

# The Uncertainty of Waiting:

## Assessing the Impact of the First Spanish Meeting for Premanifest and Potential Carriers of Huntington's Disease

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### Background & Aim

A major interventional goal in Huntington's disease (HD) is preventive treatment prior to the onset of disabling symptoms [1]. Thus, there is an exponential interest and need for persons in HD preclinical stages to participate in research, such as persons at risk for HD (HdRisk) and persons with premanifest or prodromal HD (PreHD) [2,3]. On October 2021, the European Huntington Association (EHA) launched the project Moving Forward (MF) in Spain to reach out to these specific groups and bring them closer to studies and trials [4]. Some months later, the EHA promoted the first ever event in Spain explicitly dedicated to persons with HdRisk and PreHD (see Figure 1 and Figure 2). 52 persons from all over the country converged in Madrid for a national meeting entitled "The Uncertainty of Waiting", which included a presentation about the EHA Moving Forward project, an informal debate about genetic testing moderated by a neuropsychologist, group dynamic exercises, a get-together with snacks and drinks and a leisure activity. This work aimed to assess the meeting impact through the participants' feedback.

### Methods

To learn about the participants' impressions of the meeting, the EHA created an anonymous online survey using the SurveyMonkey platform [5] - see Figure 3. The survey was sent via e-mail to all the meeting attendees three days after the event. The participants' expectations towards HD organizations were also collected. The survey included open-ended and closed-ended questions and response percentages were analysed.



Figure 1 – The Uncertainty of Waiting Flyer

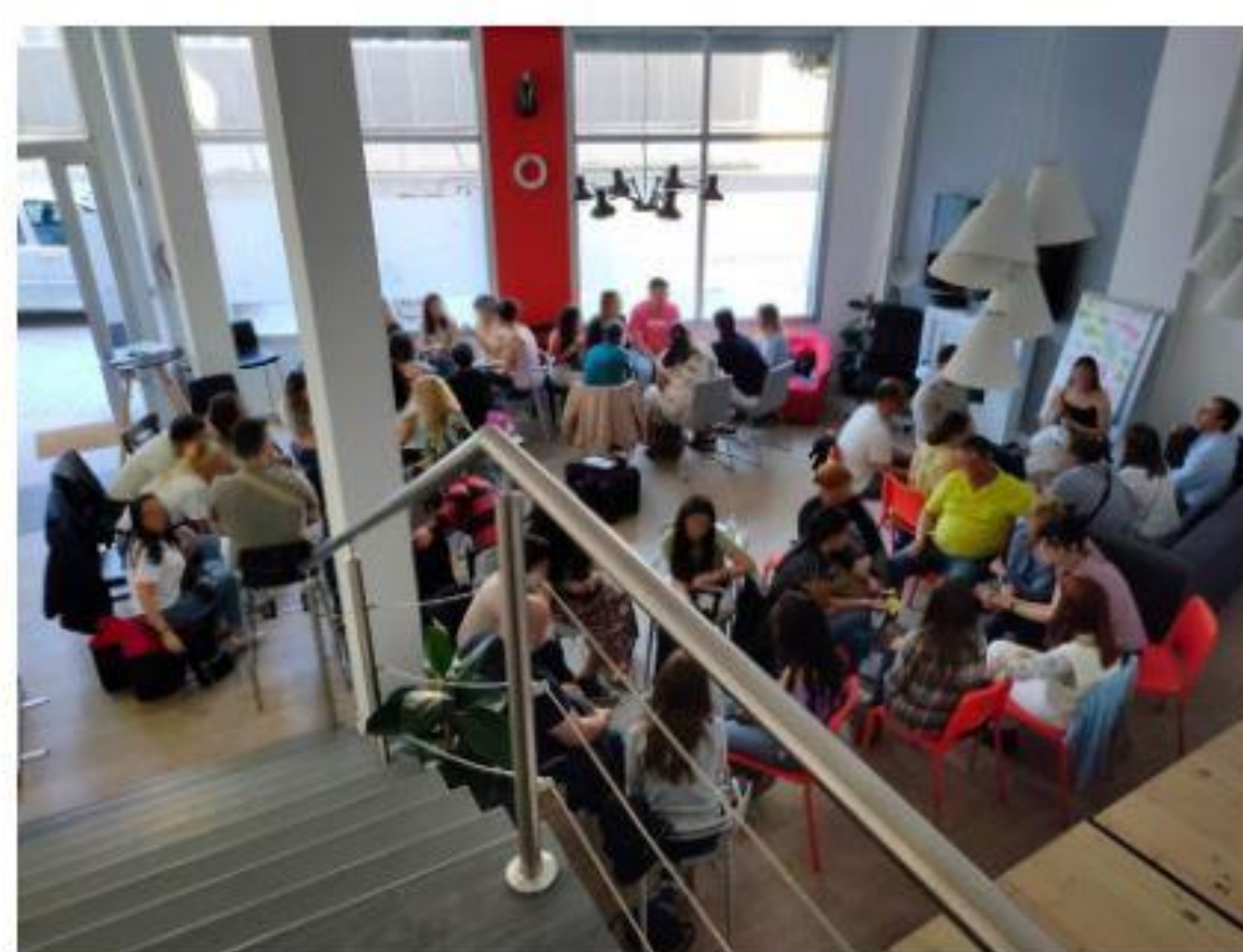


Figure 2 – Group Dynamics during the Meeting



Figure 3 – Feedback Survey

### Results

There were 34 survey respondents, 68% women, 44.11% under 35 years (see Figure 4 and Figure 5). Importantly, while 73.53% of respondents attended an HD meeting for the first time, 79.41% considered it very interesting and useful (particularly the debate) and 94.12% expressed interest in joining future HD-related events (see Table 1 and Figure 6). HD research (79.41%) and coping strategies (76.47%) were signalled as preferred topics for upcoming meetings (see Figure 7). Interestingly, most attendees reported their wish to get information about HD and HD research (85.29%) and psychological support (79.41%) from HD associations (see Figure 8).

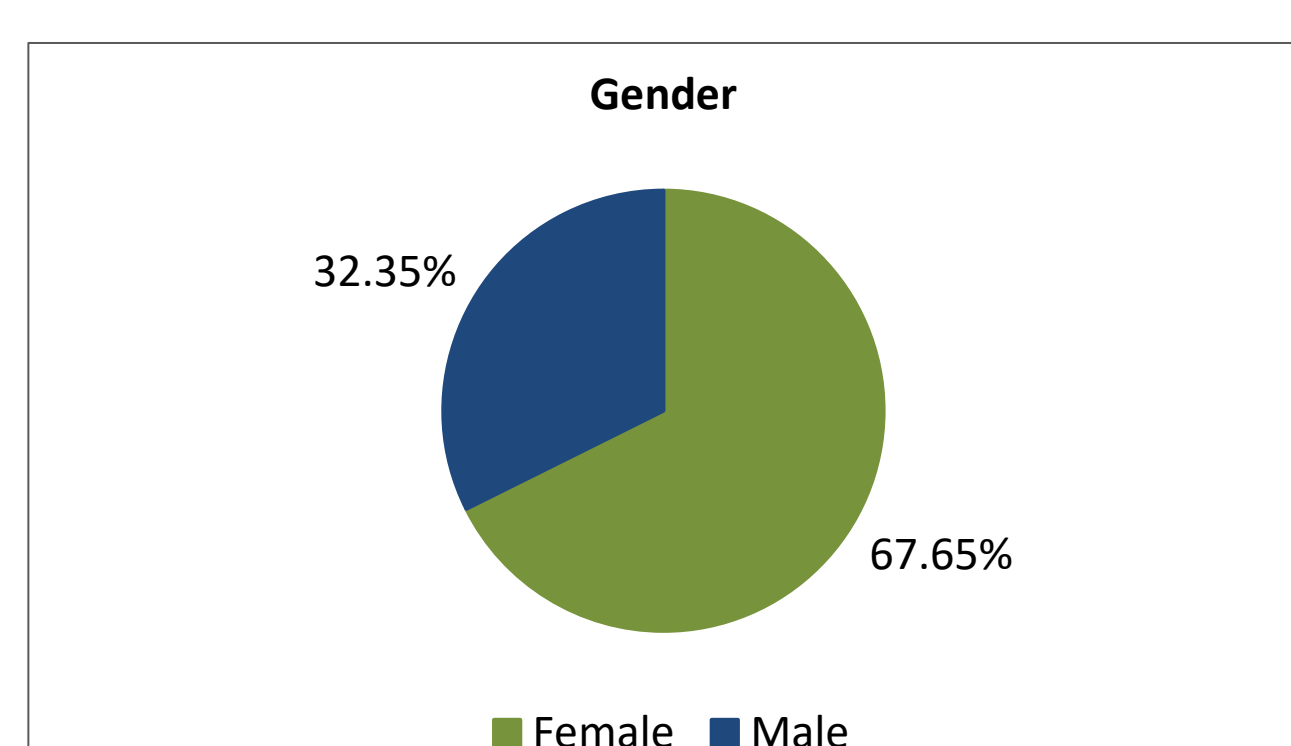


Figure 4 – Demographic Characteristics: Gender

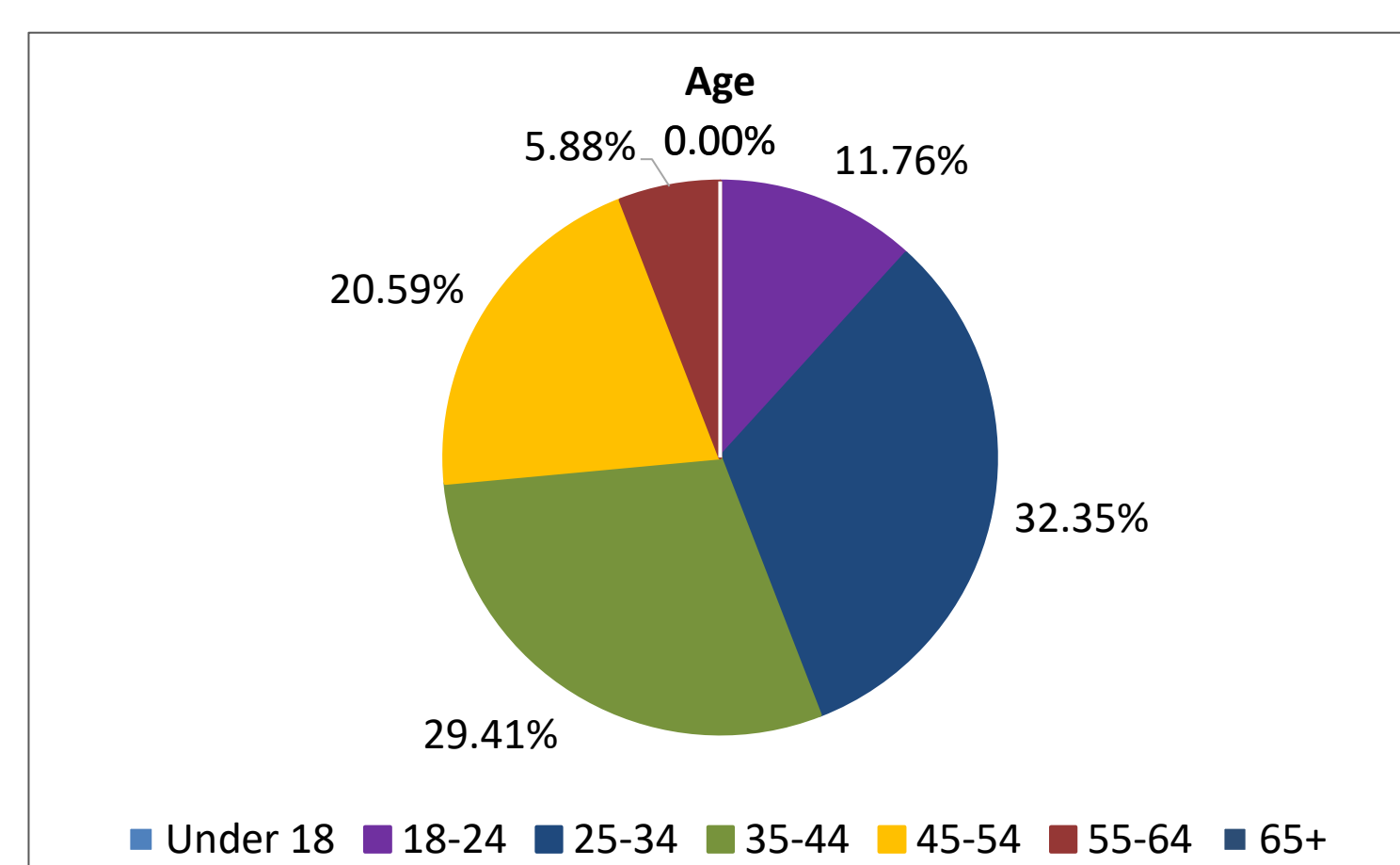


Figure 5 – Demographic Characteristics: Age

General Impressions about HD Meeting		n=34
		%
<b>First time attending an HD meeting?</b>		
Yes		73.53
No		26.47
<b>How did you learn about this HD meeting?</b>		
Family		38.24
Friends		2.94
Clinical/Research Team		8.82
HD Association		41.18
Social Networks		23.53
Online (e.g., Moving Forward Website)		5.88
<b>How would you rate this HD meeting?</b>		
Very Interesting and Useful		79.41
Interesting and Useful		17.65
Relatively Interesting and Useful		2.94
Not Interesting and Not Useful		0
<b>Interested in attending future HD-related events?</b>		
Yes		94.12
Maybe		5.88
No		0

Table 1 – General Impressions about HD Meeting

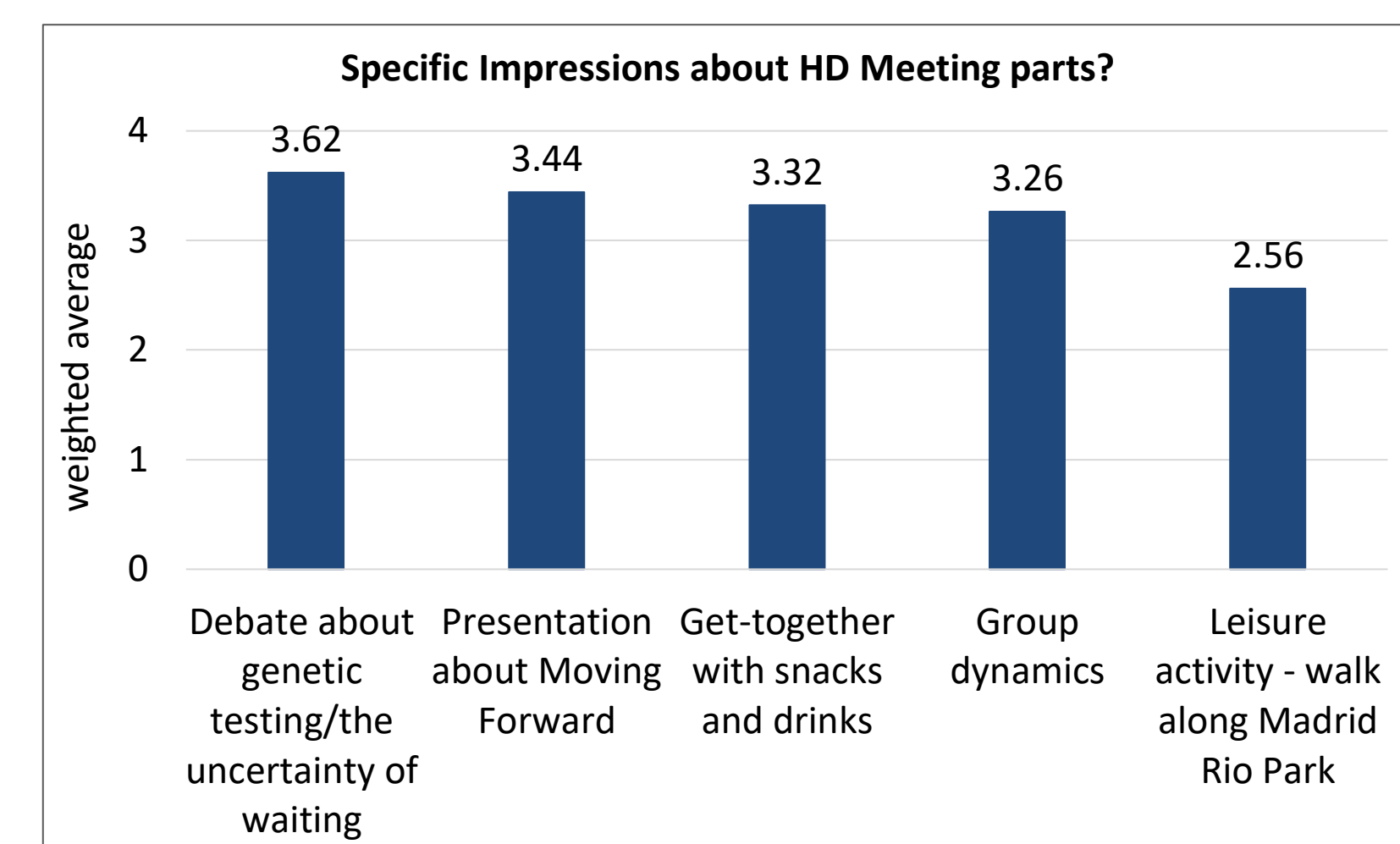


Figure 6 – Specific Impressions about HD Meeting parts. Range 1-4: not interesting/useful - very interesting/useful

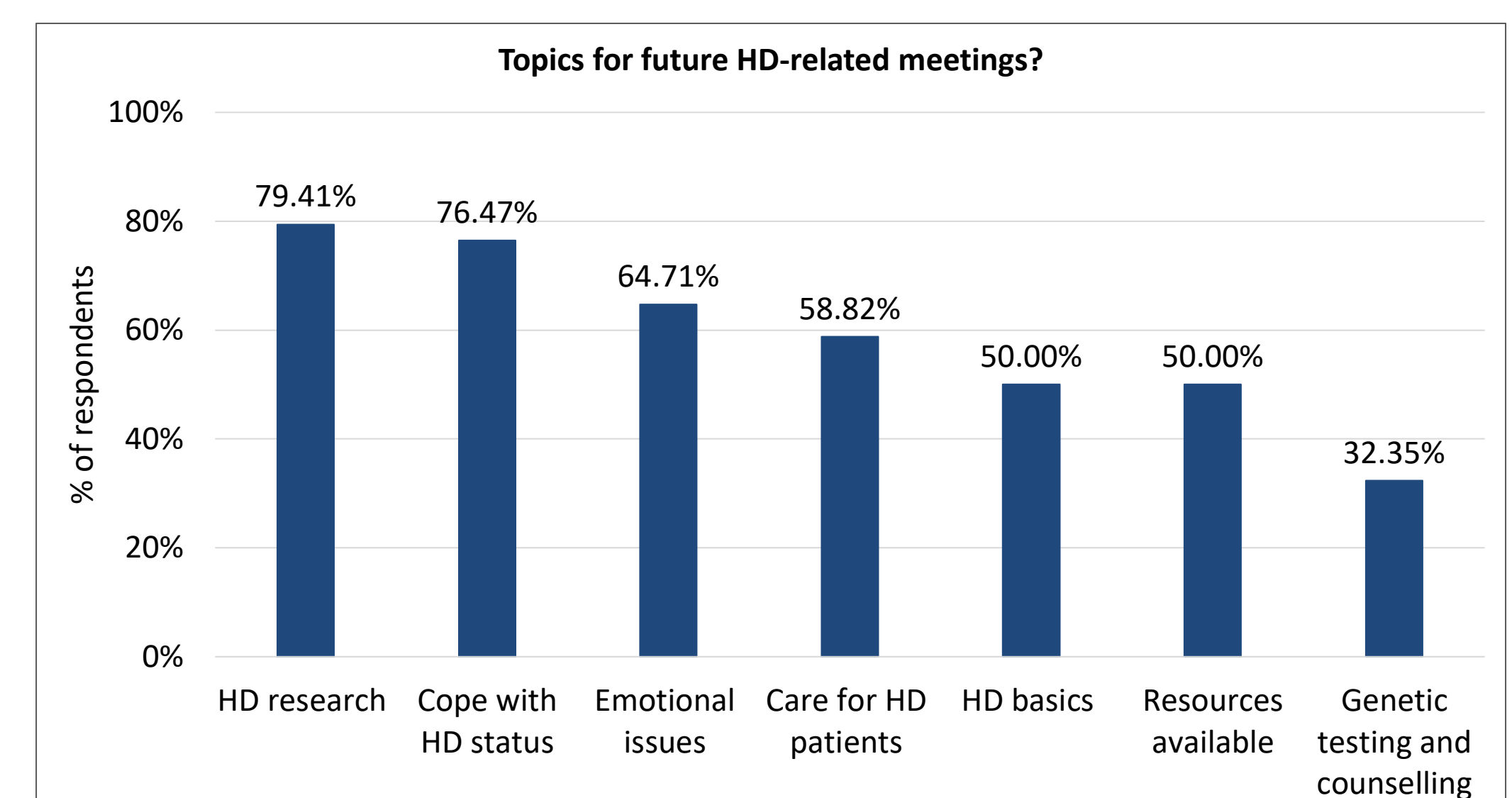


Figure 7 – Topics for future HD-related meetings

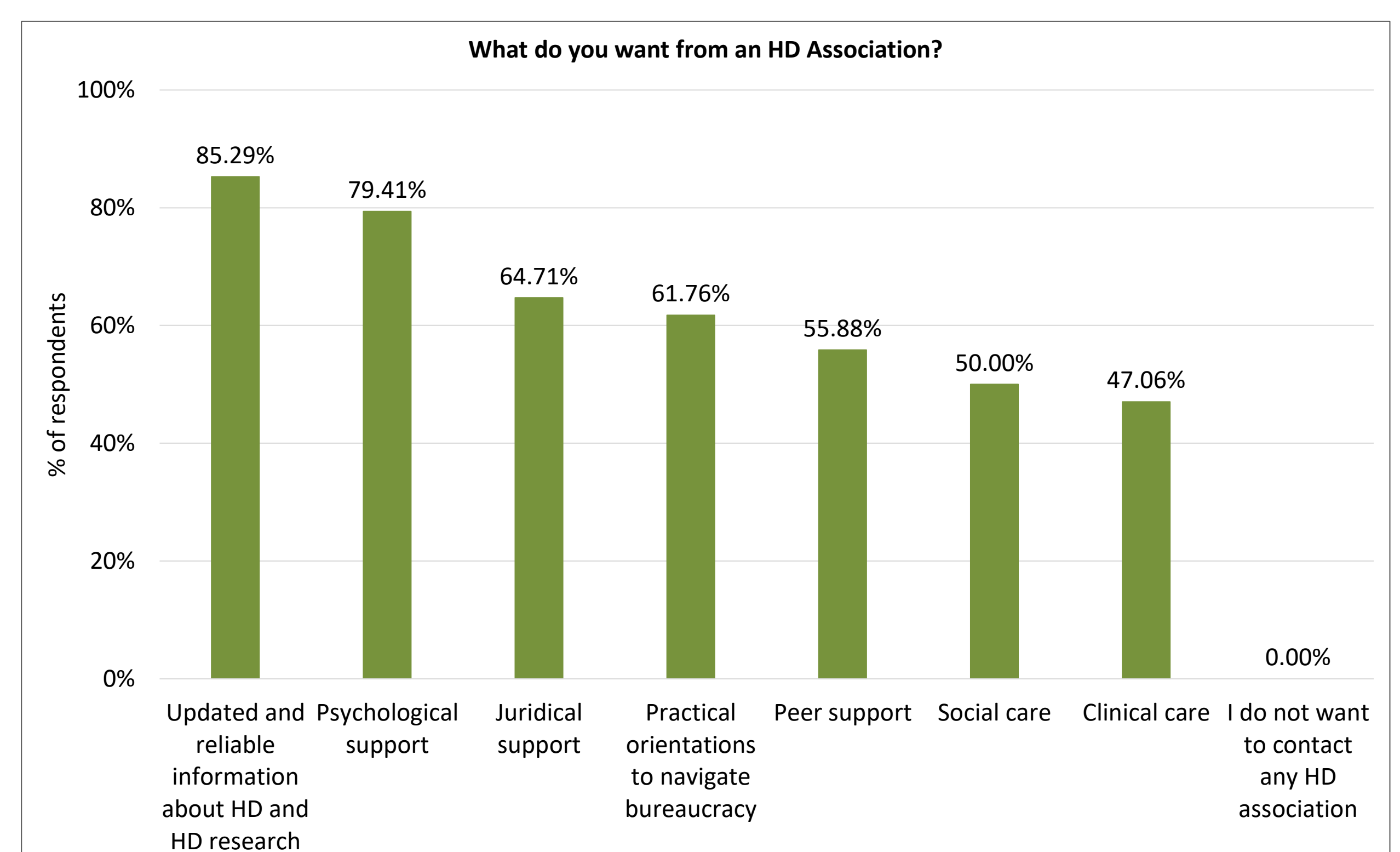


Figure 8 – Services persons would like to get from an HD Association

### Key Findings and Conclusions

- This meeting seems to have been a crucial entrance door for persons with HdRisk and PreHD in Spain to connect with their peers and engage with local associations and healthcare professionals
- The informal, non-clinical approach seems to be effective in getting these specific groups closer to information and support
- Additionally, this event generated relevant topics to address in future actions tailored to these groups and provided important guidelines for the work of local/national HD associations

### References:

- <sup>1</sup> Langbehn, D. R., & Hersch, S. (2020). Clinical Outcomes and Selection Criteria for Prodromal Huntington's Disease Trials. *Movement disorders : official journal of the Movement Disorder Society*, 10.1002/mds.28222. Advance online publication. <https://doi.org/10.1002/mds.28222>
- <sup>2</sup> Dash, D., & Mestre, T. A. (2020). Therapeutic Update on Huntington's Disease: Symptomatic Treatments and Emerging Disease-Modifying Therapies. *Neurotherapeutics : the journal of the American Society for Experimental Neurotherapeutics*, 17(4), 1645–1659. <https://doi.org/10.1007/s13311-020-00891-w>
- <sup>3</sup> Reilmann, R., Leavitt, B. R., & Ross, C. A. (2014). Diagnostic criteria for Huntington's disease based on natural history. *Movement disorders : official journal of the Movement Disorder Society*, 29(11), 1335–1341. <https://doi.org/10.1002/mds.26011>
- <sup>4</sup> <https://ehamovingforward.org/news/>
- <sup>5</sup> <https://www.surveymonkey.com/>