

Healthy Brain Ageing (HeBA)

Motivation for participating in the first online phase of HeBA (#1963)

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BACKGROUND and OBJECTIVE

Complaints such as anxiety, depression, sleep disturbances, constipation, or olfactory deficits may occur years to decades before the defining symptoms of Parkinson disease (PD) become apparent. The European multicenter Healthy Brain Ageing (HeBA) Study (for design and methods see *Abstract #1957*) aims to collect information on risk and prodromal factors in large European samples in an attempt to identify individuals at high risk for developing PD.

In the present study we aimed to understand participants' reasons and motivation for participation in the first online phase of HeBA, which may be important for enhancing recruitment and retention rates in HeBA and similar studies.

METHODS

Open communication and advertisement through various channels was launched in the regions of Innsbruck, Luxembourg, and Barcelona to invite people over 50 years of age without any known neurodegenerative disease to participate in an online survey. In addition to questions related to risk and prodromal markers, participants were asked how they became aware of the study and what their motivation to participate was through custom-made, semi-structured questionnaires, tailored to the centers' specific interests. Data are presented as percent positive answers to questions. For the present analysis datasets of Innsbruck and Luxembourg were combined as the same questions and design allowing for multiple answers were used (n=3,884, 57.4% females). Barcelona used a slightly different methodology with similar questions, but only single answers were allowed (n=3,364, 73.5% females).

RESULTS

There have been various HeBA awareness campaigns in the different centres, e.g. Innsbruck and Luxembourg initially focused on presence in newspapers, television and radio, while Barcelona focused on (electronic) newspapers and social media (Table 1).

Most common reasons for participation were: 'I would like to support research into these diseases', followed by 'A loved one (friend or relative) has PD or dementia', and 'I am concerned that I may develop PD or dementia in the future' (Figures show sex differences in % positive answers). Motivation to participate was also analyzed according to answers to high-interest questions (Tables 2A and 2B).

Table 1	INN + LUX	F / M, p-Value	BAR	F / M, p-Value
Newspaper	28.4%	28.3% / 28.6%, p=0.87	30.9%	30.1% / 33.6%, p=0.15
Television	8.7%	8.9% / 8.5%, p=0.67	0.7%	0.7% / 0.7%, p=0.99
Radio	4.2%	4.5% / 3.7%, p=0.20	5.2%	4.8% / 6.3%, p=0.23
Flyer	4.5%	4.0% / 5.1%, p=0.14	1.3%	1.0% / 2.4%, p=0.030
Word of mouth	7.1%	7.4% / 6.6%, p=0.34	8.3%	6.9% / 13.1%, p<0.001
Social media	15.0%	19.1% / 9.5%, p<0.001	33.9%	37.6% / 21.4%, p<0.001
Email	22.3%	19.2% / 26.4%, p<0.001		
My doctor	1.1%	0.6% / 1.8%, p<0.001	0.8%	0.9% / 0.4%, p=0.55

Table 1 Legend: Percent positive answer to the question on how participants became aware of the study. Significance levels were calculated as per Chi-square test. Abbreviations: BAR = Barcelona, F = female, INN = Innsbruck, LUX = Luxembourg, M = male

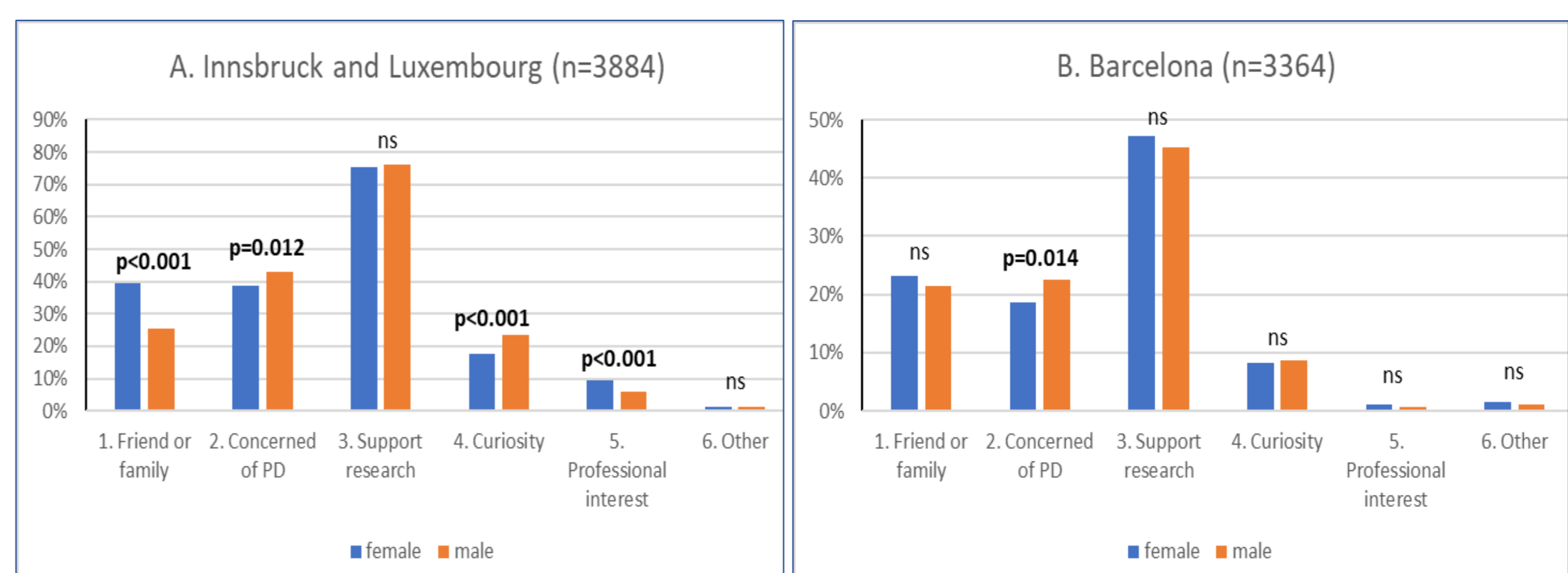


Table 2A Innsbruck and Luxembourg	Pos. PD family history	Sub. smell loss	Dream enactment	Sub. memory loss
Overall percentage	15.3%	8.0%	18.5%	16.8%
Friend or family (y/n)	35.7% / 6.4%, p<0.001	8.1% / 7.9%, p=802	18.6% / 18.5%, p=97	16.6% / 16.9%, p=82
Concerned of PD (y/n)	20.5% / 11.9%, p<0.001	10.9% / 6.0%, p<0.001	23.1% / 15.4%, p<0.001	27.6% / 9.4%, p<0.001
Support research (y/n)	13.2% / 21.7%, p<0.001	7.6% / 9.2%, p=0.129	18.0% / 20.0%, p=19	15.7% / 20.1%, p=0.002
Curiosity (y/n)	7.1% / 17.3%, p<0.001	7.2% / 8.2%, p=0.416	14.8% / 19.5%, p=0.002	11.2% / 18.2%, p<0.001
Professional interest (y/n)	12.9% / 15.6%, p=0.11	11.7% / 7.7%, p=0.016	18.4% / 18.5%, p=99	13.3% / 17.1%, p=0.095
Other (y/n)	2.3% / 15.5%, p=0.010	6.1% / 7.9%, p=0.99	14.3% / 18.6%, p=0.58	6.1% / 16.9%, p=0.052

Table 2B Barcelona	Pos. PD family history	Sub. smell loss	Dream enactment	Sub. memory loss
Overall percentage	20.1%	8.3%	11.5%	25.9%
Friend or family (y/n)	53.1% / 10.0%, p<0.001	7.7% / 8.5%, p=55	11.3% / 11.6%, p=90	25.7% / 25.9%, p=93
Concerned of PD (y/n)	24.0% / 19.2%, p=0.011	12.4% / 7.3%, p<0.001	17.5% / 10.0%, p<0.001	39.7% / 22.5%, p<0.001
Support research (y/n)	5.2% / 33.4%, p<0.001	7.4% / 9.2%, p=0.061	9.5% / 13.3%, p<0.001	20.3% / 30.9%, p<0.001
Curiosity (y/n)	6.5% / 21.3%, p<0.001	6.0% / 8.5%, p=0.18	10.0% / 11.6%, p=0.44	26.7% / 25.8%, p=0.78
Professional interest (y/n)	10.0% / 20.2%, p=0.25	8.6% / 8.3%, p=0.99	20.0% / 11.4%, p=11	22.9% / 25.9%, p=0.85
Other (y/n)	4.3% / 20.3%, p=0.003	6.3% / 8.4%, p=0.80	2.1% / 11.6%, p=0.038	20.8% / 26.0%, p=0.51

Tables 2 and 3 Legend: Motivation to participate according to answers to high-interest questions. Significance levels were calculated as per Chi-square test.

CONCLUSIONS

Announcement of the HeBA study through various channels has led to successful recruitment so far. Most common reasons for participants to take the online questionnaire were the will to support research into the area, friends or relatives with PD or dementia, or fear to develop disease. The latter reason was associated with more frequent endorsement of positive family history, subjective hyposmia, dream-enacting behaviour, and memory complaints, while the will to support research and curiosity were associated with a lower frequency of some of these complaints.

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