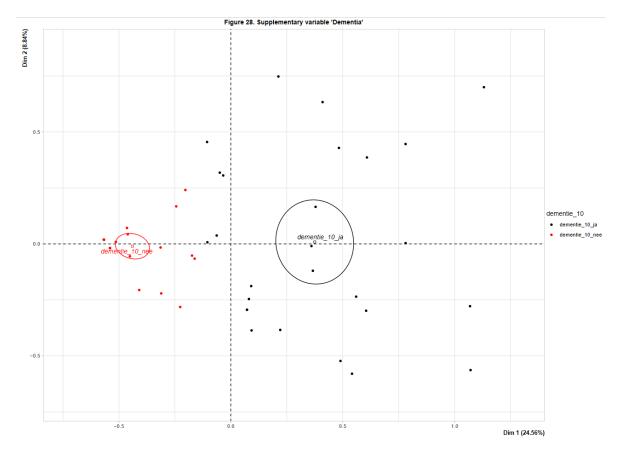
Supplementary variable 'Dementia phase indication' (item 11)



The supplementary variable 'Dementia phase indication' (item 11) has four categories: 'first phase' (black), 'second phase' (red), 'third phase' (green) and 'inapplicable' (blue). From Figure D27 it becomes clear that all four of the confidence ellipses show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between the four categories. The categories 'first phase' and 'inapplicable' do not show overlap on the first dimension. The categories 'second phase' and 'third phase', however, do show overlap on the first dimension. This means that the first dimension only sufficiently discriminates between the categories 'first phase' and 'inapplicable', but cannot be used to discriminate between the categories as a whole.

Figure D28

Supplementary variable 'Dementia' (item 10)



From Figure D28 it becomes clear, when looking at the confidence ellipses of the categories 'present' and 'absent' for the supplementary variable 'Dementia' (item 10), that both categories show no overlap on the first dimension. This means that this dimension distinguishes these categories best. Both of the ellipses show overlap on the second dimension. This means that the second dimension cannot be used to discriminate between these two categories of the variable 'Dementia'.

## **Dimension 2**

## Figure D29

Active variable 'Decreased awareness of daytime and nighttime and does not show proper response to time of day' (item 45)

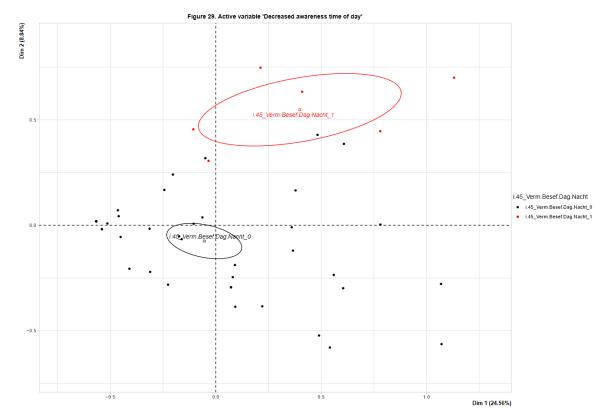
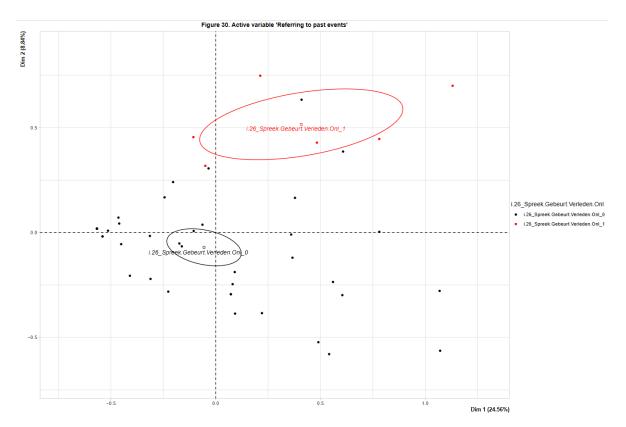


Figure D29 shows that the second dimension discriminates the categories best, because no overlap is seen between the confidence ellipses of the active variable 'Decreased awareness of daytime and nighttime and does not show proper response to time of day' (item 45). The first dimension cannot be used to discriminate between the two categories, because the confidence ellipses do show some overlap on the first dimension.

Figure D30

Active variable 'Referring to past events as if they happened recently' (item 26)



From Figure D30 it becomes clear that the second dimension distinguishes best between the two categories of the active variable 'Referring to past events as if they happened recently' (item 26), because the confidence ellipses do not show overlap on this dimension. The categories do, however, show overlap on the first dimension. This means that the first dimension cannot be used to discriminate between the two categories.

Figure D31

Active variable 'Less initiative to speak (includes sign language)' (item 29)

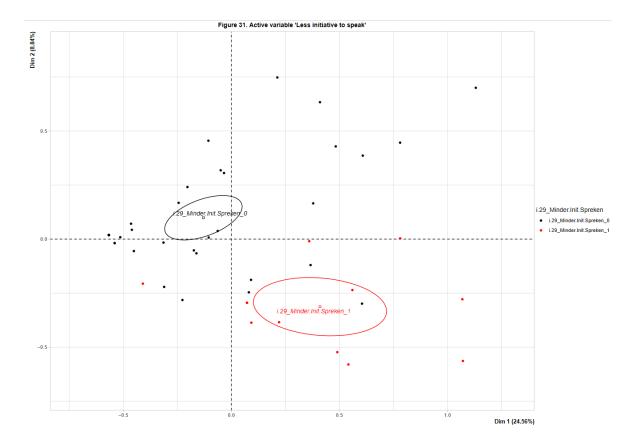
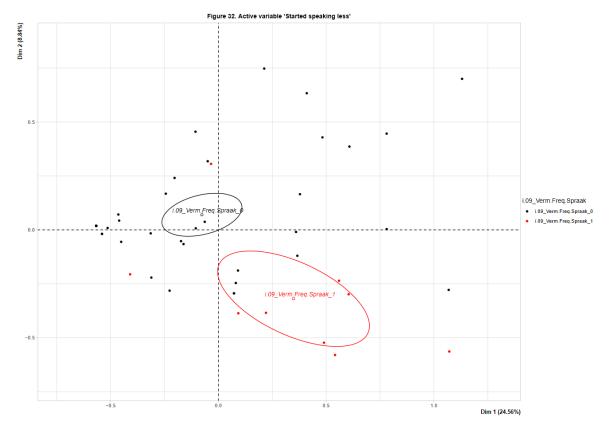


Figure D31 shows that the confidence ellipses of the active variable 'Less initiative to speak (includes sign language)' (item 29) do not overlap on either one of the dimensions. This means that both of the dimensions discriminate sufficiently between the two categories.

Figure D32

Active variable 'Less initiative to speak/ started speaking less (includes sign language)' (item 9)



From Figure D32 it becomes clear that the two confidence ellipses of the active variable 'Less initiative to speak/ started speaking less (includes sign language)' (item 9) do not show overlap on the second dimension. This means that the second dimension distinguishes sufficiently between the two categories as the categories do show overlap on the first dimension. The first dimension cannot be used to distinguish between the two categories, because the confidence ellipses show overlap on this dimension.

**Figure D33**Active variable 'Needing reassurance that supervisor is nearby and seems to be uneasy when left alone' (item 22)

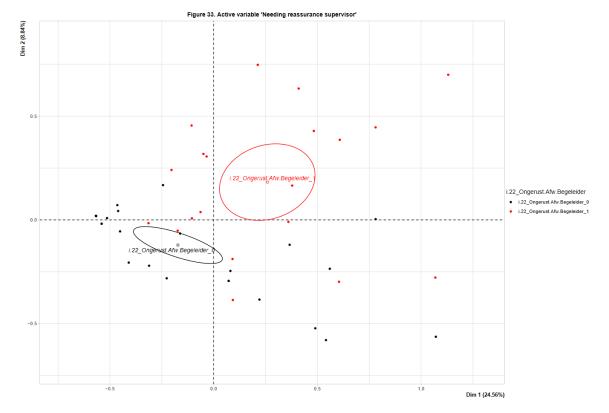
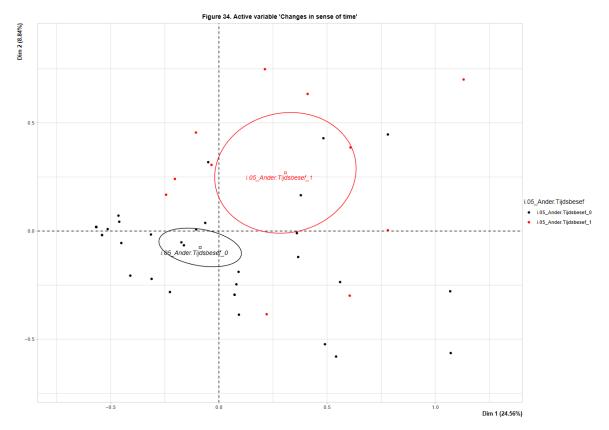


Figure D33 shows that the two confidence ellipses of the active variable 'Needing reassurance that supervisor is nearby and seems to be uneasy when left alone' (item 22) show overlap on the first dimension. This means that the first dimension does not discriminate sufficiently between the two categories. However, the confidence ellipses do not show overlap on the second dimension. This means that the second dimension can be used to discriminate between the two categories.

Figure D34

Active variable 'Changes in sense of time (e.g. wakes up at nighttime)' (item 5)



From Figure D34 it becomes clear that the two confidence ellipses of the active variable 'Changes in sense of time (e.g. wakes up at nighttime)' (item 5) show overlap on both the first and the second dimension. This means that both dimensions cannot be used to discriminate between the two categories.