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An ELPAT definition of the concept ‘Psychosocial’ in the context of Screening Living Organ Donors in Europe: A Concept Mapping approach

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Disclaimer on presented research results

The content presented in this report results from a concept mapping study on the concept 'Psychosocial' in the context of Screening Living Organ Donors in Europe.

The content is not intended to create, does not create, and may not be relied upon to create any solid conclusions; it must not be seen as the final interpretation of the results. All conclusions and interpretations in this report should be regarded as provisional. This report is intended solely for informative purposes and is meant as a first detailed description of our research.

Opinions or points of view expressed in this report represent a consensus of the authors and the members of the 'Psychological Care for Living Donors and Recipients' workgroup who participated in this work. The content is a detailed description of our investigation and of the consensus meeting with the workgroup and was made directly after the data collection and the consensus meeting, in order to allow fast communication between the members of the workgroup. As such, this report provides technical details about the methodology, extensive tables of the collected data and preliminary interpretations.

The content will serve as an easy referable and accessible collection of the (almost) raw research data, on which basis we will write peer-reviewed articles. This original report will remain available on request, for those researchers who would like to have a detailed description of our research. Note that parts of the report still reveal our early thoughts and interpretations, which are characteristic for a first report written just after finishing the data collection.

Abstract

Introduction: Across Europe, transplant centers vary in the set of psychosocial screening criteria/guidelines used for the selection of eligible living donors. Our aim was to explore whether a common framework underlies this variation in screening criteria and, based on this framework, to develop a consensus on the essential elements of psychosocial screening of living liver and kidney donors. In order to do so, a research question was set out to define a conceptual framework of the concept 'Psychosocial' in the context of screening living organ donors in Europe. We formulated the following research question: Which psychosocial screening criteria are most commonly reported and considered as most important or effective in selecting eligible kidney and liver donors?

Method: Concept mapping methodology was used to create a visual representation of the complex topic 'Psychosocial' in the context of screening living organ donors in Europe, in which underlying concepts, the relative importance of these concepts and the interplay between different concepts are organized. Initial psychosocial screening criteria (N=83) were derived from an extensive systematic literature review on guidelines, protocols and consensus statements on psychosocial screening practices, complemented by group brainstorm sessions. These criteria were then sorted and rated for their importance and effectiveness by 26 project participants. The data were analyzed using the Concept System Core© Software, which provided us with graphical depictions (concept maps) illustrating the view of project participants on these screening criteria. Pattern Matches and Go-Zones showed us the highly-common, important and effective criteria.

Results: The concept map procedure resulted in six clusters of psychosocial screening criteria: (1) Motivation and decision making (2) Personal resources (3) Psychopathology (4) Social resources (5) Ethical and Legal factors (6) Information and risk processing. Bivariate rating of these criteria revealed which important criteria are already frequently used for screening and which require more attention. Based on the cluster map and bivariate ratings we constructed a conceptual framework for non-medical risk factors that need to be considered when screening potential living organ donors.

Conclusion: We provided a conceptual framework of psychosocial screening criteria which can serve as a practical recommendation for the psychosocial screening of potential living organ donors.

Key words: Living donor, transplantation, concept mapping, psychosocial, screening

Introduction

Transplant centers across Europe vary in the set of psychosocial screening criteria used for the selection of eligible living donors. So far, no general guidelines for psychosocial screening of potential living donors exist. Here, we explored whether a common framework underlies the variation in screening criteria used in different European countries. In the present study we extended the work of Duerinckx et al. on the definition of the concept "psychosocial" in the context of screening living organ donors in Europe presented during the Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) workgroup meeting in Sofia, Bulgaria, 2010. They performed an extensive systematic literature review to list all psychosocial screening criteria (*i*=136) associated with the selection of eligible donors (1).

In this review the authors showed that thorough medical and psychosocial evaluation of potential living donors is essential to determine a person's suitability for donation. However, the current practice focuses on the medical evaluation and pays less attention to psychosocial screening of donors. There are few widely adopted standards, evidence-based studies or systemic reviews of psychosocial criteria for living donor screening. The few reported studies which include psychosocial aspects generally lack a clear definition of the term "psychosocial" which leads to heterogeneity in terminology, and moreover in screening criteria. The results of these studies are difficult to apply in clinical practice, because they did not result in the formulation of strict relative and absolute psychosocial (contra-) indications. For example, there are often no guidelines on translating theoretical criteria into practical and clinical cut-off values. In addition, guidelines found in literature are inconsistent in the timing of the evaluation of psychosocial aspects. Finally, Duerinckxs et al reported that the use of standardized interviews or valid psychosocial tests is rare (1).

Therefore the aim of this study is to define a more detailed description of the term "psychosocial" and to develop a consensus on the essential criteria underpinning a thorough psychosocial screening of living donors, starting from the results of the above mentioned systematic review. We used the methodology of Concept Mapping of Kane & Trochim (2) to define the concept "psychosocial" in the context of living kidney and liver donor screening. In this report we will explain the methodology "concept mapping" and report the preliminary results.

Methods

Concept mapping method

The concept mapping method enables us to create a visual representation of a complex topic, in which underlying concepts, the relative importance of these concepts and the interplay between different concepts is organized (3). This visual representation is the result of the combination of construct building processes (e.g. defining suitable constructs, sorting of concepts within related constructs) and different multivariate statistical analyses (e.g. multi-dimensional scaling, hierarchical clustering analyses).

The concept mapping process involves six major phases (Figure 1) [2]. For this project, we have completed the first five out of six phases. The sixth phase "Utilization of the Maps" falls beyond the scope of this report. Details about the first four phases are described in the methodology section, results of these first four phases are presented in the results section and the fifth phase is covered in the discussion section.

Phase 1: Preparation

The "Preparation phase" consists of the formulation of the research question and the selection of the experts. The participants were selected based on their affiliation with clinical or research experience in the field of transplantation of organs from living donors. All participants were members of the ELPAT organization and were invited to the ELPAT meeting in Berlin to participate in this study. Sorting and rating was performed using a web-application (http://www.conceptsystemsglobal.com/) with restricted registration. All participating members received a user name and a password. Drop-outs were defined as participations that were initially assigned, but did not complete any of the questionnaires, after repeated reminders. There is no lower threshold for the number of raters, however, no statistical improvement of sorting will be obtained beyond 30-35 participants [2]. A systematic review on 37 concept mapping projects showed an average number of 15 sorters and 14 raters [3].

Phase 2: Generation of statements

For the "Generation of statements" a systematic literature review was conducted in order to list all the criteria described in literature that might be important for screening of potential living donors. Details about the methodology of this review are described elsewhere (1). This

list was expanded by the authors and members of the psychological care workgroup. The aim of this stage is not to evaluate the added value of each criterion but to generate an exhaustive list of potential criteria upon which the following concept mapping stages are based.

Phase 3: Structuring statements

In this phase, the list of criteria was sorted by the extended group of participants into constructs of related concepts and rated according to relative importance, effectiveness and commonness. All ratings where performed using a Likert scale 1-7. The sorting exercises were performed according to the web-based instructions (Figure 4A). An example of a sorting result is shown in Figure 4B. Participants were asked to sort the list of statements into groups of related statements. The participants were allowed to create as many groups of constructs as deemed appropriate based on their personal judgment.

Phase 4: Representation of statements

All statistical analyses were performed using the software program 'The Concept Systems' (Concept Systems Inc., 2003), which is able to combine multidimensional scaling and cluster analysis.

Firstly, all sorting data were assembled at the level of the individual participant and converted to an "individual binary similarity matrix", containing a number of rows(x-axis) and columns (y-axis) that is equal to the number of sorted statements (Figure 2A and 2B). A cell in this matrix contains the number 1 if the statements on the y-axis are sorted into the same group as the corresponding criteria at the x-axis. If both criteria are sorted in different constructs this cell will contain the number 0. These individual matrices are summed, which results in a "combined group similarity matrix". This matrix also contains an equal number of rows and columns, which is again equal to the number of statements sorted. The value in a given cell now represents the number of participants that sorted these two statements into the same group, which is independent of the sorting of all other statements. The values in the "combined group similarity matrix" represent the degree of similarity between two criteria according to the participants.

Secondly, we performed a nonmetric multidimensional scaling (MDS)-procedure on the "combined within group similarity matrix", in order to map the similarities and dissimilarities among the data. This map plots all statements in a two dimensional plane. Statements that are frequently sorted into the same construct appear as dots in close proximity to each other. We selected the two dimensional approach to facilitate the interpretation and

visualization of the data (4). We also computed the final stress value, which is indicative for the validity of our MDS procedure (2). This value can vary between 0 (no discrepancy between MDS values and the "combined group similarity matrix) and 1 (the MDS distances between statements appear to be completely random).

Next, we performed a hierarchical cluster analysis, to identify non-overlapping clusters between the statements in the point-map. The X and Y coordinates of the statements in the point map are the input data for the hierarchical cluster analysis according to Ward's algorithm (5). The algorithm starts with the point map in which statements merge step by step in line with the nearest neighbor principle. A point is linked to the nearest neighbor point, resulting in a tree like structure depicting the hierarchical clustering of the criteria. This procedure can be stopped when the requested number of clusters has been formed. However, mathematical criteria to determine the optimal number of clusters are lacking (6), hence, determining the number of clusters is arbitrary and therefore requires a subjective procedure. The optimal number of clusters should be determined based on the desired level of specificity and the application of the concept map (2). The maintenance of differences and the merging of similarities should be carefully balanced.

Correlation analyses between the three rating categories were performed based on Pearson correlations. Based on these correlations we computed Go-Zones, to visualize which statements might be important for psychosocial screening of living kidney and liver donors. Go-zones graphically display which statements are above or below the mean across two separate rating criteria, within a specific cluster of statements. Go-Zones are depicted in four quadrants, the cut-offs off these quadrants are determined by the mean score of all statements at the rating scale plotted on the corresponding axis (Figure 3). Within the upper right green quadrant (number 2), statements which receive high ratings in both plotted rating scales are located. Statements which received low rating points in both plotted rating scales are located in the lower left purple quadrant (number 3). If a statement received a high rating using only one of the plotted rating scales, this statement is located within the orange, upper left (number 1), or yellow, lower right quadrant (number 4).

Results

In this section we describe the results of the application of concept mapping in line with the steps of the flow chart shown in Figure 1.

Phase 1: Preparation

Formulation of the research question

The aim of this study was to define the concept "psychosocial" in the context of living organ donor screening in Europe and to develop a consensus on essential elements that can be used to generate a valid and thorough psychosocial screening of living organ donors.

Expert selection

The core group of participants consisted of MK, SI, ND, FB, WW, EM and JB (N=7). The extended group of participants consisted of members of the psychological care working group of ELPAT who attended the meeting organized in Berlin, Germany, 4-6 November 2011 (see page 2, n = 12). Additional members from other workgroups were also invited to participate. Twenty experts were invited for the brainstorming phase, of which 16 participants actually participated (Table 1A). The majority of the participants were female (n=12), had a degree in psychology and were either Dutch, Belgian or English. The other professions that were mainly represented were physicians and transplant surgeons.

Phase 2: Generation of statements

Criteria generated from the systematic review of Duerinckx et al. (i=136) were initially used. This list was first reduced to (i =67) by removing duplicated criteria. The remaining criteria were used as the first draft list of potential screening criteria, and in the following weeks new criteria were added by the participants to a total of 83 criteria. Following this, the main aim shifted towards the reformulation of all listed criteria. The overlap in criteria was reduced again and presented to the core group. The list was supplemented, some criteria were reformulated and organized into themes according to expert opinions. Additionally, the extended group was requested to analyze the list and propose any missing potential criteria. A preliminary list consisting of 75 statements was further criticized by the core group regarding relevance, clarity, formulation (concise and specific), abstraction level and manageability for further steps in the concept mapping process (i<80). This list was screened for unclear statements and redundancy by the members of the psychological care

workgroup (Appendix 1). The final number of statements was 75. This list was used in the following phases by all the participants.

Phase 3: Structuring statements

The statements were first sorted by participants into groups of related concepts and secondly rated according to their relative importance, effectiveness and commonness. Regarding statistical power, a minimum number of 10-15 participants was required for the interim analysis before the ELPAT meeting in Berlin. At day one of the conference the results of the interim analysis of 12 participants were presented. Additional raters and sorters were recruited from ELPAT members attending the meeting. Sorting and rating continued online for a further two months.

All participants were required to be ELPAT members and consequently be (partly) affiliated to transplant centers. In total twenty-nine ELPAT members were recruited, of which twenty-six actually finished the sorting phase (drop-out rate of 10.3%) and seventeen participants completed the rating phase (drop-out rate of 41%), which is well above the 10-15 participants needed in order to obtain reliable data (Table 1A). The mean age of the participants was 37 years (24-64 years) (Table 1B). An equal number of males and females were enrolled (Table 1C). The most predominant professional background of the participants was psychology (N=10), transplant surgery (N=5) and medicine (N=5) (Table 1D). The nationality of the participants was predominantly Dutch (N=10), or Belgian (N=4) (Table 1E). Ninety-three percent of the participants work or are at least partly affiliated to a center where living donor transplant takes place (Table 1F).

Each statement was rated on 3 aspects: 1) the importance of a statement in differentiating between high and low risk potential donors (R1), 2) the effectiveness of the statement to discriminate between high and low risk potential donors (R2), and 3) the commonness of the statement used to discriminate between high and low risk potential donors in clinical practice (R3). In this case, risk for donors was defined as the risk for a potential deterioration of mental health after the donation. The rating of the participants was regarded as valid, if that particular participant had completed the rating for at least half of the statements. All ratings were performed using a Likert scale (1=unimportant; 7=very important). In total 17 participants fully completed the rating categories R1 (importance), 18 participants completed the rating of R2 (effectiveness) and 19 participants completed the R3

(commonness) category (Figure 1A). An example of the rating application is depicted in Figure 5.

Phase 4: Representation of statements

We performed all statistical analyses using Concept Systems (2003). All statements were represented in a point-map. Using hierarchical cluster analysis, we identified non-overlapping clusters between the statements in the point-map. Since the total number of clusters is subjective, the extended group agreed that a total of 6 clusters would be the optimal number, discussed during the consensus meeting. On day 1 of the meeting a cluster map based on the data of the first 12 participants was presented (data not shown). Next we collected more data during the first and second day of the meeting and during the two subsequent months further online recruitment was completed. There was no change in the number of clusters. Based on this data-set the following six clusters were identified and labeled: 1) Motivation and decision making, 2) Personal resources, 3) Psychopathology, 4) Social resources, 5) Ethical and legal factors and 6) Information and risk processing (Figure 6A). The name of each cluster was chosen to optimally represent the statements and was agreed upon during the consensus meeting. Limiting the number of clusters to a total of 5 resulted into the merging of cluster 4 and 5 (Figure 6B). Increasing the number of clusters to seven resulted in the fragmentation of cluster 6 into the clusters “medical” and “undefined risk” (Figure 6C). For validity purposes, the total number of cluster was subsequently further increased to eight and nine (Figure 6D and Figure 6E) however these results did not surpass the 6 cluster solution.

Next, the bridging value for each cluster was analyzed. These values represent the homogeneity within a cluster between participants. If certain criteria are sorted into the same group by all participants, the resulting bridging value will be low (approximation to 0). This is represented by a single layer of the cluster in Figure 6A-D. A bridging value near to 0 is indicative of high homogeneity within the cluster and a strong correlation between the statements within the cluster. High bridging values (approximation of 1), are indicative of a cluster with low homogeneity (indicated by multiple layers on the cluster map in Figure 6A-E). In this case statements within a certain cluster are also often sorted into a cluster together with statements from other clusters (7). Tables showing the cluster bridging values are supplemented to each point map (Figure 6A-E). Especially clusters 5 and 6 in the point map with a total number of 6 clusters have a high bridging value, indicating that these clusters contain statements that are associated with statements from other clusters (Figure 6A). The

lowest bridging values were observed for cluster 3 (Psychopathology), indicating that the statements within this cluster are ubiquitously sorted within this cluster (Figure 6A). This is also illustrated by how close the individual points are to another in the cluster, indicative for the conceptual proximity.

Furthermore, we calculated the correlation between the three rating categories (importance, effectiveness, and commonness), using Pearson correlations. The strongest correlation was found between the mean importance score and the mean effectiveness score per statement (r = 0,96; Figure 7A). We also found a strong correlation between importance and commonness (r = 0,88) and between effectiveness and commonness (r = 0,88; Figure 7B and Figure 7C). These data indicate a good overlap between the three different rating categories. Figure 8 shows a specification of the correlation between the rating scores at the importance and commonness scale per cluster. Clusters that are regarded as important are predominantly also commonly used in clinical practice (r = 0,77). However, cluster 2: personal resources, is regarded as the most important cluster for screening, while it is less commonly used in practice compared to the less important clusters 1 and 3. Cluster 5: ethical and legal factors, is regarded as more important, compared to the commonness of this factor in current clinical practice.

Based on the average scores per statement according to two different rating categories, ‘Go-zones’ were computed per cluster (Figure 9 A-F). The cut-off lines indicate the average score of all statements, using the rating category on the corresponding axis. Based on these ‘go-zones’ statements that are rated as important, but are not commonly used in the screening of living organ donors were identified: within cluster 1: statement 18 (Intensity of the donor's motivation), cluster 2: statements 35 (Ability of potential donor (and family) to cope effectively with stresses associated with transplantation (before and after donation)) and 55 (Ability to cope with adverse outcomes for recipients), cluster 3: statement 8 (Personality characteristics and traits), and cluster 4: statement 53 (Ability to deal with the economic implications that may arise throughout the donation process). We also identified statements that were considered as less important, but were commonly used in screening procedures: cluster 2: statement 41 (Current stressors (e.g. relationships, home, work, financial)), cluster 3: statements 36 (Current use of psychotherapeutic interventions (counseling, medication)) and 68 (Substance abuse and/or history of), cluster 4: statements 56 (Availability of disability & health insurance) and 75 (Potential implications for donor's current job and their future insurability), cluster 5: statement 7 (Visa status (legal presence in the country)).

Phase 5: interpretation of maps

The results of this phase are presented in the discussion section.

Discussion

To our knowledge, this study was the first to define the concept ‘psychosocial’ in the context of living organ donation and to develop a consensus on essential screening elements by using a concept mapping methodology. This study was initiated as a response to the lack of uniform guidelines for psychosocial screening, partly caused by the large discrepancy in the interpretation of the term ‘psychosocial’ across and within European countries. A uniform description of the term ‘psychosocial’ can be used as a fundament to generate a valid and thorough psychosocial screening of living organ donors. In this technical report we present the raw data of our analysis and the first inferences of this data. Here, we described the importance, effectiveness and commonness of “psychosocial” screening criteria for living organ donors. We listed important “psychosocial” screening criteria that can be integrated in future screening guidelines. Here, we discuss the methodology of our study, while the discussion of the results and the implications of our findings falls beyond the scope of this report.

Phase 1: Preparation

In order to generate a list of screening criteria for living donor selection, a group of experts in the organ transplantation field was recruited from the ELPAT society. The ratio of males and females within the group of selected experts was approximately equal, and a large range of age was covered. Almost half of the total number of participants is working as a psychologist, while other professions were less represented. It might have been of additional value to select extra participants with other professional backgrounds such as transplant nurses or nephrologists to try to capture the term ‘psychosocial’ from a greater variety of perspectives. The majority of participants are working in The Netherlands which improved the practical feasibility of the study, but which is a potential risk for selection and rating bias in the statements. A more geographically diverse group of countries that carry out living donor screening would be preferable.

Phase 2: Generation of statements

In order to generate a list of psychosocial screening criteria a systematic literature review was conducted and reported elsewhere (1). This review provided a comprehensive overview of screening criteria that have been described in literature over the last decades. Because most of the screening criteria for living organ donors encountered in literature are focused on the medical evaluation, the list of psychosocial criteria was extended according to the opinion of the core group. Although this procedure might be sensitive to selection bias (most of the authors have a Dutch nationality, and practice as a psychologist), it was logistically the best and most effective approach possible within the current setting of ELPAT. However, most statements were derived from the literature review, thereby reducing this selection bias. Hence, publication bias is still an issue, which has to be taken into account. Moreover, some statements might be missed, due to strict inclusion criteria used for the selection of suitable articles.

Phase 3: Structuring statements

A review on three concept map based studies showed that reliable sorting results could be obtained if the sorting phase is completed by a minimum of 15 and a maximum of 30-35 participants. In our first pilot analysis the sorting phase was performed by some members of the extended group (N=12). The results of this sorting phase were presented at the ELPAT meeting. Since the lower threshold of 15 participants for the sorting session was not met before the meeting, more participants were invited during the following two months. The number of participants was increased to a total number of 26 (Table 1A). A further increase in the number of participants is not likely to have had a significant effect on the statistical power of the current analysis results (2). Since the West-European nationalities were highly represented among the selected participants during the sorting phase, we invited additional East- and South-European ELPAT members with affiliation to organ transplantation, to increase the generalizability of our results to East- and South-European countries. However, since far from all nationalities were represented in the sorting phase, there might be a lower extendibility of our results to non-represented countries.

The sorted statements were initially rated based on their commonness and effectiveness. However, according to the extended group of participants the term ‘effectiveness’ was poorly defined and ambiguous. Therefore, a third rating category was added namely, ‘importance’. For further analysis we specifically focused on the rating scales “importance” and “commonness”. There was a slight difference in the total number of participants that finished the sorting and rating phase, since not all participants completed the

rating phase. Although drop-outs might have introduced some selection bias, the number of drop-outs was relatively low with respect to the number of participants who completed the sorting phase. All rating scales were completed by approximately the same number of participants, which enhanced the statistical significance of our analysis.

Phase 4: Representation of statements

Firstly, a cluster analysis was conducted, to generate clusters of related statements. Upon data analysis, the effect of the additional participants during the sorting phase was clearly visible in the point and cluster maps, indicating the amount of participants is influencing the results of the sorting process. The most apparent difference between the sorting phases with 12 and 26 participants, is the emerging of a distinct cluster with “medical factors” in the cluster map with 26 participants (Figure 5A), which was not present in the cluster map with 12 participants (data not shown). Although the listed statements were mainly focusing on psychosocial aspects, apparently some of these criteria are still considered as medical factors. It is likely that lower proportion of psychologist in the additional 14paticipants compared to the initial 12 participants may account for the appearance of this “medical” cluster. Another difference in the demographics between the initial set of participants and the final number of participants was the addition of participants with Southern-European and Eastern-European nationalities. Alternatively, since most of the participants in the initial group (N=12) work and live in The Netherlands or Belgium the differences in the final cluster map (N=26) relative to the former could be also partially explained by the increased heterogeneity of the nationalities of the participants.

At the ELPAT meeting the cluster maps were extensively discussed. The most important point of discussion was the total number of clusters. As mentioned above general guidelines for this process are lacking. The number of clusters is arbitrary and depending on the level of specificity and the final aims for the concept map (2). During the workgroup consensus meeting of ELPAT 2011 in Berlin, the members of the workgroup Psychological Care for Living Donors and Recipients agreed that a total of 8 clusters was the optimal amount of clusters, Limiting the amount of clusters to 7 or less clusters resulted into the integration of cluster 6 (Legal) and 7 (Medical factors) (Figure 5D). However, according to the working group sufficient differences between these two clusters are present to justify separation.

However, this consensus was based on the cluster maps derived from only 12 participants that completed the sorting phase. Since we extended the number of participants

towards 26, the cluster maps slightly changed. Our general approach of finding the most optimal cluster this time was based on a combination of 1) respecting the clustering 'criteria' as set during the consensus meeting in and 2) our aim to stay close to the data-driven clusters. We started with encountering that increasing the amount of clusters to nine did not further improve the accuracy of the sorting process, since the bridging values of the additional clusters were high, indicating low coherence of the statements within the additional clusters. In contrast, reducing the amount of clusters from eight to seven resulted in the merging of the clusters 4 (Financial) and 5 (Social), which can be considered as one cluster (social resources); without increasing the bridging value of either individual clusters. The discussion with the expert group in Berlin already had defined this cluster (Social resources) based on the 12 participants. Within the cluster map with a total number of seven clusters, cluster 7 (undefined risk piles) consists out of only four statements with very low coherence. Reducing the number of clusters to six led to the merging of cluster 6 (Medical) and 7 without reducing the quality of the clusters. Further reducing the number of clusters to five resulted in combining cluster 4 (Social resources) and 5 (Ethical and Legal), resulting in an increase in bridging value, indicating a lower coherence of the statements within the combined cluster. Therefore, the cluster map with a total number of 6 clusters was considered as the optimal cluster map. This result was presented to the extended group in an earlier draft of this report and consensus was thus achieved.

The number of layers per cluster corresponds to the mean bridging value of that cluster. Multiple layers indicate that the statements within a certain cluster are often sorted as statements from other clusters. The relatively high bridging values of the clusters we identified are indicative for a high variation between the sorters. To limit the variation, the number of sorting categories could have been fixed, or a list of possible categories could have been provided during the sorting procedure. However, the result would have been a more supervised sorting process, which is very sensitive for a priori selection bias. By introducing fewer restrictions into the sorting process the statements can be sorted in an un-supervised way, improving the generalizability of the results. The lowest bridging value and the highest internal association have been found in the cluster of psychopathology. Apparently, there is a priori more consensus on this construct than on others.

Phase 5: Interpretation of statements

Since participants were allowed to create any desirable number of constructs during the sorting phase, the number of sorting constructs is highly variable. In case of a high number of clusters (>8) the statements cluster perfectly. When the number of allowed clusters is lower than the maximum number of clusters possible, some criteria will be categorized in a 'non-optimal' cluster, resulting in apparent mismatches. These specific mismatches also increase the bridging values of the corresponding clusters, since these statements also match with statements from other clusters. There are several ways to cope with this limitation, which were extensively discussed during the ELPAT meeting 2011 in Berlin. One option would have been to fix the number of total constructs which could have been used by the participants for the sorting process. In this way it is possible to match the number of created constructs to the number of clusters that will be used during the data analysis. A second option might be to place the mismatched statements manually into other, more suitable clusters. Although spanning analysis could facilitate this process, the data of the statistical analysis are subjectively manipulated with this method. Furthermore, the establishment of the boundaries of the resorting process is arbitrary. For example: what is considered as a mismatched statement and what are the thresholds for the subsequent spanning analysis? Therefore, we did not perform such resorting, to stay as close as possible to the data-driven solutions. The name that was most commonly used to describe a cluster by participants was used as the initial cluster name. However, the names of some clusters did not exactly cover the whole content of the cluster. In these cases we changed the name of the cluster to a more suitable name during the consensus meeting.

Cluster 1 Motivation and decision making: Initially the name 'decision making' was addressed to cluster 1. However, this cluster contains mainly three sub-constructs: motivation, decision making and donor-recipient relations.

Cluster 2 Personal resources: The name of cluster two was changed from 'personality' into *Personal resources,* because this name covers the statements within this cluster more accurately.

Cluster 3 Psychopathology: As previously mentioned this cluster is very homogenous, with low bridging values. This indicates that all statements within this cluster are highly associated with other statements within cluster 3, but not with statements from any other cluster. This cluster is regarded as a perfect cluster. Therefore, there was no need to change the name.

Cluster 4 Social resources: Initially the name 'social support' was assigned to cluster 4. However, a more suitable name was assigned to this cluster upon discussion with the work

group, providing a more detailed description of this cluster.

Cluster 5 Ethical and legal factors: Since also some ethical statements are included into this cluster, the term ethical was added to the term legal, resulting in the new name of the cluster: *Ethical and legal factors*.

Cluster 6 Information and risk processing: Initially the name 'risk factors' was assigned to cluster 6. A new name, providing a more detailed description of this cluster, was chosen during the consensus meeting: *Information and risk processing*.

Finally, we analyzed the ratings of the different statements based on the different rating categories, using Pearson correlations. We showed that all three rating categories (importance, commonness and effectiveness) were highly correlated. The majority of statements were considered to be both important and common. More interesting are the statements that received a high score on one of the rating categories, and a low score in the other (e.g. criteria which are considered to be important and uncommon at the same time and vice versa). These particular criteria can be deduced from the bivariate 'go-zone' plots. The following statements are considered to be **important and are not commonly used** in screening practice:

- Statement 18 (Intensity of the donor's motivation) within cluster 1.
- Statements 35 (Ability of potential donor (and family) to cope effectively with stresses associated with transplantation (before and after donation)) and 55 (Ability to cope with adverse outcomes for recipients) within cluster 2.
- Statement 8 (Ability to make their own decisions / vulnerability for the reactions of others) within cluster 3.
- Statement 53 (Ability to deal with the economic implications that may arise throughout the donation process) within cluster 4.

However, the following statements were rated as being **used commonly and regarded as relatively less important** in the screening process of potential donors:

- Statement 41 (Current stressors (e.g. relationships, home, work, financial)) within cluster 2.
- Statements 36 (Current use of psychotherapeutic interventions (counseling, medication)) and 68 (Substance abuse and/or history of) within cluster 3.
- Statements 56 (Availability of disability & health insurance) and 75 (Potential implications for donor's current job and their future insurability) within cluster 4.

Considering the nature of this technical report (making fast communication of raw data possible), we will not go into further interpretation and discussion of the aforementioned results. This as well as the practical implication of the results with respect to commonness and

importance of the statements will be further discussed in further publications based on this study.

In conclusion ‘go-zone’ plots may function as important tools for the selection of relevant screening criteria for physicians and clinical psychologists with regard to the screening of potential donors. Future research in the clinical practice, to underpin this theoretical framework is needed to further explore which psychosocial criteria that can be measured prior to donation can discriminate between high and low risk living kidney and liver donors.

Acknowledgement

We would like to thank specifically members of other ELPAT workgroups who also participated in the rating and/or sorting:

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S. Sharma, PhD

A.N. Warrens, PhD

W.C Zuidema

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Appendix 1
Sorting and rating statements

1	Pressure to donate (Some kind of coercion)
2	Financial benefit
3	Ability to make their own decisions / vulnerability for the reactions of others
4	Country of residence (is this different to where the transplant will take place)
5	Ability to obtain health checks after donation (e.g. if the donor lives in another country)
6	Objection to the donation in the social network
7	Visa status (legal presence in the country)
8	Personality characteristics and traits
9	Illness and cure theory of the donor
10	Social support
11	Conflicts or dependencies in the donor-recipient relationship
12	Ability to make conscious decisions
13	Ability to process information on risks/surgery
14	Phobias about hospitals, blood or needles
15	Cognitive disturbance
16	Degree of the emotional closeness of the donor to the recipient
17	Other high-risk motives-extreme religiosity, Role of "saving people", inability to say "no"
18	Intensity of the donor's motivation
19	Unrealistic expectations (about the process, reaction of friends and family etc.)
20	Memory functioning (short-term, remote, and long-term)
21	Personality disorder (e.g. paranoid, schizophrenia, borderline, narcissistic, etc.) and/or history of
22	Coping strategies/mechanisms
23	Body image disorder
24	Mood disorders and/or history of
25	Comprehension/knowledge/awareness/understanding of the recipient process
26	Recent or significant losses
27	Sexual Promiscuity
28	Values, (religious) beliefs, sense of charity and community
29	Psychopathology in general (not specified which disorders and not clear if they mean current or in the past)
30	Health concern during and after donation
31	Potential occupational risks associated with the donation
32	Subordinate relationship (e.g. employer and employee)
33	Orientation issues, thought processing, thought disturbances (hallucinations, delusional thinking, or illusions)
34	Decision-making process (how the decision to donate was made)
35	Ability of potential donor (and family) to cope effectively with stresses associated with transplantation (before and after donation)
36	Current use of psychotherapeutic interventions (counseling, medication)
37	Guilt
38	Anxiety disorder
39	Tattoos
40	Low self-esteem
41	Current stressors (e.g. relationships, home, work, financial)
42	Vulnerability to coercion/pressure
43	Potential implications for donor's current job and their future employability
44	Able to withstand time away from work or established role, including unplanned extended

	recovery time
45	Employment status
46	Understanding of the right to reconsider
47	Altruism
48	Competence to give informed consent for donation
49	Feelings, perspectives or reactions of family members or another significant about donation and the donation decision of the donor
50	Expectations of effect on relation with recipient
51	Health expectation for the recipients
52	Living situation
53	Ability to deal with the economic implications that may arise throughout the donation process
54	Psychiatric disorders and/or history of
55	Ability to cope with adverse outcomes for recipients
56	Availability of disability & health insurance
57	Embedment of the donation into a meaningful context
58	Body piercing
59	Victim of physical, psychological or sexual abuse
60	Legal offense history and citizenship
61	History of suicidality
62	Homosexual behavior
63	Level of autonomy
64	Educational level
65	Health issues of other family members
66	History of family mental health issues
67	Motivation/reasons for donation
68	Substance abuse and/or history of
69	Financial status
70	Past use of therapeutic interventions (counseling, medication)
71	Prostitution
72	Sense of Coherence/belonging
73	Ambivalence
74	Understanding, acceptance and respect for the specific donor protocol
75	Potential implications for donor's current job and their future insurability

Appendix 2
Participants Questions Report

Participant Question 1
Name: Age
Question Text: What is your age?
Type: Continuous
Minimum: 18
Maximum: 100
Precision: 0

Participant Question 2
Name: Gender
Question Text: What is your gender?
Type: Categorical
Choice 1: Female
Choice 2: Male

Participant Question 3
Name: Professional background
Question Text: What is your professional background?
Type: Categorical
Choice 1: Psychologist
Choice 2: Physician
Choice 3: Medical ethicist
Choice 4: Lawyer
Choice 5: Philosopher
Choice 6: Anthropologist
Choice 7: Theologist
Choice 8: Sociologist
Choice 9: Transplant nurse/coordinator
Choice 10: Other
Choice 11: Transplant Surgeon

Participant Question 4
Name: Currently working in…
Question Text: In which country are you currently working?
Type: Categorical
Choice 1: Austria
Choice 2: Belgium
Choice 3: Bulgaria
Choice 4: Cyprus
Choice 5: Czech Republic
Choice 6: Denmark
Choice 7: Estonia
Choice 8: Finland
Choice 9: France
Choice 10: Germany
Choice 11: Greece
Choice 12: Hungary

Choice 13:	Ireland
Choice 14:	Italy
Choice 15:	Latvia
Choice 16:	Lithuania
Choice 17:	Luxembourg
Choice 18:	Malta
Choice 19:	Netherlands
Choice 20:	Poland
Choice 21:	Portugal
Choice 22:	Romania
Choice 23:	Slovakia
Choice 24:	Slovenia
Choice 25:	Spain
Choice 26:	Sweden
Choice 27:	United Kingdom
Choice 28:	Croatia
Choice 29:	Former Yugoslav Republic of Macedonia
Choice 30:	Iceland
Choice 31:	Montenegro
Choice 32:	Turkey
Choice 33:	Albania
Choice 34:	Andorra
Choice 35:	Armenia
Choice 36:	Azerbaijan
Choice 37:	Belarus
Choice 38:	Bosnia and Herzegovina
Choice 39:	Georgia
Choice 40:	Liechtenstein
Choice 41:	Moldova
Choice 42:	Monaco
Choice 43:	Norway
Choice 44:	Russia
Choice 45:	San Marino
Choice 46:	Serbia
Choice 47:	Switzerland
Choice 48:	Ukraine
Choice 49:	Vatican City State

Participant Question 5

Name:	Mainly working the area of...
Question Text:	Do you work or are affiliated to a center where they work with living organ donors?
Type:	Categorical
Choice 1:	Yes
Choice 2:	Partly
Choice 3:	No

Figure 1 ***Representation of the concept mapping process.***

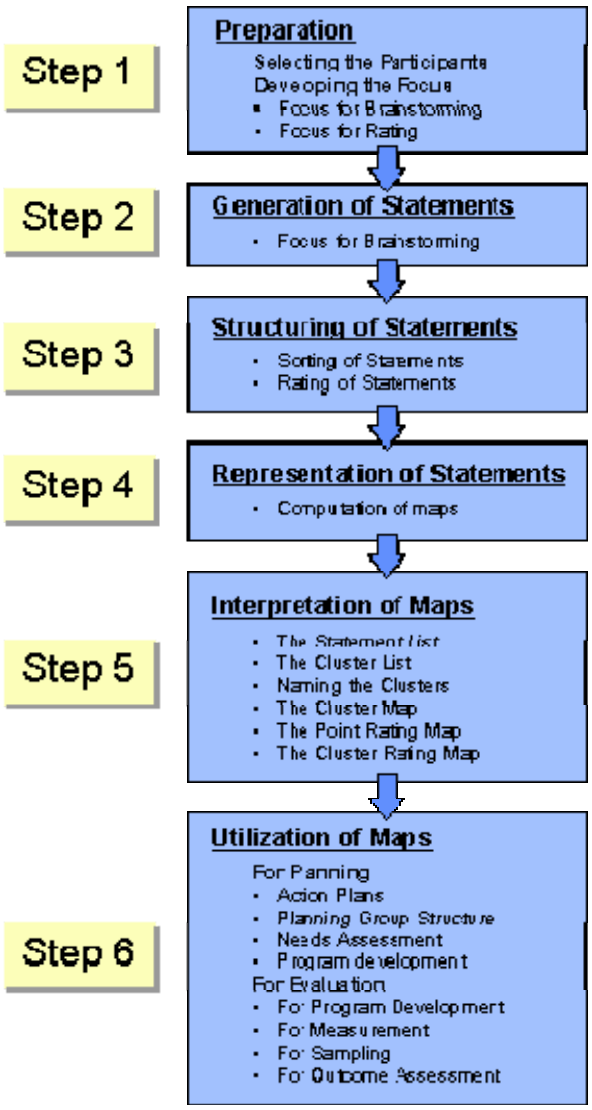
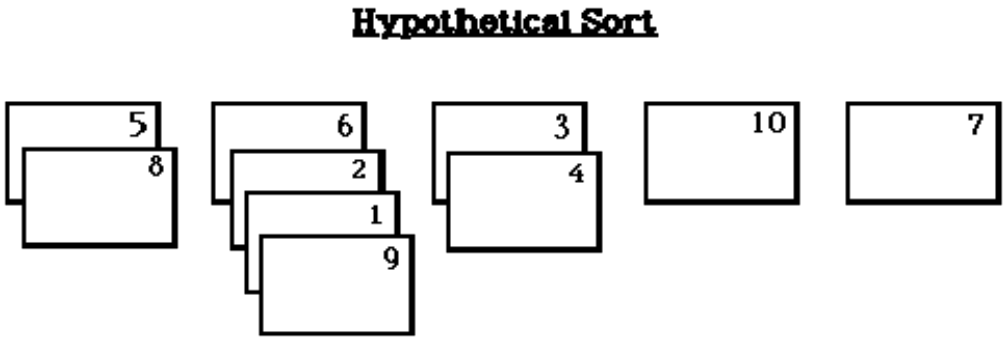


Figure 2

A) Hypothetical overview of the sorting results. In this example, criteria 5 and 8 were sorted in the same group (2).

B) Example of an individual binary similarity matrix (2). Rows and columns represent the listed criteria. Each cell of the matrix compares the groups in which the corresponding criteria on the y-axis and x-axis are sorted. When both criteria are sorted into the same group the cell will contain the number 1 and when both criteria are sorted into different groups, the cell will contain the number 0.

A



B

Binary Square Symmetric Similarity Matrix

	1	2	3	4	5	6	7	8	9	10
1	1	1	0	0	0	1	0	0	1	0
2	1	1	0	0	0	1	0	0	1	0
3	0	0	1	1	0	0	0	0	0	0
4	0	0	1	1	0	0	0	0	0	0
5	0	0	0	0	1	0	0	1	0	0
6	1	1	0	0	0	1	0	0	1	0
7	0	0	0	0	0	0	1	0	0	0
8	0	0	0	0	1	0	0	1	0	0
9	1	1	0	0	0	1	0	0	1	0
10	0	0	0	0	0	0	0	0	0	1

Figures are derived from Trochim et al.

Figure 3

'Go-zones' are depicted in four quadrants, the cut-offs off these quadrants are determined by the mean score of all statements at the rating scale plotted on the corresponding axis. Within the upper right green quadrant (number 2), statements which receive high ratings in both plotted rating scales are located. Statements which received low rating points in both plotted rating scales are located in the lower left purple quadrant (number 3). If a statement received a high rating using only one of the plotted rating scales, this statement is located within the orange, upper left (number 1), or yellow, lower right quadrant (number 4).

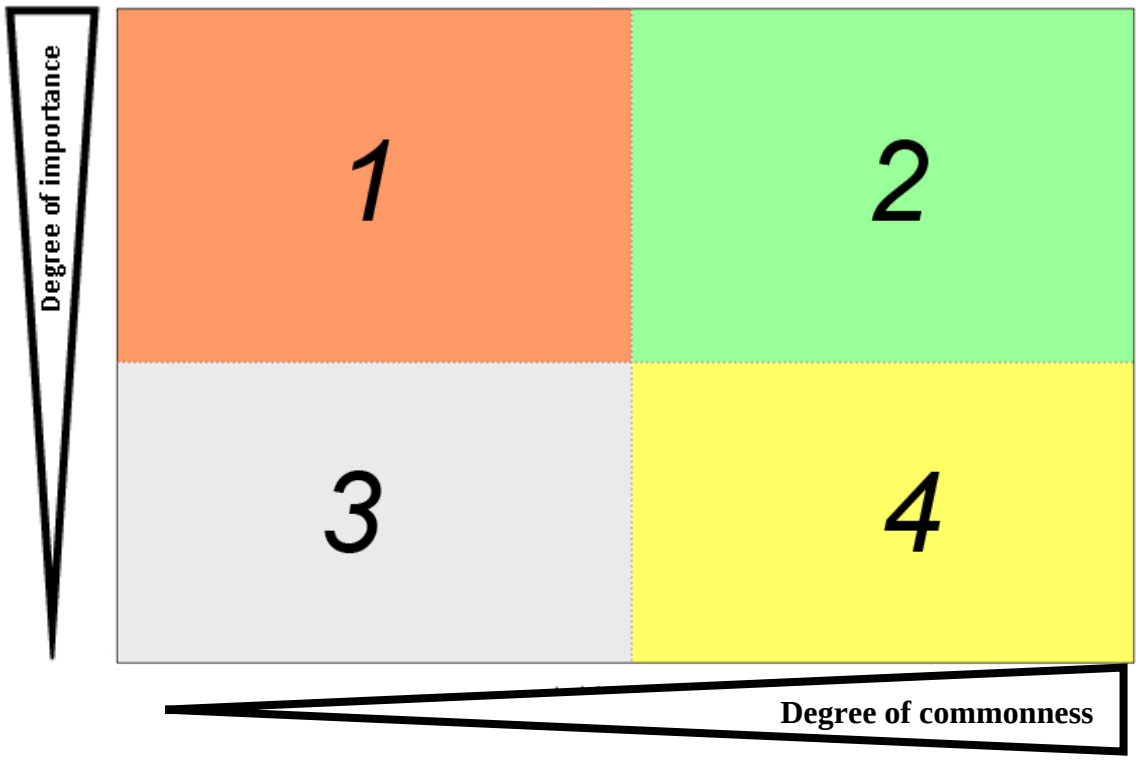


Table 1

A) Overview of the participating experts in each phase of the concept mapping process. B: brainstorm phase; S:sorting phase; R1:rating based on importance of criteria; R2 rating based on effectiveness of criteria; R3: rating based on commonness of criteria in literature. Overview of the age **(B)**, gender **(C)**, professional background **(D),** working countries **(E),** and their affiliation with living organ donations **(F)** of the selected participants in the sorting phase.

A

Project Totals *(including anonymous participants)*					
B	S	R1	R2	R3	
20	29	29	29	29	Assigned
16	28	20	23	23	Started
0	26	17	17	19	Finished
0	26	17	18	19	Checked

Code	Assignment
B	Brainstorming
S	Sorting
R1	Important
R2	Effective
R3	Common

B

Participant Question	Option or Statistic		Frequency	%
Age	Minimum:	24		
	Maximum:	64		
	Count:	28		
	Low:	24		
	High:	58		
	Median:	39		
	Mode:	49		
	Average:	39.71		
	Std. Dev.:	10.73		
	did not respond:	1		

C

Gender	Female	14	48.28%
	Male	14	48.28%
	did not respond	1	3.45%
		29	**100.00%**

D

Professional background	Psychologist	10	34.48%
	Physician	5	17.24%
	Lawyer	2	6.90%
	Philosopher	1	3.45%
	Sociologist	1	3.45%
	Transplant nurse/ coordinator	4	13.79%
	Transplant Surgeon	5	17.24%
	did not respond	1	3.45%
		29	**100%**

E

Currently working in	Belgium	4	13.79%
	Czech Republic	1	3.45%
	Germany	1	3.45%
	Italy	1	3.45%
	Netherlands	10	34.48%
	Romania	2	6.90%
	Spain	1	3.45%
	Sweden	1	3.45%
	United Kingdom	4	13.79%
	Former Yugoslav Republic of Macedonia	1	3.45%
	Moldova	1	3.45%
	Saudi Arabia	1	3.45%
	did not respond	1	3.45%
		29	**100.00%**

F

Participant Question	Yes	20	68.97%
Mainly working the area	Partly	6	20.69%
	No	2	6.90%
	did not respond	1	3.45%
		29	**100.00%**

Figure 4

(A) Instruction panel for the participants to sort all listed criteria into groups of related criteria/concepts. Each participant was allowed to create the desirable amount of groups.

(B) Example of a sorting results of a random participant.

A

INSTRUCTIONS: In this activity, you will categorize the statements, according to your view of their meaning or theme. To do this, you will sort each statement into categories in a way that makes sense to you.

1. First, read through the statements in the Unsorted Statements column below.
2. Next, sort each statement into a category you create. Group the statements for how similar in meaning or theme they are to one another. Give each category a name that describes its theme or contents.

Do NOT create categories according to priority, or value, such as 'Important', or 'Hard To Do.'

Do NOT create categories such as 'Miscellaneous' or "Other" that group together dissimilar statements. Put a statement alone in its own category if it is unrelated to all the other statements. Make sure every statement is put somewhere. Do not leave any statements in the Unsorted Statements column.

People vary in how many categories they create. Usually 5 to 20 categories works well to organize this number of statements.

B

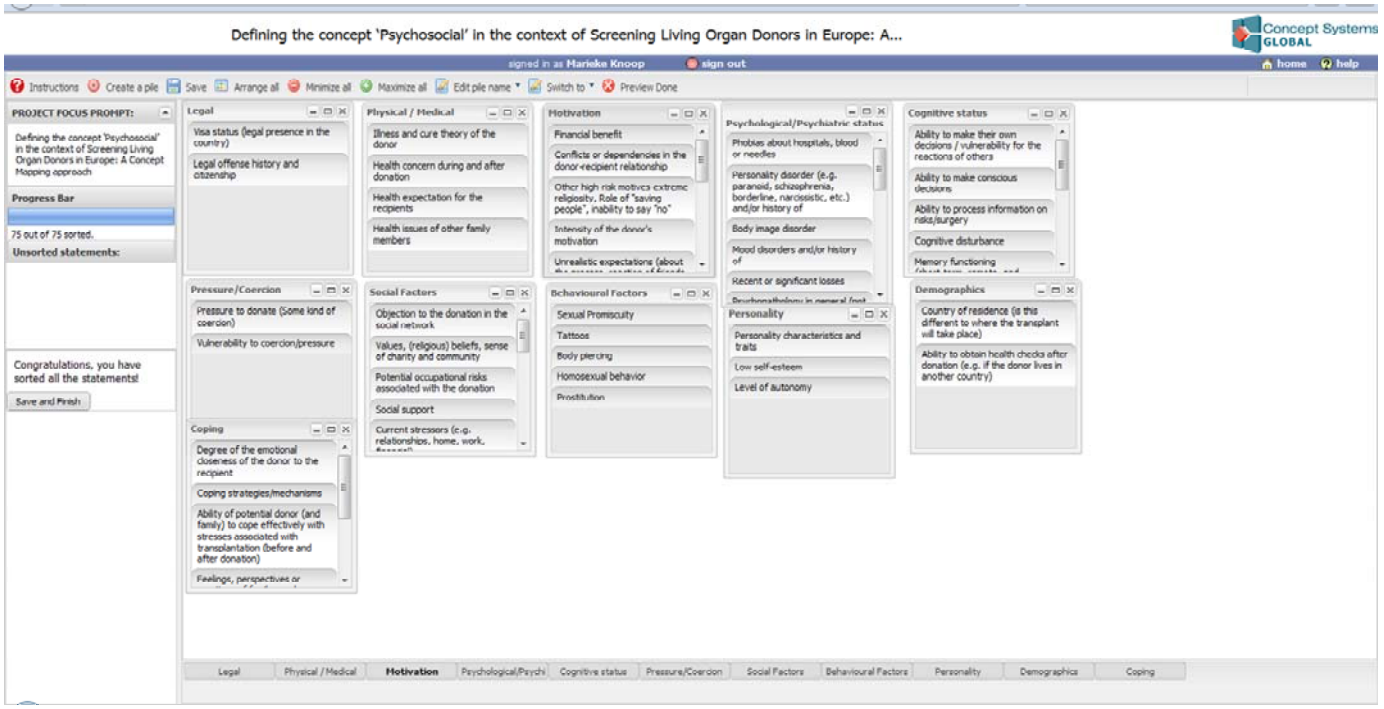


Figure 5

Example of the internet application of the rating phase. All ratings were performed at a seven point Likert scale (1=unimportant; 7=very important).

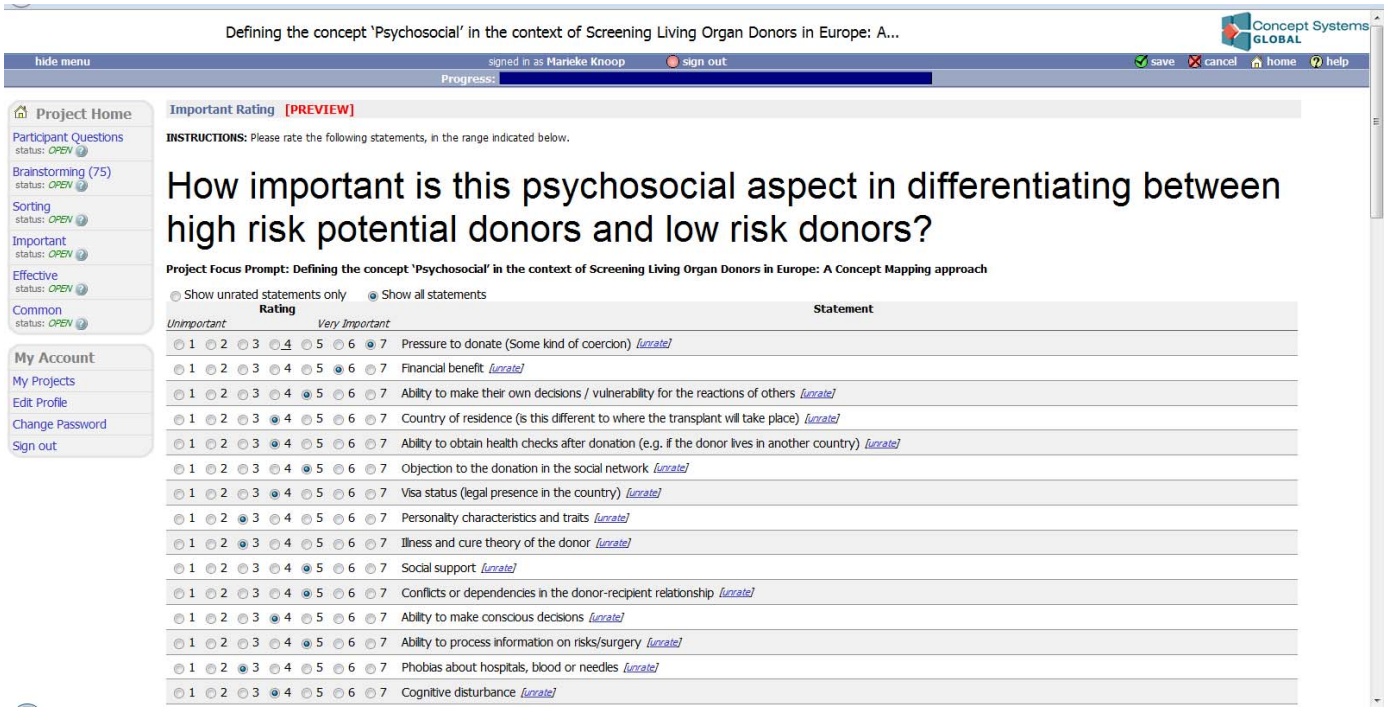
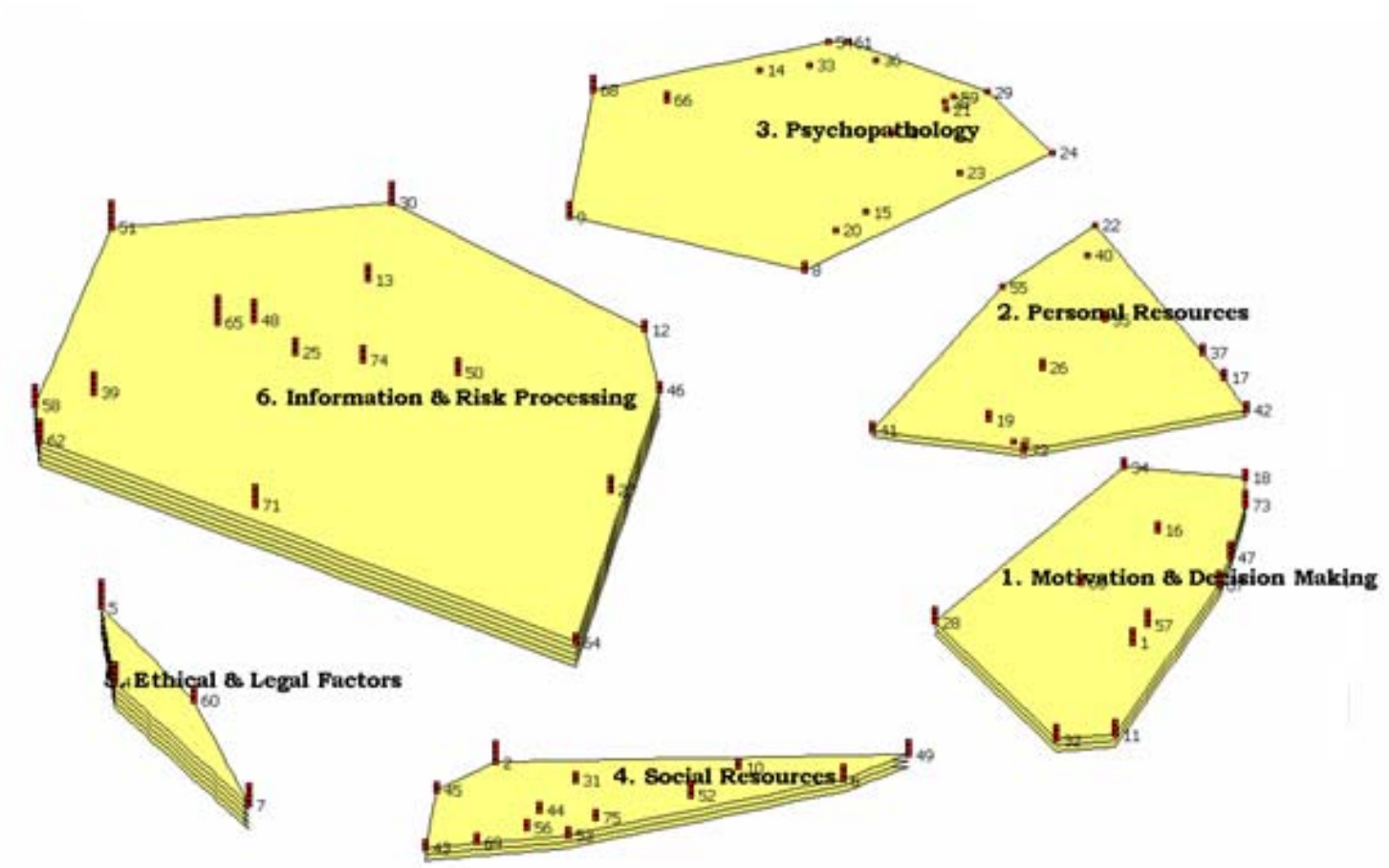


Figure 6

(A) Point map representation of the pooled sorting results of authors and additional participants, limiting the amount of clusters to six **(A)** five **(B)**, seven **(C)**, eight **(D)**, or nine **(E)**. Bridging values are listed in the tables below the figure. Each number of layers is corresponding with a certain range of bridging values. The more layers are drawn, the higher the bridging value of the corresponding clusters.

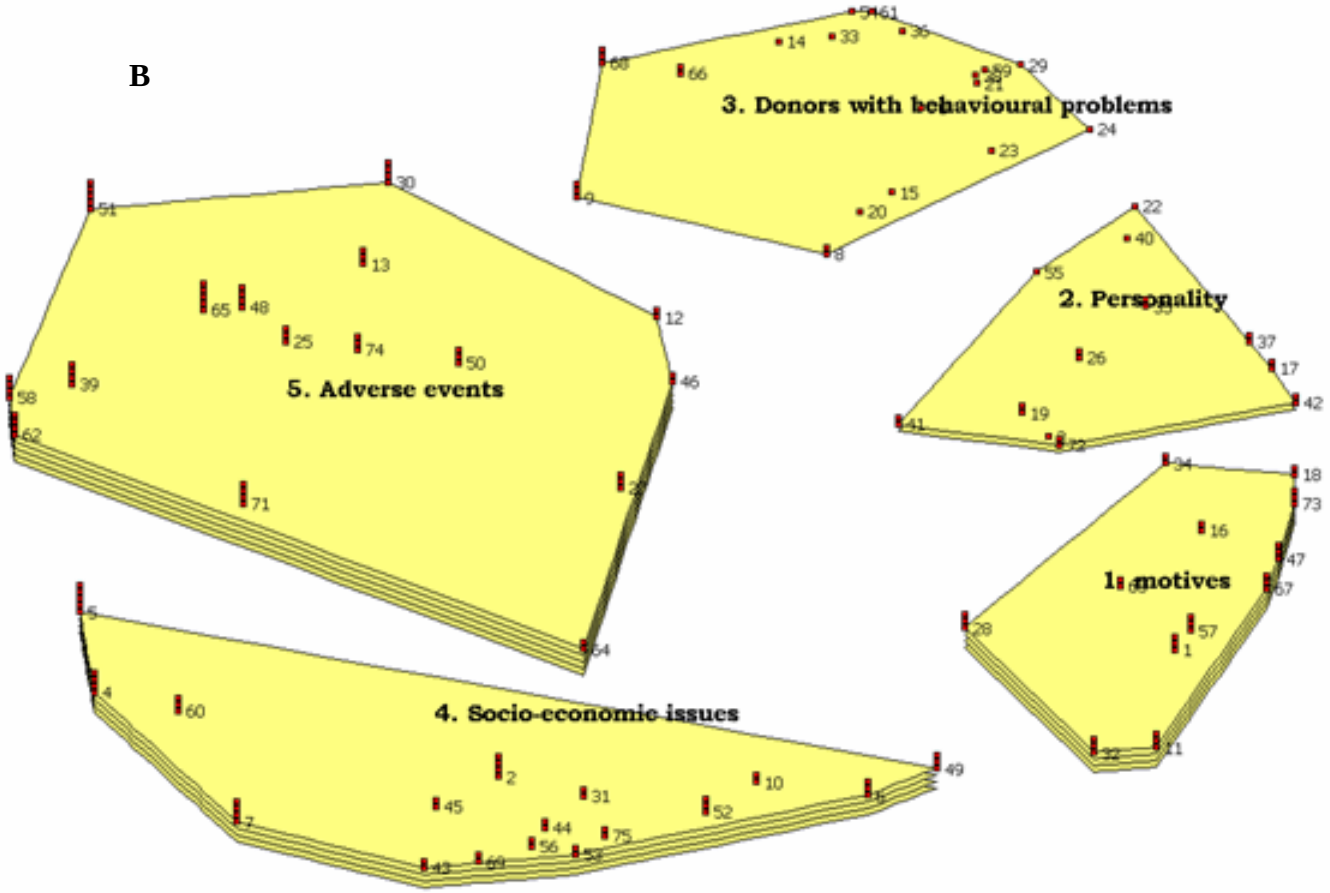
A



Cluster legend

Layer	Bridging value
1	0,13 to 0,24
2	0,24 to 0,35
3	0,35 to 0,46
4	0,46 to 0,56
5	0,56 to 0,67

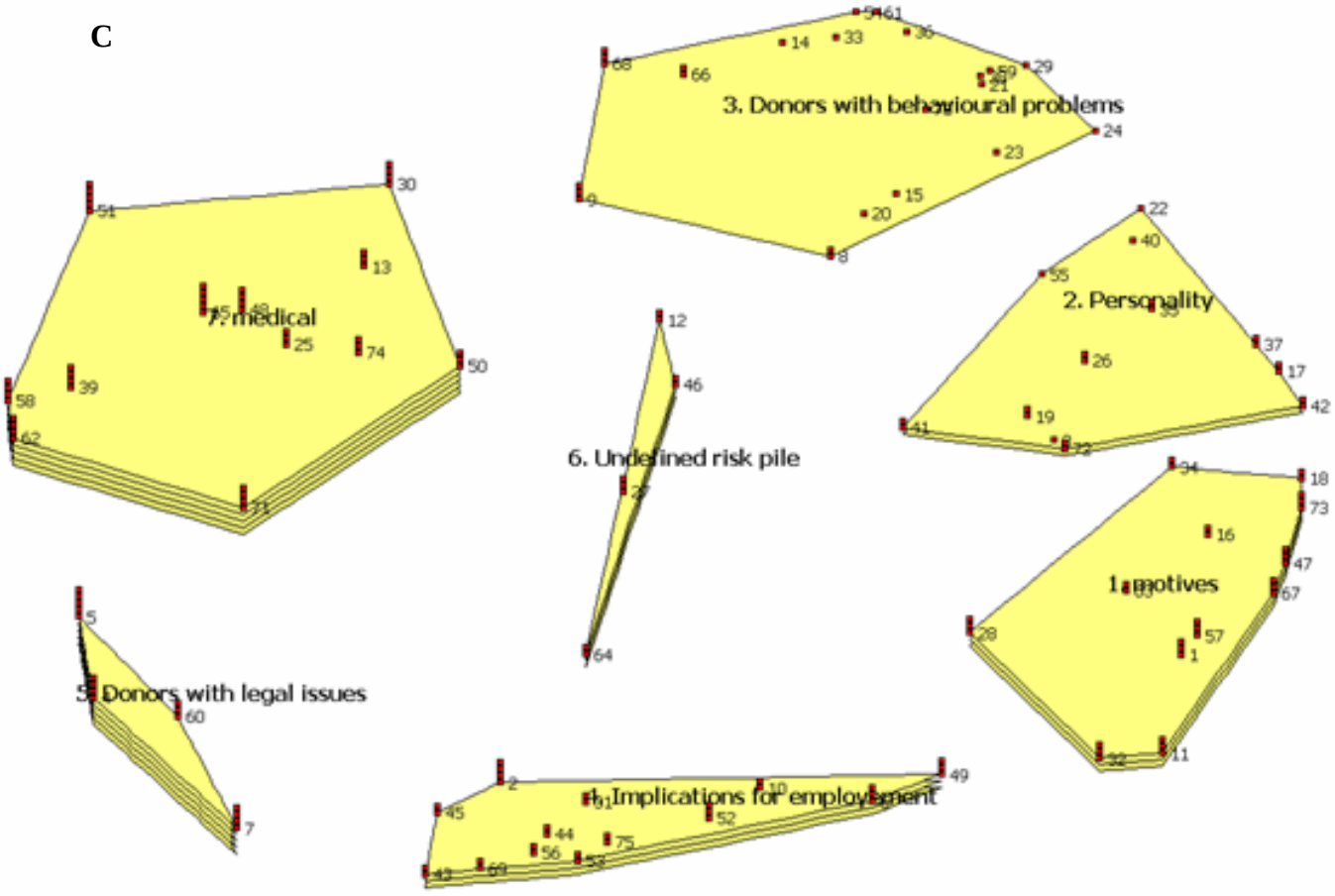
B



Cluster legend

Layer	Bridging value
1	0,13 to 0,22
2	0,22 to 0,32
3	0,32 to 0,41
4	0,41 to 0,50
5	0,50 to 0,59

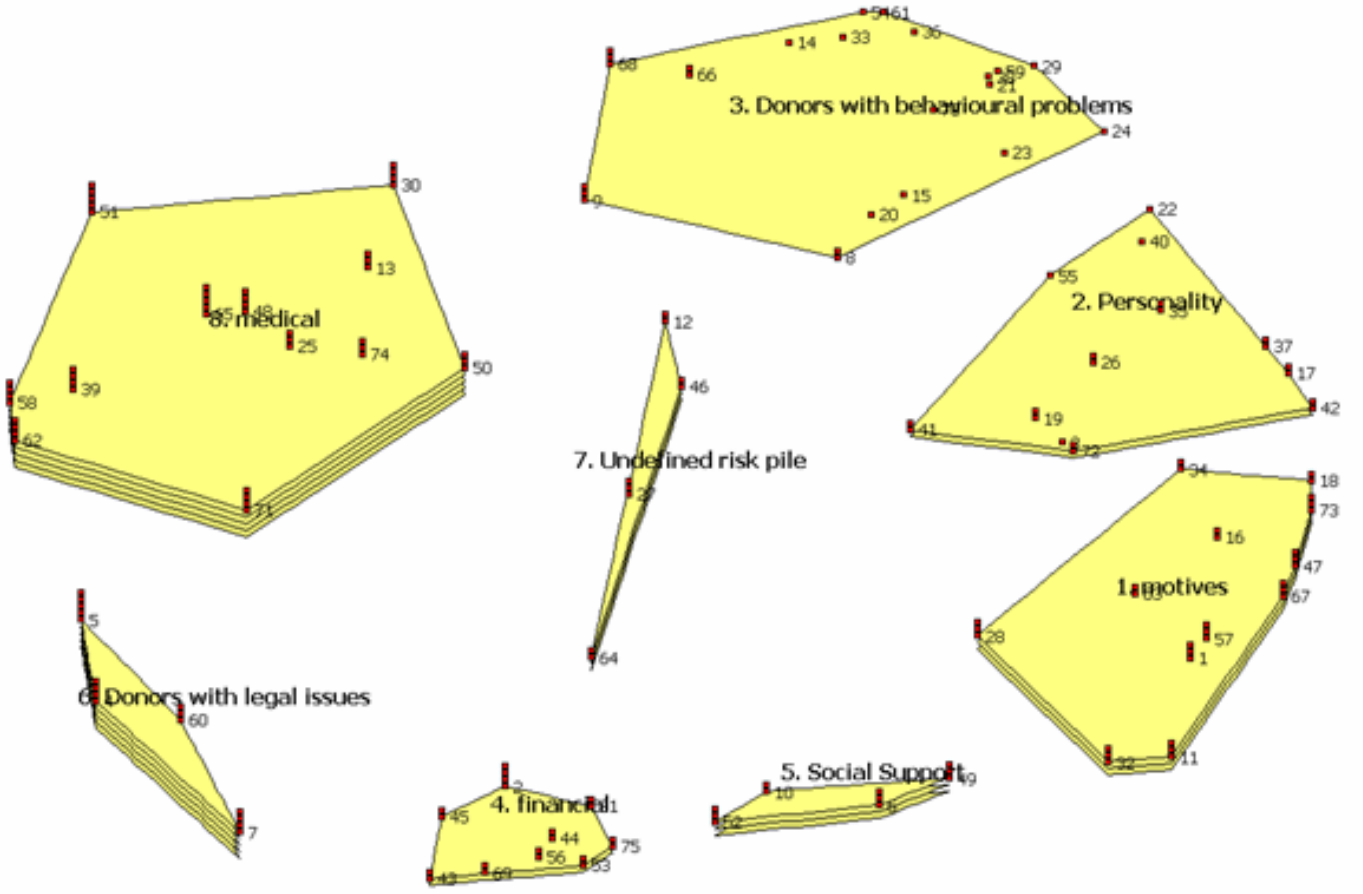
C



Cluster legend

Layer	Bridging value
1	0,13 to 0,24
2	0,24 to 0,35
3	0,35 to 0,46
4	0,46 to 0,56
5	0,56 to 0,67

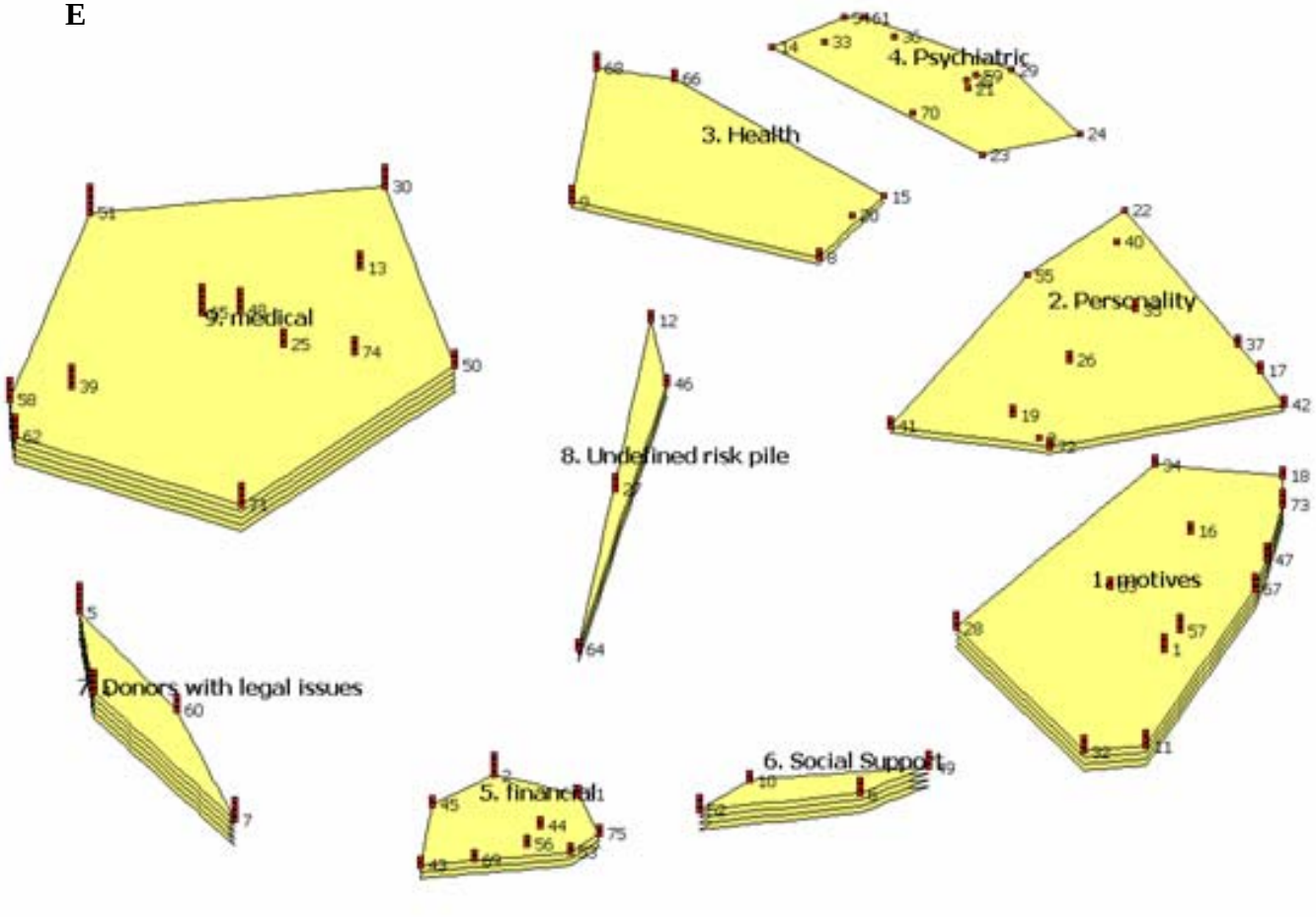
D



Cluster legend

Layer	Bridging value
1	0,13 to 0,24
2	0,24 to 0,35
3	0,35 to 0,46
4	0,46 to 0,56
5	0,56 to 0,67

E



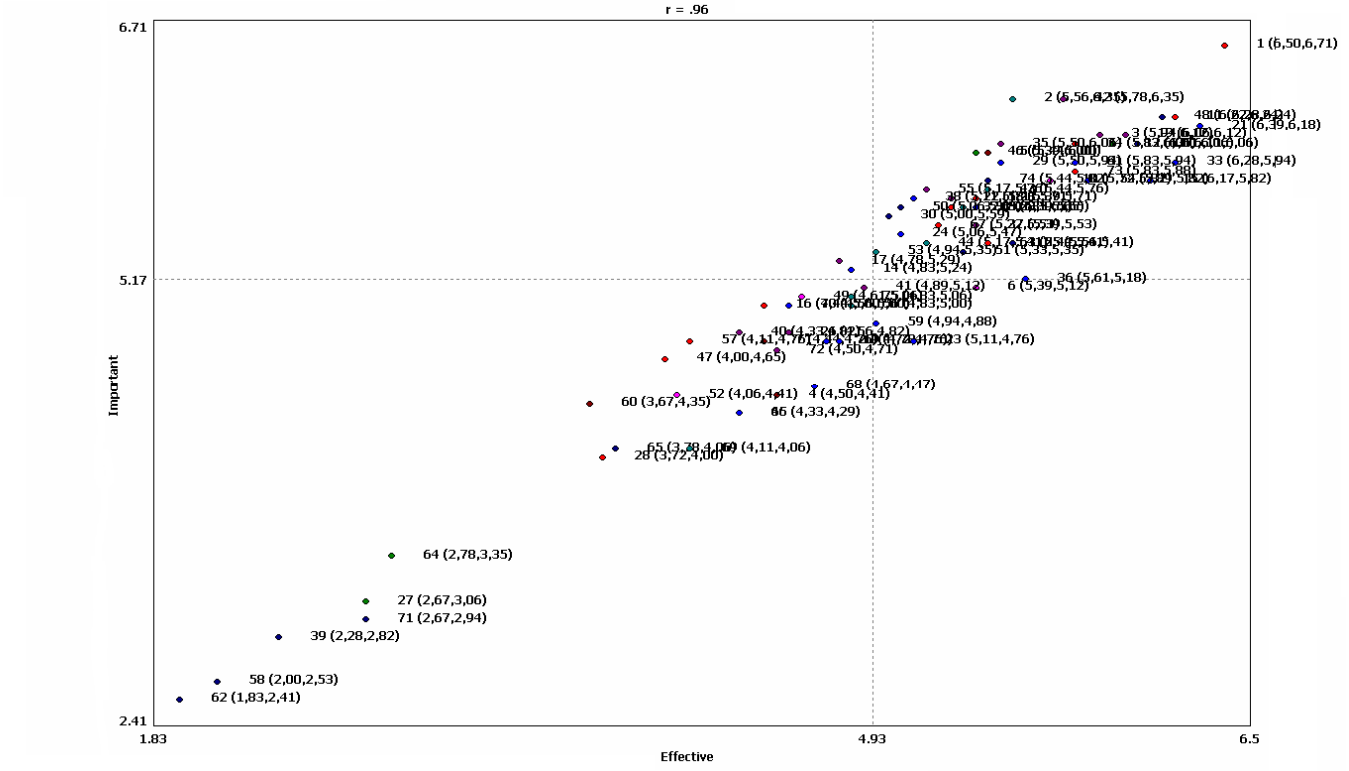
Cluster legend

Layer	Bridging value
1	0,06 to 0,18
2	0,18 to 0,30
3	0,30 to 0,42
4	0,42 to 0,55
5	0,55 to 0,67

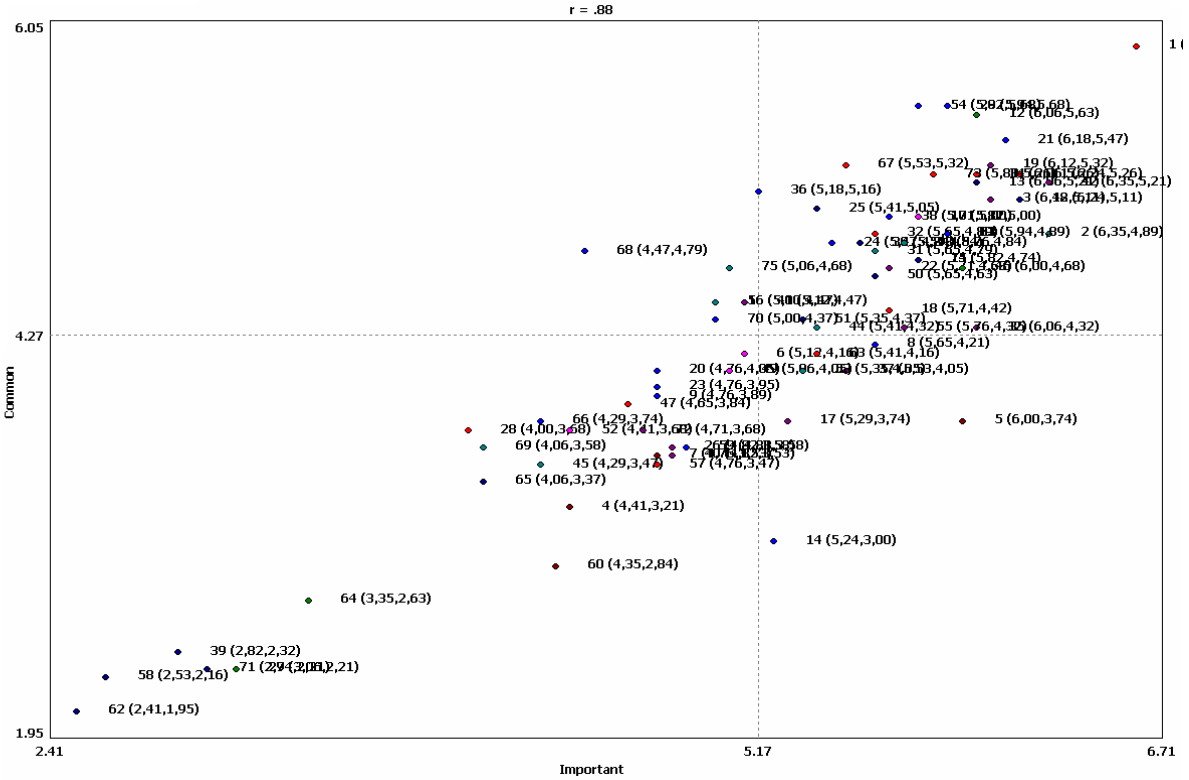
Figure 7

Correlation plot of the rating scores based on importance and effectiveness **(A)**, importance and commonness **(B)**, and effectiveness and commonness **(C)**. Within the upper right quadrant statements are located which receive high ratings in both plotted rating scales. Statements which received low rating points in both plotted rating scales are located in the lower left quadrant. If a statement received a high rating using only one of the plotted rating scales, this statement is located within the upper left, or lower right quadrant. The Y and X-axis represent the mean scores of the statements using the corresponding rating scale.

A



B


r = .88
6.05
4.27
1.95
2.41
5.17
6.71
Common
Important
68 (4,47,4,79)
75 (5,06,4,68)
36 (5,18,5,16)
25 (5,41,5,05)
21 (6,18,5,47)
12 (6,06,5,63)
67 (5,53,5,32)
2 (6,35,4,89)
18 (5,71,4,42)
8 (5,65,4,21)
17 (5,29,3,74)
5 (6,00,3,74)
14 (5,24,3,00)
4 (4,41,3,21)
60 (4,35,2,84)
64 (3,35,2,63)
39 (2,82,2,32)
58 (2,53,2,16)
62 (2,41,1,95)

C

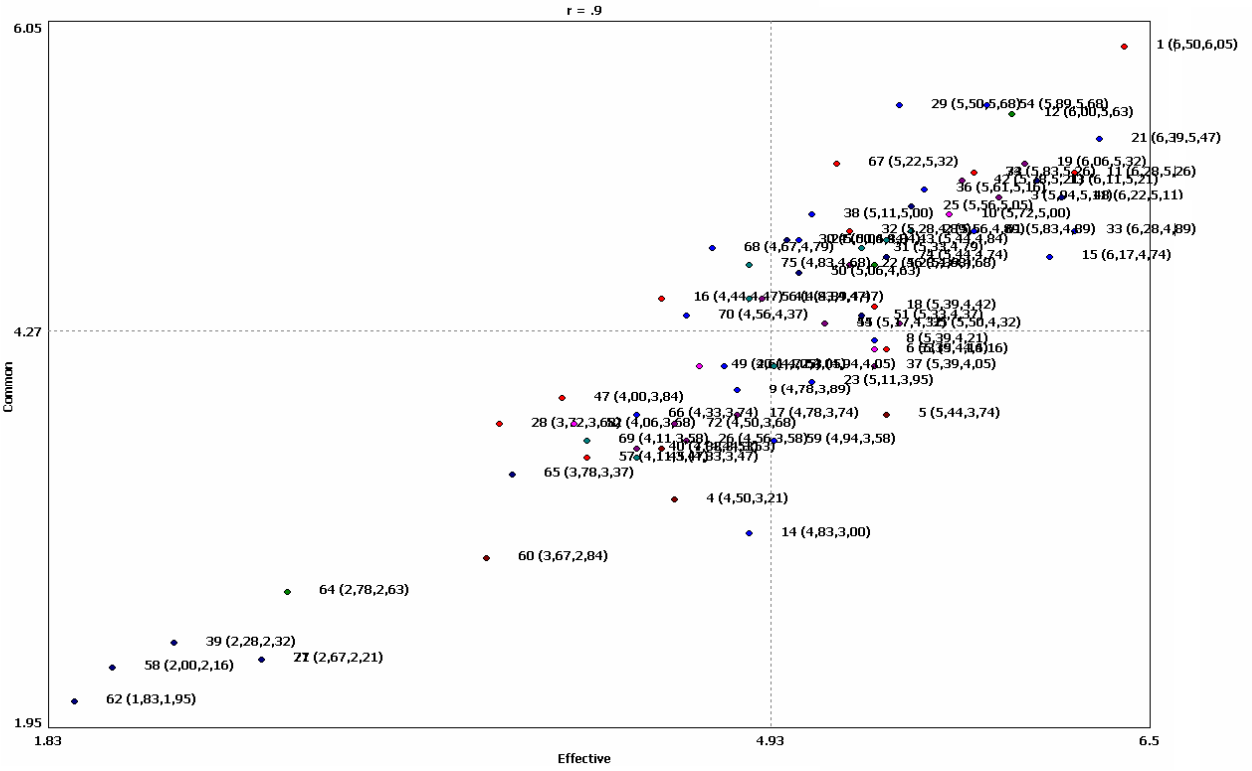

r = .9
6.05
4.27
1.95
1.83
4.93
6.5
Common
Effective
1 (6,50,6,05)
29 (5,50,5,68)
12 (6,00,5,63)
21 (6,39,5,47)
67 (5,22,5,32)
15 (6,17,4,74)
18 (5,39,4,42)
8 (5,39,4,21)
5 (5,44,3,74)
4 (4,50,3,21)
14 (4,83,3,00)
60 (3,67,2,84)
64 (2,78,2,63)
39 (2,28,2,32)
58 (2,00,2,16)
62 (1,83,1,95)

Figure 8

A ‘pattern mach’ based on the concept map (7A) that shows the relationship between the rating scores at the importance and commonness scale per cluster. Horizontal lines suggest relative agreement while diagonal lines suggest relative differences. The position of the cluster names is random, although in a descending order for the respective rating. Pattern matches are especially valuable for detecting high-level patterns. Absolute values for ratings range from 1.0-7.0

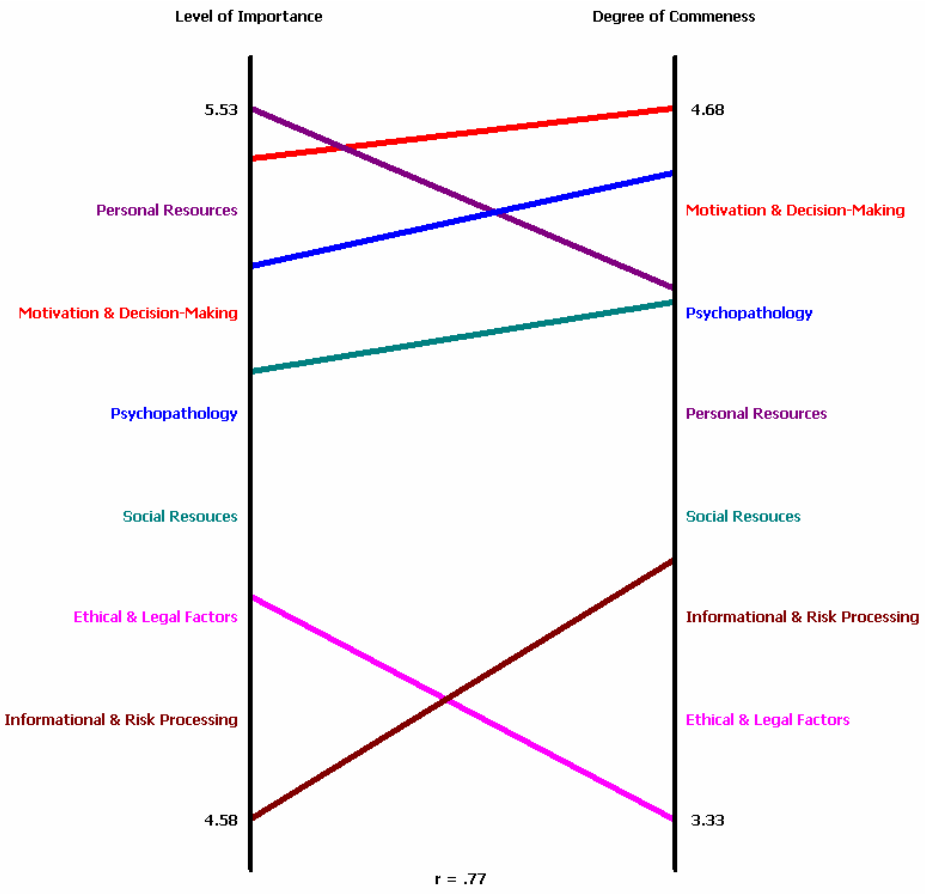
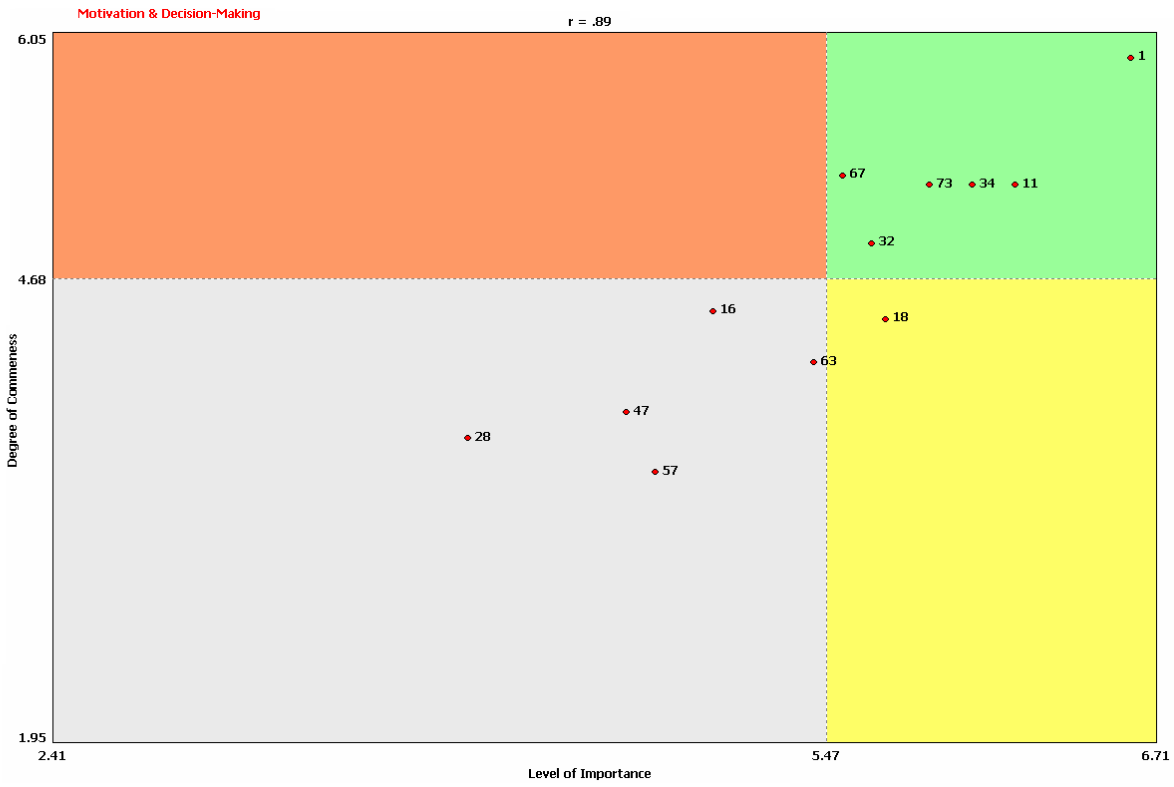


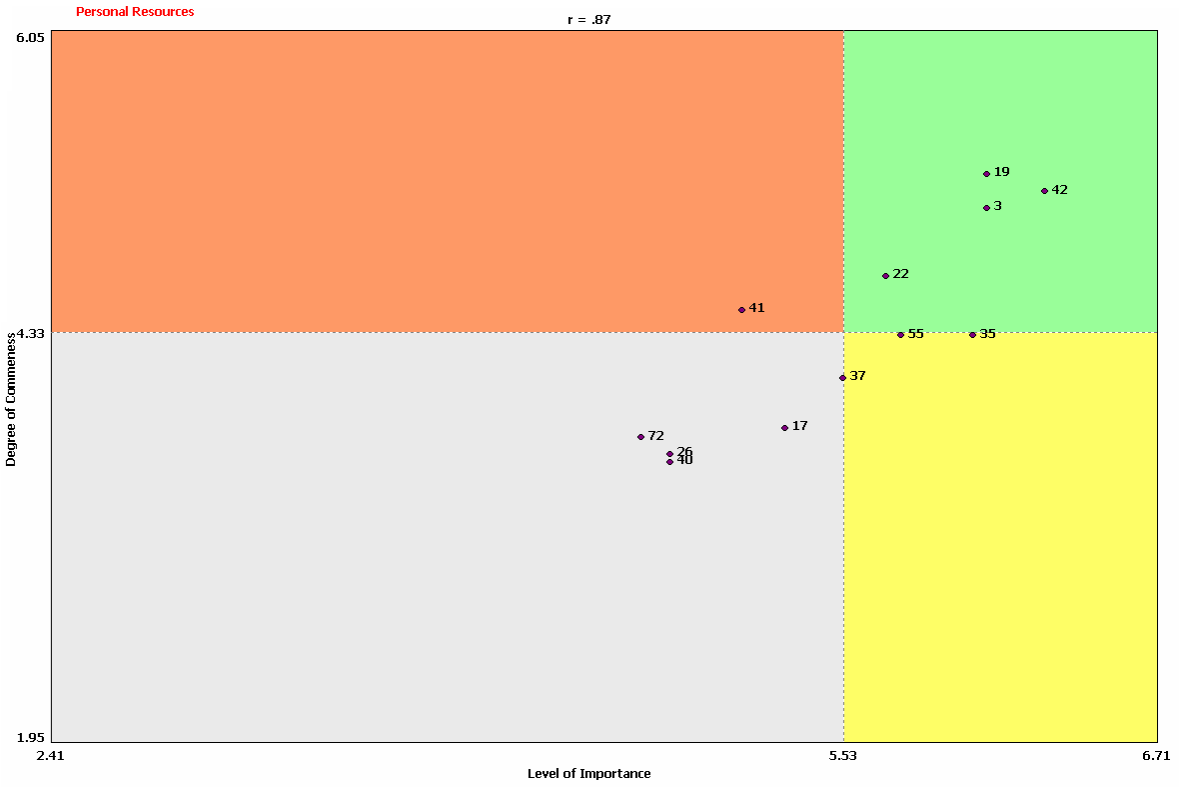
Figure 9

A bivariate ‘go-zone’ plot per cluster based on the cluster map (7A). The quadrants are constructed using the average *x* (importance) and *y* (commonness) values. On the figures A to F the go-zone quadrant on the upper right shows that all statements that are above average in both importance and commonness. Statements which received low rating points in both plotted rating scales are located in the lower left purple quadrant. If a statement received a high rating using only one of the plotted rating scales, this statement is located within the orange, upper left, or yellow, lower right quadrant. The Y and X-axis represent the mean scores of the statements using the corresponding rating scale. Go-zones are particularly valuable for detailing subsequent planning or evaluation efforts.

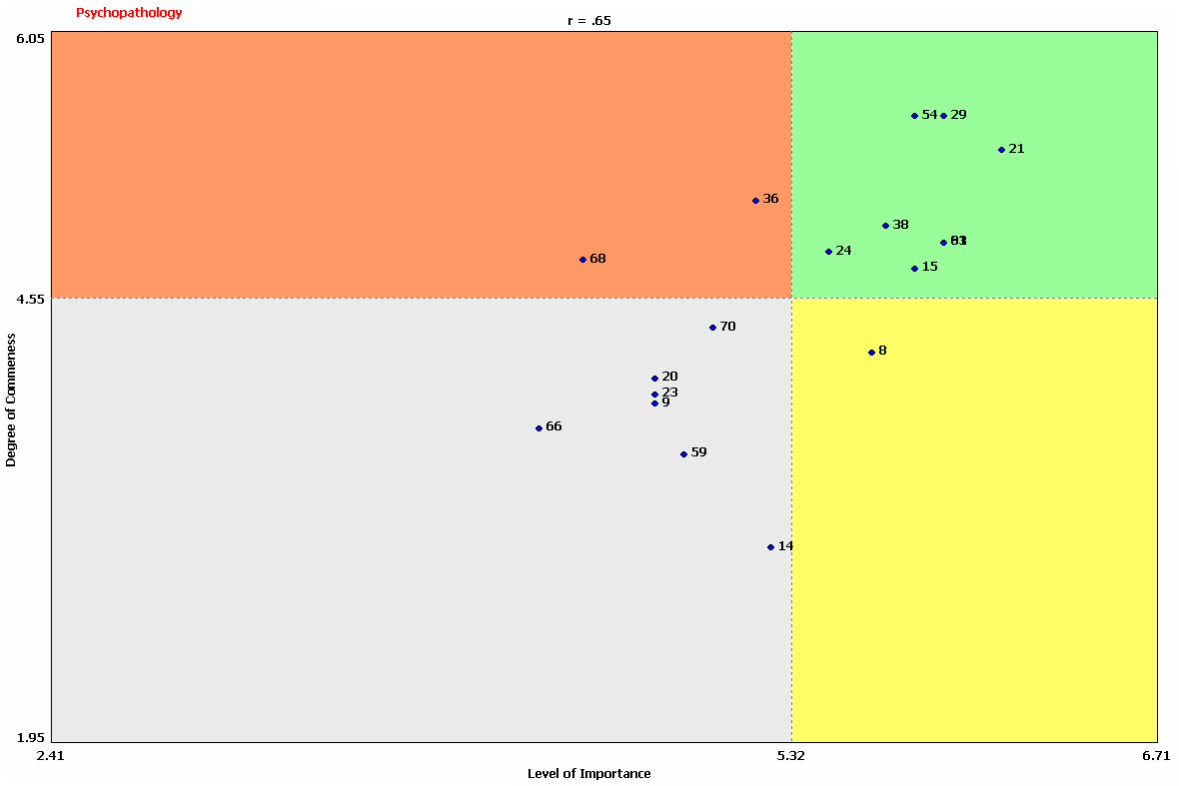
A Cluster 1



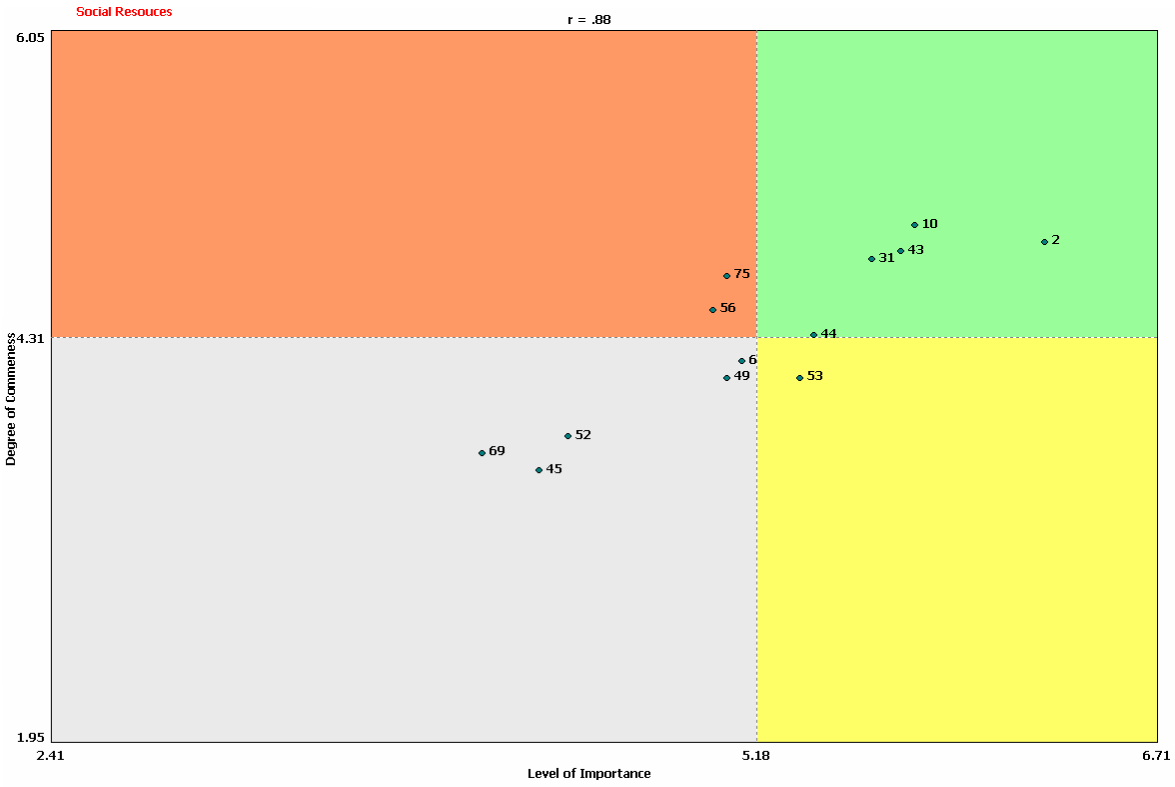
B Cluster 2



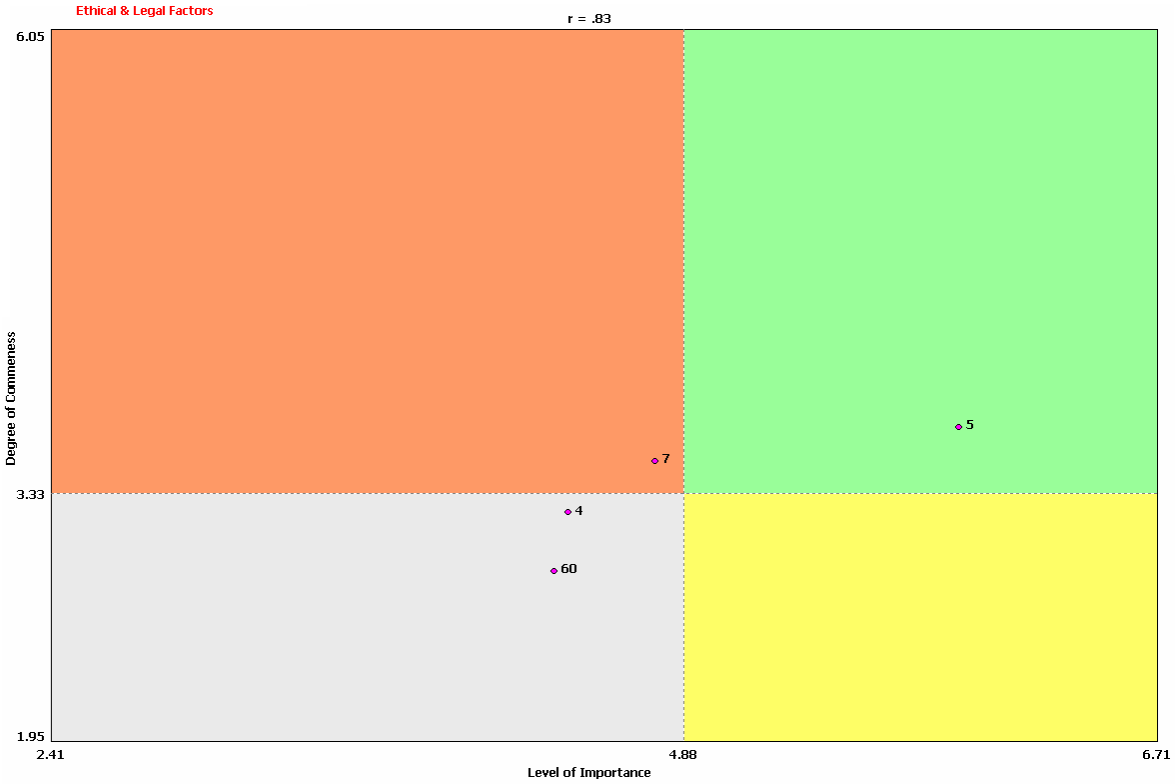
C Cluster 3



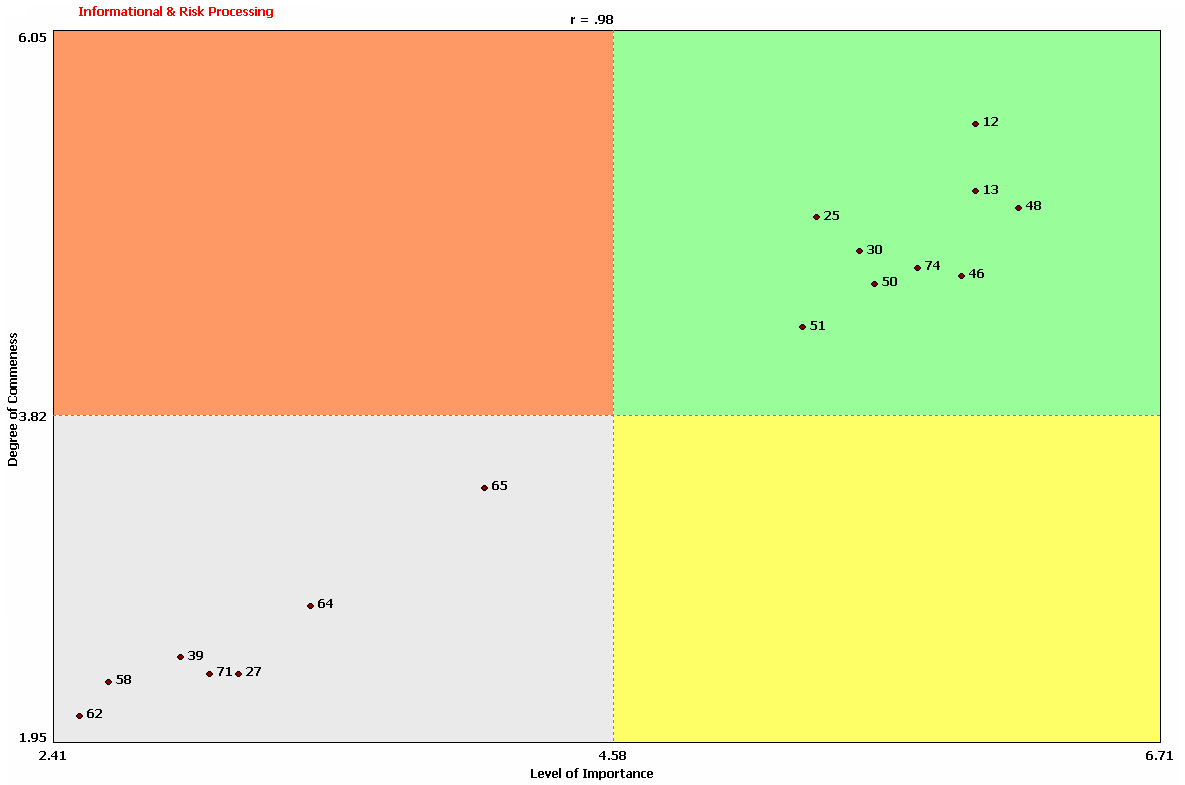
D Cluster 4



E Cluster 5



F **Cluster 6**


Informational & Risk Processing
r = .98
6.05
3.82
1.95
Degree of Commeness
2.41
4.58
6.71
Level of Importance
12
13
48
25
30
74
46
50
51
65
64
39
71
27
58
62