Journal of Clinical Medicine

MDPI

Supplementary Materials

Parkinson Network Eastern Saxony (PANOS): Reaching Consensus for a Regional Intersectoral Integrated Care Concept for Patients with Parkinson's Disease in the Region of Eastern Saxony, Germany

Kai F. Loewenbrück[1,2,*], Doron B. Stein[3], Volker E. Amelung[3], Robert Bitterlich[1], Martin Brumme[3], Björn Falkenburger[1,2], Annekathrin Fehre[6], Tim Feige[1], Anika Frank[1,2], Carola Gißke[5], Claudia Helmert[4], Linda Kerkemeyer[3], Andreas Knapp[4], Caroline Lang[4], Annegret Leuner[6], Carina Lummer[3], Mirella M.N. Minkman[9,10], Gabriele Müller[4], Marlena van Munster[7], Hannes Schlieter[5], Peter Themann[8], Nick Zonneveld[9,10], Martin Wolz[6]

[1] Department of Neurology, University Hospital Dresden, 01307 Dresden, Germany; kai.loewenbrueck@uniklinikum-dresden.de
[2] German Center for Neurodegenerative Diseases (DZNE) Dresden, 01307 Dresden, Germany;
[3] Institute for Applied Health Services Research (inav), Schiffbauerdamm 12, 10117 Berlin, Germany; stein@inav-berlin.de
[4] Center for Evidence-based Healthcare, Faculty of Medicine Carl Gustav Carus, Technische Universität Dresden, Germany, caroline.lang@uniklinikum-dresden.de
[5] Chair of Wirtschaftsinformatik, Especially Systems Development, Faculty of Business and Economics, Technical University of Dresden, 01062 Dresden, Germany, bjoern.falkenburger@uniklinikum-dresden.de
[6] Department of Neurology, Elblandklinikum Meißen, 01662 Meißen, Germany; martin.wolz@elblandkliniken.de
[7] Department of Neurology, University Hospital Marburg, Marburg, Germany; munster@med.uni-marburg.de
[8] Department of Neurology, Klinik am Tharandter Wald Hetzdorf, Herzogswalder Straße 1, 09633 Halsbrücke, Germany, themann@reha-hetzdorf.de
[9] Vilans, National Centre of Expertise in Long Term Care, Utrecht, The Netherlands, m.minkman@vilans.nl
[10] Tilburg University / TIAS School for Business and Society, Tilburg, the Netherlands

* Correspondence: kai.loewenbrueck@uniklinikum-dresden.de; Tel.: +49 351 458 18518 (K.F.L)

Received: 31/07/2020; Accepted: date; Published: date

Supplementary Materials

Supplementary table:

Table S1: Questions and items of online surveys

43

Table S1: Questions and items of online surveys

General questions on demographic and care structure of the target region

Question	General Medicine	Neurology
What medical specialty do you represent?	67%	33%

Question	>30	16-30	5--15	<5
How many PD patients schedule consultations with you every quarter year?	16%	16%	52%	16%

Question	Metropolis	Small town	Rural area
How would you characterize the geographic location of your practise?	33%	33%	33%

Question	Item	Good	Rather good	Rather bad	Bad	Don't know
How would you rate care for PD patients in your region?	Care by GPs	24%	42%	24%	0%	9%
	Care by outpatient specialists	24%	39%	18%	18%	0%

Question	Item	Fully agree	Agree	Moderately agree	Do not agree	Don't know
Which statement on the care of PD patients would you agree with?	Care is predominantly provided in accordance with guidelines	12%	61%	6%	6%	15%
	Timely referral to specialists	15%	45%	27%	6%	6%
	Patients are treated intersectorally	6%	33%	27%	15%	18%
	Patients receive individually required treatment	9%	45%	27%	9%	9%
	PD patients often receive insufficient or incorrect care	6%	33%	33%	12%	12%

Question	Item	Very large	Large	Moderate	None	Don't know
What challenges do you perceive in daily usual care reality?	Barriers regarding timely access to specialists	18%	30%	36%	9%	6%
	Insufficient education and / or insufficient sensitation of nursing staff	12%	33%	36%	9%	9%
	Lack of structured support material (specific and updated information and recommendations for the treatment of PD patients)	6%	27%	36%	15%	15%
	Unstructured coordination of treatment	6%	27%	33%	21%	9%
	Lack of communication, resp. lack of exchange with other physicians and therapists	6%	39%	30%	15%	6%
	Lack of digital components in the care concept (EPR, Apps, etc.)	9%	39%	9%	21%	18%
	Lack of telemedical approaches in usual care	6%	30%	15%	24%	21%

Motivation of participants

Question	Item	Very much	Much	A little bit	Not at all	Don't know
How much would the following items motivate you personally to participate in the network?	Rising demand among patients	6%	36%	36%	18%	3%
	Availability of a structured care pathway	27%	48%	9%	12%	3%
	Support by case managers	6%	42%	24%	24%	0%
	Adequate offer of therapies	24%	55%	9%	12%	0%
	Advanced training curricula (for doctors, therapists and nurses)	9%	45%	30%	6%	3%
	Education curricula for patients and their relatives	9%	58%	12%	15%	6%
	Networking with other healthcare service providers	27%	42%	12%	15%	0%
	Electronic Health Record	6%	15%	30%	39%	6%
	Availability of the results of repetitive patient self-monitoring	3%	30%	30%	18%	15%

	Telemedical offers	3%	9%	36%	30%	18%	
	Adequate reimbursement	12%	33%	36%	12%	6%	
	Adequate (human and technical) resources	18%	45%	27%	6%	3%	

Importance of different care aspects

Question	Item	5 (relevant)	4	3	2	1 (irrelevant)	Cannot judge	No answer
Which of the following dimensions do you consider to be generally relevant for PD treatment?	General health related quality of life	59%	18%	18%	0%	0%	0%	0%
	PD-specific quality of life	64%	23%	9%	0%	0%	0%	0%
	Motor function (e.g. gait insecurity, falls, voice)'	64%	27%	5%	0%	0%	0%	0%
	Non-motor function (e.g. sleep, sexual function)'	18%	41%	36%	0%	0%	0%	0%
	Cognitive function (e.g. memory, weak concentration, perceptual disorder)	32%	50%	14%	0%	0%	0%	0%
	Emotional function (e.g. depression, anxiety, mood, impulse control disorder)	41%	41%	14%	0%	0%	0%	0%
	Social function (e.g. aggression, social participation)	32%	36%	27%	0%	0%	0%	0%
	Role function (e.g. occupation, parental role)	18%	23%	50%	5%	0%	0%	0%
	Pain	45%	41%	5%	5%	0%	0%	0%
	Adverse drug events	41%	36%	14%	5%	0%	0%	0%
How important do you rate the following general contents of PANOS?	Performance of a social and nursing assessment by the case manager twice a year			0%	10%	70%	20%	0%
	Home visit (after registration to PANOS) by the case manager to patients/their family			0%	20%	50%	30%	0%
	Coordination and management of patients' appointments with GPs and neurologists by the case manager			0%	0%	50%	30%	20%
	Ability for the GPs and neurologists to request services from case managers via the electronic PANOS platform			10%	40%	50%	0%	0%
	Performance of tests (e.g. MOCA, UPDRS, etc.) by case managers			10%	10%	60%	20%	0%
	Having a permanent personal contact person in the case managers regarding GPs' and neurologists' collaboration in PANOS			30%	20%	30%	0%	0%
	Regular surveys among GPs and neurologists by case managers on the satisfaction of cooperation within PANOS			20%	10%	20%	30%	10%
	Possibility of the case manager being the central contact person for patients and relatives			0%	20%	50%	10%	10%

Question	Item	5 (willing)	4	3	2	1 (not willing at all)	Cannot judge	No answer
Which of the following dimensions would you be willing to survey and record in a structured way in the context of your own work?	General health related quality of life	36%	18%	23%	5%	5%	9%	5%
	PD-specific quality of life	36%	41%	9%	5%	0%	5%	5%
	Motor function (e.g. gait insecurity, falls, voice)'	50%	18%	18%	5%	0%	5%	5%
	Non-motor function (e.g. sleep, sexual function)'	32%	23%	18%	18%	0%	5%	5%
	Emotional function (e.g. depression, anxiety, mood, impulse control disorder)	27%	41%	14%	5%	5%	5%	5%
	Social function (e.g. aggression, social participation)	27%	23%	23%	14%	5%	5%	5%

	Role function (e.g. occupation, parental role)	18%	18%	27%	23%	5%	5%	5%
	Pain	36%	32%	14%	9%	0%	5%	5%
	Adverse drug events	41%	32%	14%	5%	0%	5%	5%

Electronic Health Record

Question	Item	essential	Im-por-tant	optional	not impor-tant	irrelevant	Cannot judge	No answer
What information about PD patients should be provided in the EHR?	Medication plan	82%	14%	0%	0%	0%	0%	5%
	Diagnostic reports (e.g. discharge letters, neuro-imaging-reports)	41%	50%	5%	0%	0%	0%	5%
	Medical history reports (e.g. comorbidities, allergies, family)	50%	36%	9%	0%	0%	0%	5%
	Social history and care situation at home (e.g. problems at home, long-term care level)	32%	50%	14%	0%	0%	0%	5%
	Vital signs	5%	55%	32%	5%	0%	0%	5%
	Laboratory results	9%	45%	41%	0%	0%	0%	5%
	Clinical scales / scores	9%	36%	45%	5%	0%	0%	5%
	Structured self-assessment questionnaires (e.g. BDI-II or UPDRS)'	0%	41%	50%	5%	0%	0%	5%
	Other contents	5%	9%	23%	9%	9%	0%	45%
What functions should be provided in the EHR?	Platform Function: Interactive Calendar for scheduling appointments	14%	27%	45%	0%	9%	0%	5%
	Platform Function: Secured internal messaging system	23%	55%	18%	0%	0%	0%	5%
	Platform Function: DICOM-Viewer for radiological and nuclear medical image data	0%	18%	68%	9%	0%	0%	5%
	Platform Function: Electronic interface for the use of clinical scales/scores	5%	59%	27%	5%	0%	0%	5%
	Platform Function: Other	0%	0%	23%	9%	5%	0%	64%

Question	Item	5 (Always)	4	3	2	1 (Never)	Cannot judge	No answer
Have you ever used tools for structured reporting in the context of PD?'		0%	14%	14%	5%	64%	0%	5%
Can you imagine using tools for structured reporting in the context of PD in the future?		18%	59%	9%	9%	0%	0%	5%

Patient self-management education program

Question	Item	Extremely important	Very impor-tant	Moderately important	Little impor-tant	Not impor-tant
How important do you rate the following contents of a structured patient self-management education program?	Knowledge about adverse drug events	30%	50%	20%	0%	0%
	Knowledge about drug mechanisms and effects	20%	60%	20%	0%	0%
	Strengthening of well-being	20%	50%	30%	0%	0%
	Coping with anxiety	20%	40%	40%	0%	0%
	Coping with depression	20%	40%	40%	0%	0%
	Promotion of social support	20%	40%	40%	0%	0%
	Strengthening of social competence	20%	10%	70%	0%	0%
	Knowledge about the origin of the disease	10%	50%	40%	0%	0%
	Coping with stress	10%	40%	50%	0%	0%
	Knowledge about complex therapies (deep brain stimulation, medication pump)	10%	30%	60%	0%	0%
	Ability of self-observation and introspection	0%	80%	20%	0%	0%

How important are the following goals of the structured patient self-management education program for the referral of a patient	Improvement of physician-patient communication	22%	22%	11%	33%	11%
	Strengthening of health-promoting behavior	22%	22%	55%	0%	0%
	Improvement of emotional well-being	11%	22%	44%	22%	0%
	Relief of physical symptoms	33%	33%	33%	0%	0%
How important do you find the availability of a separate training session for caregiving relatives?		30%	60%	10%	0%	0%

Structured professional continuous education program

Question	Item		Annualy	Twice per year	Every quarter	No answer
How often should Parkinson-specific training courses be offered as part of PANOS?			27%	59%	9%	5%
Question	**Item**	**Extremely important**	**Very important**	**Moderately important**	**Little important**	**Not important**
How important do you rate the following contents of a structured professional continuous education curriculum?	General PANOS program structure	20%	0%	40%	30%	10%
	PANOS integrated care pathway	20%	10%	40%	30%	0%
	PANOS case managers	20%	30%	20%	20%	10%
	Structured patient self-management education program	30%	20%	40%	10%	0%
	Structured education program for relatives	20%	30%	30%	20%	0%
	Electronic Health Record	20%	10%	30%	40%	0%
	Data security	40%	10%	20%	20%	10%
	Care structures	20%	30%	20%	30%	0%
	General case management	10%	10%	60%	20%	0%
	General medical aspects of PD	10%	50%	30%	10%	0%
	Societal impact of PD	10%	10%	50%	20%	10%
	Epidemiology	0%	20%	50%	30%	0%
	Neurobiology	0%	30%	60%	10%	0%
	Genetics	0%	50%	40%	10%	0%
	Diagnostics	10%	40%	40%	10%	0%
	Therapy	20%	50%	20%	10%	0%
	Drug therapy	20%	30%	40%	10%	0%
	Adverse events & Drug interaction	20%	10%	60%	10%	0%
	Sensor technology for use with PD	0%	20%	50%	30%	0%
	Rehabilitation programs for PD patients	10%	50%	30%	10%	0%
	General comorbidities	0%	40%	50%	10%	0%
	Internistic comorbidities	10%	70%	10%	10%	0%
	Psychiatric comorbidities	10%	40%	40%	10%	0%
	Psychosocial support	10%	40%	40%	10%	0%
	Psychotherapy	10%	10%	30%	40%	0%
	Sociotherapy	10%	20%	50%	20%	0%
	Self-help	20%	10%	60%	10%	0%
	Occupational therapy	20%	50%	20%	10%	0%
	Physiotherapy	30%	40%	20%	10%	0%
	Speech therapy	30%	40%	20%	10%	0%
	Foster care for PD patients	20%	10%	50%	10%	0%
	Motor complications	10%	40%	40%	10%	0%

Question	Item	Selected by
What are your preferred training formats (multiple selection possible)?	Personal information events with workshop character	40%
	Online training, E-learning formats (self-study courses)	40%
	Online trainings (live with speakers)	50%
	Classroom training	60%
	Case studies	50%
	Advanced trainings during the meetings of existing regional quality circles	20%
	Regional training courses in a new PANOS-specific format	50%
	Central training courses (e.g. in PD centers)	40%

Information on the program

Question	Item	Selected by
How would you like to be informed about current developments in the project (multiple selection possible)?	Collaborative platforms like Confluence	0%
	Print-Newsletters	20%
	PANOS-Website	40%
	Regular information events	50%
	E-Mail-Newsletters	80%

Miscellaneous

Question	Item	Yes	No	Cannot judge	No answer
Did you take part in the 1st PANOS Workshop on 29.01.2020?		55%	45%	0%	0
Are you registered for the 2nd PANOS Workshop (11.03.2020) or do you plan to participate?		68%	27%	0%	5%
Are you registered for the 3rd PANOS Workshop (22.04.2020) or do you plan to participate?		68%	18%	0%	14%
Do you consider it sufficient to be able to contact a specialist via the internal messaging system of the PANOS platform in case of emergencies or uncertainties?		77%	18%	0%	5%
Would it be generally practicable for you if the PANOS users involved were to communicate via the internal PANOS news platform?		86%	9%	0%	5%