

# Let Us Talk: A Communication Skills Training Course for Russian Healthcare Professionals Working with 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 July 2021, the European Huntington Association (EHA) launched the project Moving Forward (MF) in Russia to reach out to these specific groups and bring them closer to studies and trials [4]. To understand the situation in the country, the EHA created an anonymous online survey to determine which factors affect the willingness of persons with HdRisk and PreHD in Russia to participate in research [5]. This survey showed that there were significant challenges in the access of these HD groups to the healthcare professionals in Russia. Accordingly, the EHA developed "Let Us Talk", an experimental web-based communication skills training course to educate healthcare professionals on ways to effectively communicate and relate to HD patients and families. This course was thought to affect the quality of the care provided and, consequently, improve the quality of life of everyone involved. Moreover, it was thought to facilitate the research participation of the Russian HD community.

## Methods

The EHA implemented the 12-hour online training course for Russian healthcare professionals over three Saturdays via Zoom (see **Figure 1**). Russian and non-Russian HD experts addressed topics such as verbal/non-verbal communication, HD-related communication changes, communication in clinical settings or communication during genetic testing (see **Figure 2**). Simultaneous translation was provided by a professional company. Original learning formats were used, including the screening of interviews with HD families, group discussions and polls with instant feedback. To assess the "Let Us Talk" impact, the MF team created a structured 20-item online questionnaire about communication skills in clinical settings, which included 7 sentences describing bad communication practices (e.g., "I use medical jargon with patients or family members who may not understand it") and 13 sentences describing good communication practices (e.g., "When the patient or family member talks to me, I try to see their perspectives") - see **Figure 3**. Respondents had to score the frequency with which they engage in each communication behaviour in a five-level Likert scale ranging from 1- Never to 5- Always. The questionnaire was administered at the beginning of the course and one week after its end. The results of the two measurements were analysed and compared.



Figure 2 - Let Us Talk Flyer



Figure 1 - The Course Interface

## Results

111 Russian healthcare professionals, mainly neurologists (79.2%), attended the three-day course. 59 participants answered the questionnaire at baseline and 30 answered it one month later. Respondents were mostly women between 25 and 45 years old, with prior HD experience but little formal training in HD and in communication skills (see **Table 1**).

We observed a general improvement in the communication skills exhibited by the course participants before and after "Let Us Talk".

There was an increase in the frequency of ten of the thirteen good communication practices and a decrease in the frequency of four of the seven bad communication practices.

Significant differences were found in specific behaviours adopted before and after the training: participants reported a reduction in the use of medical jargon with HD patients or family members who may not understand it, a greater acknowledgement of HD patients or family members' questions and concerns and a higher recognition of the importance of giving patients and family members' time to speak (see **Figure 3**).

1. I tend to say what I think, without worrying about how the patient or family member perceives it	1. Never 2. Rarely 3. Sometimes 4. Often 5. Always
2. If I don't understand something that the patient or family member said, I tend to keep this to myself and figure it out later	
3. I'm surprised to find that the patient or family member has not understood what I've said	
4. When the patient or family member talks to me, I try to see their perspectives	
5. I use email or text message to communicate complex issues with patients or family members because it's quick and efficient	
6. When talking to a patient or family member, I pay attention to their body language	
7. Before I communicate, I think about what the patient or family member needs to know, and how best to convey it	
8. When a patient or family member says something I'm not sure about I ask for clarification	
9. I consider cultural and social barriers when I communicate with a patient or family member	
10. I become impatient with patients or family members who do not express their thoughts and opinions clearly	
11. When I'm negotiating and debating complex issues with patients or family members, I view them as an opponent	
12. When I ask questions for clarification, they tend to be open ended and cannot be answered with a simple "yes" or "no"	
13. I make the patient or family member feel listened to first so that they can listen to me after	
14. I restate the patient or family member message in my own words as a way of checking on the accuracy of what I heard	
15. I use medical jargon with patients or family members who may not understand it	
16. I try not to use words that may distress or confuse the patient or family member	
17. I make an honest effort to listen to the patients' or family members' ideas with which I don't agree	
18. I usually check if there is a mutual understanding of diagnostic and/or treatment plans	
19. I understand that what I say to patients or family members is equally important to how I say it	
20. I ask patients or family members if they have questions, concerns, or other issues and give them time to speak about it	

Figure 3 - Communication Skills Questionnaire

Demographics		
	First Assessment n= 59	Second Assessment n= 30
	%	%
<b>Gender</b>		
Female	88.1	90
Male	11.9	10
<b>Age Interval (years)</b>		
18 to 24	5.1	0
25 to 34	33.9	20
35 to 44	30.5	36.7
45 to 54	16.9	23.3
55 to 64	11.9	20
65 to 74	1.7	0
75 or older	0	0
<b>Prior HD Experience</b>		
Yes	64.4	56.7
No	35.6	43.3
<b>Previous HD Training</b>		
Yes	25.4	26.7
No	74.6	73.3
<b>Previous Communication Skills Training</b>		
Yes	23.7	30
No	76.3	70

Table 1 - Demographic Characteristics

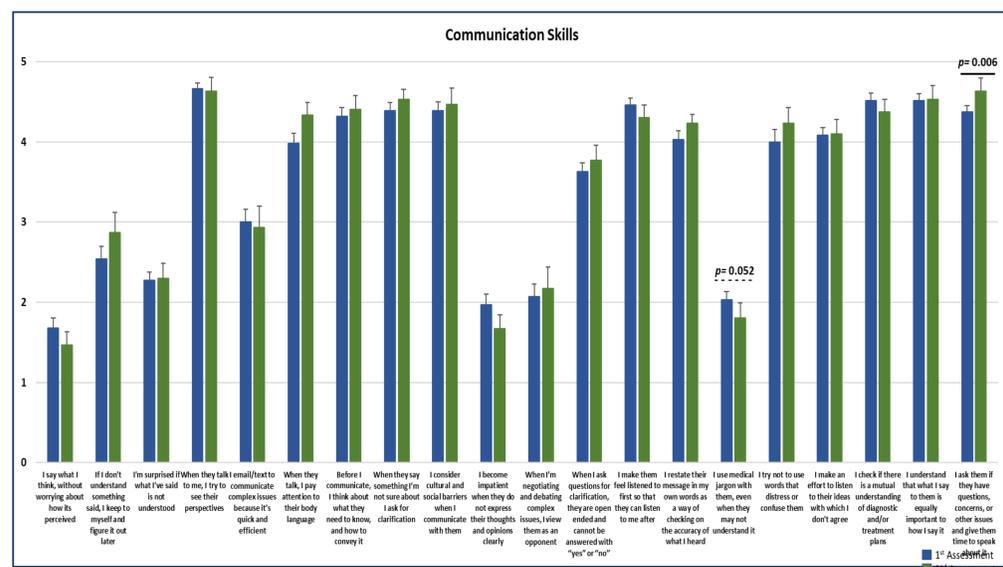


Figure 3 - Good and Bad Communication Skills | weighted average: 1- Never, 2 - Rarely, 3 - Sometimes, 4 - Often, 5 - Always

## Key Findings and Conclusions

- "Let Us Talk" has improved the communication skills of Russian healthcare professionals, who reported more appropriate behaviours towards HD patients and family members after the course
- The training was particularly effective in making verbal communication more easily understood (decreased use of medical jargon) and improving the active listening skills of healthcare professionals (increased attention and time to hear HD patients and family members)
- "Let Us Talk" seems to be a good educational model for the European Huntington Association/Moving Forward team to replicate in other European countries and enhance the doctor-patient relationship among HD communities in which this topic is identified as an obstacle to research participation.

## References:

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- <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://ehamovingforward.org/2021/09/moving-forward-survey-in-russia/>