PSYCHOSOCIAL FUNCTIONING DOMAIN (IMPACTS)

Note Patient panel proposed concept category B Concept category Concept	Category/Concept	Coherence in Measurement & Classification		Adequacy of Data		Relevance of Concept		
INDIPENDINCE - Patient panel proposed concept category - Important aspect of indepence per patient panel. - Important a		Concerns	Explanation	Ī		Bothersome	Prevalence	
Cooking/meal preparation - Important aspect of indepence per patient panel - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel includes gardening - Important aspect of indepence per patient panel includes gardening - Important aspect of indepence per patient panel includes gardening - Important aspect of indepence per patient panel includes gardening - Important aspect of indepence per patient panel includes gardening - Important aspect of indepence per patient panel includes gardening - Important aspect of state panel p						mean %	mean %	[Range]
Housework/home maintenance - Important aspect of indepence per patient panel; Limited research - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence per patient panel; includes patient of indepence - Important aspect of indepence per patient panel; includes gardening - Important aspect of indepence - Important aspect of stagence - Important aspect of indepence - Impor	INDEPENDENCE	-	Patient panel proposed concept category	В	х	24%	13%	-
Housework/home maintenance Travel/driving Travel/dr	Cooking/meal preparation	-	Important aspect of indepence per patient panel	В	х	2%	29%	[13-28%]
Travel/driving Important aspect of indepence per patient panel B	Shopping	-	Important aspect of indepence per patient panel; Limited research	D	х	2%	-	-
SELF-CONCEPT Minor Concept category; May comprise multiple aspects or specific experiences B x 35% 49% Embarassment/self-conscious Minor May have overlap with concept of stigma B x 11% 53% Feeling stigmatized Minor May have overlap with concept of stigma B x 11% 53% Feeling stigmatized Minor May have overlap with concept of stigma B x 11% 53% Self-efficacy Proposed concept encompassing several aspects of perceived ability to manage B x	Housework/home maintenance	-	Important aspect of indepence per patient panel; Includes gardening	В	х	2%	39%	[32-43%]
SELF-CONCEPT Embarassment/self-conscious Minor Minor May have overlap with concept of stigma Minor May have overlap with concept of stigma Minor May have overlap with concept of stigma Minor May have overlap with embarassment/self-conscious; Limited research Decreased self-confidence UA Limited research CC x 88% 65% Sense of helplessness UA Limited research CDPING UNION Limited research CDPING UA Limited research CDPING UA Limited research COPING COPI	Travel/driving	-		В	х	-	40%	[18-53%]
Feeling stigmatized Minor May have overlap with embarassment/self-conscious; Limited research Proposed concept encompassing several aspects of perceived ability to manage B X - Decreased self-confidence Sense of helplessness UA Limited research C X 8% 65% Sense PD limits what you can do UA Limited research C X 8% 65% Proposed concept category; May comprise multiple aspects or specific experiences B X 29% 18% Living with uncertainty UA Limited research C concept category; May comprise multiple aspects or specific experiences B X 29% 18% Living with uncertainty UA Limited research Preoccupation with disease Moderate Limited research: Unclear what constitutes preoccupation; definitions needed C X - 41% Any overlap with fear of future Fear of falling Minor May overlap with fear of future Moderate Unclear in reference to what; definitions needed C X - 12% Concealing diagnosis UA Limited research Unclear in reference to what; definitions needed C X - 12% Concealing diagnosis UA Limited research D X - 134% Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D X - 19% Annoyance/bothered Moderate May overlap with Annoyance/bothered; definitions needed B X 9% 24% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D X - 19% 19% 19% 19% 19% 19% 19%	SELF-CONCEPT	Minor		В	х	35%	49%	[26-72%]
Self-efficacy Decreased self-confidence Sense of helplessness Sense PD limits what you can do UA Limited research Sense PD limits what you can do UA Limited research CC X 28% 913% COPING Minor Concept category; May comprise multiple aspects or specific experiences Living with uncertainty UA Limited research COPING UNION Living with uncertainty UA Limited research UNION Preoccupation with disease Living with uncertainty UA Limited research: Unclear what constitutes preoccupation; definitions needed CC X - 413% Fear of falling Minor May encompass different specific experiences; definitions needed CC X - 413% Fear of falling Minor May overlap with fear of future DD X 7% Fear of the future Minor May overlap with fear of falling Avoidance Moderate Unclear in reference to what; definitions needed CC X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD < 3YSD D- X - 34% Concealing diagnosis UA Limited research DD X - 19% Annoyance/bothered Moderate	Embarassment/self-conscious	Minor	May have overlap with concept of stigma	В	х	11%	53%	[43-63%]
Decreased self-confidence Sense of helplessness UA Limited research CC X 28% 91% Sense PD limits what you can do UA Limited research COPING Minor Concept category; May comprise multiple aspects or specific experiences B X 29% 18% Living with uncertainty UA Limited research Preoccupation with disease Limited research: Unclear what constitutes preoccupation; definitions needed CC X - 50% Increased fear Minor May encompass different specific experiences; definitions needed CC X - 41% As yellow yellow with fear of future Fear of falling Minor May overlap with fear of future DD X 7% - Fear of the future Minor May overlap with fear of falling B X 11% 46% Avoidance Moderate Unclear in reference to what; definitions needed CC X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD <3YSD Concealing diagnosis UA Limited research Moderate Moderat	Feeling stigmatized	Minor	May have overlap with embarassment/self-conscious; Limited research	С	x	22%	44%	-
Sense of helplessness Sense PD limits what you can do UA Limited research UA Limited research COPING Minor Concept category; May comprise multiple aspects or specific experiences B X 25% 18% 18% Living with uncertainty UA Limited research D X - 50% Preoccupation with disease Increased fear Minor May encompass different specific experiences; definitions needed C X - 41% Increased fear Minor May encompass different specific experiences; definitions needed A X 9% 46% Fear of fulling Minor May overlap with fear of future D X - Fear of the future Minor May overlap with fear of fulling Avoidance Unclear in reference to what; definitions needed C X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD<3YSD D- X - 34% Concealing diagnosis UA Limited research Moderate Moderate Moderate Moderate May overlap with Frustration/anger; definitions needed D X - 59% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B X 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D X - 53% Cothers perceptions/reactions Severe Ambigous concept; Needs definition D X - 11% Cothers perceptions/reactions Severe Ambigous concept; Needs definition D X - 118% - 18% - 18	Self-efficacy		Proposed concept encompassing several aspects of perceived ability to manage	В	х	-	-	-
Sense PD limits what you can do UA Limited research COPING Minor Concept category; May comprise multiple aspects or specific experiences B	Decreased self-confidence	UA	Limited research	С	х	8%	65%	-
COPING Minor Concept category; May comprise multiple aspects or specific experiences B x 29% 18% Living with uncertainty UA Limited research Limited research D x - 55% Preoccupation with disease Moderate Limited research: Unclear what constitutes preoccupation; definitions needed C x - 41% Increased fear Minor May encompass different specific experiences; definitions needed A x 9% 46% Fear of falling Minor May overlap with fear of future D x 7% - Fear of the future Minor May overlap with fear of falling B x 11% 46% Avoidance Moderate Unclear in reference to what; definitions needed C x - 12% Denial Minor One Tier 1 study disconfirming presence in early PD<3YSD D - x - 34% Concealing diagnosis UA Limited research D x - 19% Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D x - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B x 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D x - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x - 47% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Sense of helplessness	UA	Limited research	С	х	-	18%	[11-25%]
Living with uncertainty Living with uncertainty UA Limited research Preoccupation with disease Increased fear Minor May encompass different specific experiences; definitions needed Minor May overlap with fear of future Minor May overlap with fear of falling Minor Moderate Unclear in reference to what; definitions needed Minor One Tier 1 study disconfirming presence in early PD<3YSD D- x - 12% Annoyance/bothered Moderate Mo		UA	Limited research	С	х	28%	91%	-
Preoccupation with disease Moderate Increased fear Minor May encompass different specific experiences; definitions needed A A 9% 46% Fear of falling Minor May overlap with fear of future Pear of the future Minor Moderate Unclear in reference to what; definitions needed C A 11% 46% Avoidance Moderate Unclear in reference to what; definitions needed C A 12% Denial Minor One Tier 1 study disconfirming presence in early PD<3YSD D- Annoyance/bothered Moderate		Minor	Concept category; May comprise multiple aspects or specific experiences	В	х	29%	18%	[11-25%]
Increased fear Minor May encompass different specific experiences; definitions needed D X 7% - Fear of falling Minor May overlap with fear of future B X 11% 46% Avoidance Moderate Unclear in reference to what; definitions needed C X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD <3YSD D - X - 34% Concealing diagnosis UA Limited research D X - 19% Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D X - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B X 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B X 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D X - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D X - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D X 19% - Relationships with others Minor Variably includes family, friends, co-workers B X 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition	Living with uncertainty	UA	Limited research	D	х	-	50%	-
Fear of falling Minor May overlap with fear of future Minor May overlap with fear of falling Avoidance Moderate Unclear in reference to what; definitions needed C X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD <3YSD Concealing diagnosis UA Limited research Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B X 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B X 6% 24% Finding ways to compensate Moderate May overlap with Annoyance/bothered; definitions needed B X 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D X - 53% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category Relationships with others Minor Variably includes family, friends, co-workers Ambigous concept; Needs definition D X - 11%	Preoccupation with disease	Moderate	Limited research: Unclear what constitutes preoccupation; definitions needed	С	х	-	41%	[23-59%]
Fear of the future Minor May overlap with fear of falling Avoidance Moderate Unclear in reference to what; definitions needed C X - 12% Denial Minor One Tier 1 study disconfirming presence in early PD <3YSD D- X - 34% Concealing diagnosis UA Limited research Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D X - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B X 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B X 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D X - 53% Patient panel proposed concept category D X 19% - 47% Others perceptions/reactions Severe Ambigous concept; Needs definition D X - 11%	Increased fear	Minor	May encompass different specific experiences; definitions needed	Α	х	9%	46%	[27-59%]
Avoidance Moderate Unclear in reference to what; definitions needed C x - 12% Denial Minor One Tier 1 study disconfirming presence in early PD <3YSD D - x - 34% Concealing diagnosis UA Limited research D x - 19% Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D x - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B x 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D x - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x 19% - Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition	Fear of falling	Minor	May overlap with fear of future	D	х	7%	-	-
Denial Minor One Tier 1 study disconfirming presence in early PD <3 YSD D- x - 34% Concealing diagnosis UA Limited research D x - 19% Annoyance/bothered Moderate May overlap with Frustration/anger; definitions needed D x - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B x - 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x - 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D x - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x - 19% - Relationships with others Minor Variably includes family, friends, co-workers B x - 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition	Fear of the future	Minor	May overlap with fear of falling	В	х	11%	46%	[27-59%]
Concealing diagnosis UA Limited research Annoyance/bothered Moderate Mod	Avoidance	Moderate	Unclear in reference to what; definitions needed	С	х	-	12%	[6-17%]
Annoyance/bothered May overlap with Frustration/anger; definitions needed D x - 69% Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B x 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D x - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x 19% - Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Denial	Minor	One Tier 1 study disconfirming presence in early PD <3YSD	D -	х	-	34%	-
Frustration/anger Moderate May overlap with Annoyance/bothered; definitions needed B x 6% 24% Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS Patient panel proposed concept category Patient panel proposed concept category Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Concealing diagnosis	UA	Limited research	D	х	-	19%	-
Stress/distress Moderate May overlap with Annoyance/bothered; definitions needed B x 9% 27% Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts D x - 53% Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x 19% - Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Annoyance/bothered	Moderate	May overlap with Frustration/anger; definitions needed	D	х	-	69%	-
Finding ways to compensate UA Limited research; Patient panel recommendation to include positive impacts Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS Patient panel proposed concept category D x 19% Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Frustration/anger	Moderate	May overlap with Annoyance/bothered; definitions needed	В	х	6%	24%	[20-27%]
Positive changes to take control UA Limited research; Patient panel recommendation to include positive impacts D x - 47% INTERPERSONAL INTERACTIONS - Patient panel proposed concept category Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Stress/distress	Moderate	May overlap with Annoyance/bothered; definitions needed	В	х	9%	27%	[14-44%]
INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x 19% - Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%	Finding ways to compensate	UA	Limited research; Patient panel recommendation to include positive impacts	D	х	-	53%	-
INTERPERSONAL INTERACTIONS - Patient panel proposed concept category D x 19% - Relationships with others Minor Variably includes family, friends, co-workers B x 9% 53% Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%				D		-		-
Others perceptions/reactions Severe Ambigous concept; Needs definition D x - 11%		-		D			-	-
	Relationships with others	Minor	Variably includes family, friends, co-workers	В	х	9%	53%	[30-66%]
Communication Moderate May included written or spoken: Needs definition	Others perceptions/reactions	Severe	Ambigous concept; Needs definition	D	х	-	11%	
winderate with the spoken, vecas definition	Communication	Moderate	May included written or spoken; Needs definition	Α	х	9%	39%	[19-75%]
Loneliness/isolation - No concerns A x 1% 22%	Loneliness/isolation	-	No concerns	А	х	1%	22%	[16-31%]

PSYCHOSOCIAL FUNCTIONING DOMAIN (IMPACTS)

ROLES & RESPONSIBILITIES		Patient panel proposed concept category	<u> </u>				
Taking care of family	UA	Limited research; No disconfirming evidence	С	х	2%	3%	-
Taking care of pets	UA	Limited research; No disconfirming evidence	С	х	1%	3%	-
Impact on Job/profession	-	No disconfirming evidence	В	x	11%	54%	[40-72%]
Financial impact/paying bills	Moderate	One Tier 1 study disconfiming presence in early PD	D -	x	-	3%	-
IMPORTANT ACTIVITIES		Patient panel proposed concept category	T 				
Pleasurable activities	Moderate	Very limited research; may overlap with other concepts in category	D	x	19%	-	-
Loss of things you enjoy	Moderate	Very limited research; may overlap with other concepts in category	D	х	14%	-	-
Social life	UA	Very limited research	D	х	17%	-	-
Playing an instrument	UA	Limited research; may overlap with other concepts in category	С	х	2%	13%	-
Spiritual/Religious activities	UA	Very limited research	D	х	-	9%	-
Hobbies & liesure activities	Moderate	May overlap with other concepts in category	Α	4	2%	47%	[34-86%]

Notes. PD= Parkinson's disease; UA=Unable to assess due to limited data; YSD=Years since diagnosis of Parkinson's disease; Tier 1 Grade A+=100% (Green), A=75-99% (Green), B=50-74% (Yellow), C=25-49% (Orange), D=1-24% (Gray), X=No studies supporting presence in early PD (Black); Tier 2 & 3 Level 1=75-100% (Green), 2=50-74% (Yellow), 3=25-49% (Orange), 4=1-24% (Gray), x=No Tier 2 or 3 studies supporting presence in early PD (Black). Minus sign "-" in Grade or Level indicates presence of disconfirming evidence. Color coding is used for visual identification of concepts with greater supporting evidence in Grade and Level. For bothersomeness and prevalence, darker colors indicate higher average frequency in studies reporting.