EUROPEAN Huntington Association

The Power of HD Families:
Driving Progress in Clinical Trials

HUNTINGTON ACADEMY

Real-life Experiences for Better Care

MOVING FORWARD

The Power of HD Families: Driving Progress in Clinical Trials

WAVE™ LIFE SCIENCES

Roche

Goals

- Empower HD families and HD Associations
- Strengthen clinical trial networks
- Accelerate recruitment
- Improve retention
- Speed progress toward effective therapies for HD

Image by Newcastle University

Pilot Phase

- Map active and potential HD trial sites to guide sponsors
- Strengthen ties with the local HD community and prepare families for research
- Partner with local HD associations and advocates to identify sites and gather family feedback
- Visit clinics, build relationships, and highlight underrepresented but trusted centres
- Share insights with stakeholders to improve trial experiences and plan next steps

Image by Laura Nye

HUNTINGTON ACADEMY

Real-life Experiences for Better Care

Small-Scale Partnership in Adult Education
Call Erasmus+ October 2023
February 2024 – July 2025

European Huntington Association (Applicant/Coordinator)

Astri Arnesen, Filipa Júlio, Claudia Azañedo Vázquez | Beatriz Campaniço

Ligue Huntington Francophone Belge (Partner Organization)

Albert Counet, Olivier Graf

Bulgarian Huntington Association (Partner Organization)

Nataliya Grigorova, Regina Gospodinova

Asociacion De Corea De Huntington Española (Partner Organization)

Ruth Blanco, Jarelys López

- **Team**

- **Goals**

  - Ensure Free Access for All
  - Offer Multilingual Resources
  - Represent Diverse HD Realities
  - Promote Co-Creation of Knowledge
  - Foster a Multidisciplinary, Holistic Approach to Care
  - Encourage Knowledge Sharing and Peer Learning
  - Support Practical Application
  - Adapt to Evolving Needs

• Contributors

32 knowledgeable HD Experts

- 14 Family Members
- 18 Professionals

FRANCISCO IRUELA

MARIYANA GOERGIEVA

JAVIER LAFUENTE TORRALBA

ISABEL ANTÚNEZ

RUDY VERA

JESSICA HENDRICKX

SAUL MARTINEZ-HORTA

JUAN M. GARCÍA MONTAÑO

IVA IVANOVA

LAMIA GUETTAT

ANNETTE CARLSSON

HUNTINGTON ACADEMY COURSE CREATION PROCESS

DESIGN INTERVIEW SCRIPTS

Two interview scripts were designed – **one for informal and another for formal** caregivers.

CONDUCT SEMI-STRUCTURED INTERVIEWS

A total of **32 semi-structured interviews with contributors** were conducted both online and in person.

TRANSCRIBE, REVIEW, AND SUMMARIZE INTERVIEWS

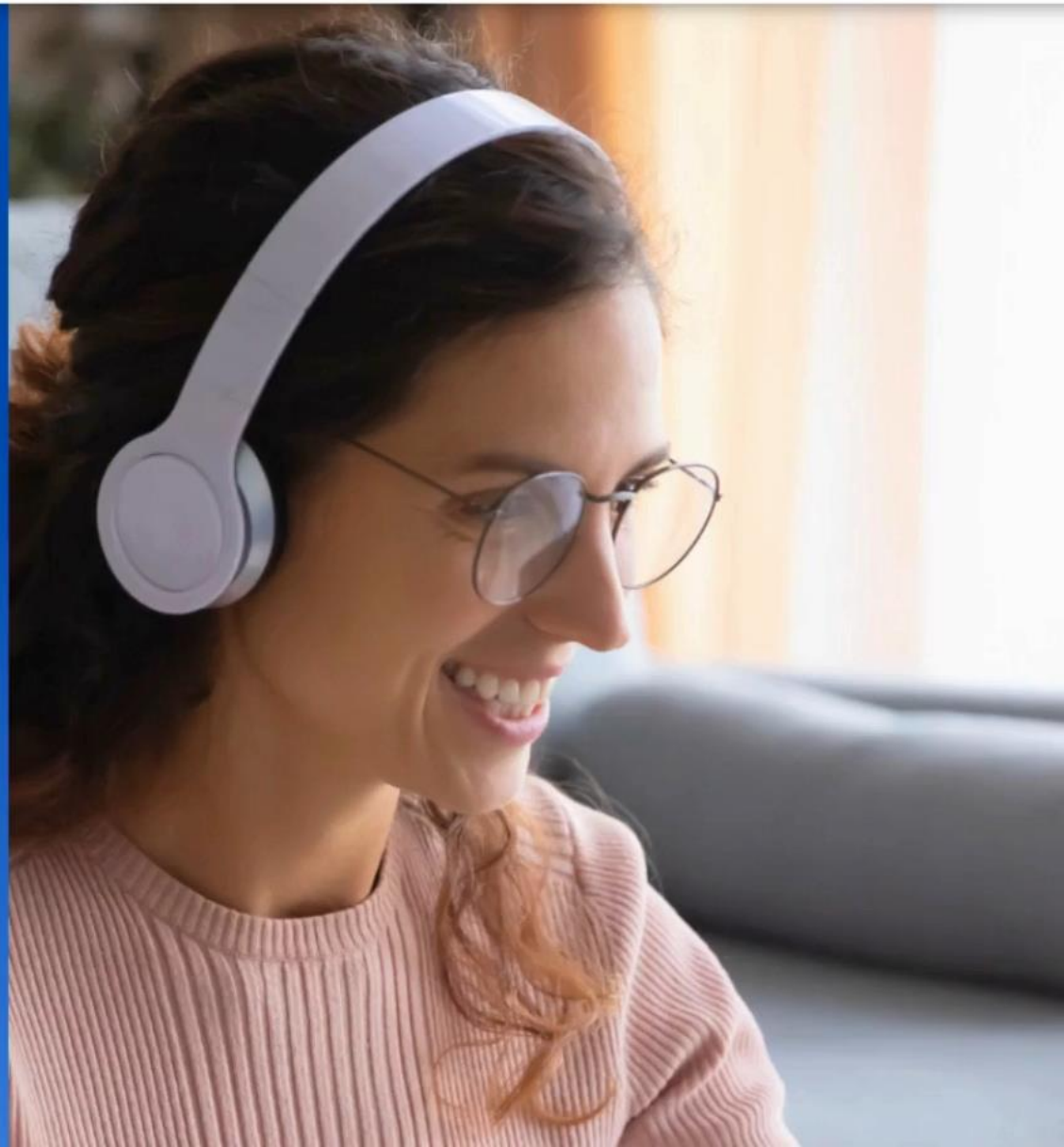
Each interview was transcribed, then reviewed, summarized, and **sent back to the contributor for validation**.

TRANSLATE VALIDATED MATERIAL

Once validated, the **content was translated and used to develop the educational materials** for each course.

HUNTINGTON ACADEMY

REAL-LIFE EXPERIENCES FOR BETTER CARE



Psychology and Huntington's Disease (HD)

Course Description:

This course is designed to equip both formal and informal caregivers of individuals with Huntington's Disease (HD) with the essential knowledge and skills for providing comprehensive care. While each Huntington Academy course focuses on a specific aspect of HD care provision, it's important to recognize that HD challenges should be approached in a holistic way. As a result, many of the Huntington Academy courses are interconnected, with overlapping content that reinforces a comprehensive approach to care.

This course explores the critical role of psychologists in supporting individuals and families affected by HD. It highlights the importance of providing personalized psychological support, fostering communication, and managing crisis situations. Emphasis will be placed on understanding the impact of HD on family dynamics and helping caregivers navigate emotional challenges. Practical strategies for assessment, intervention, and enhancing quality of life will be covered.

Course Objectives:

By the end of this course, participants will be able to:

1. Understand the critical role of psychologists in the multidisciplinary care of individuals with HD and their families across all

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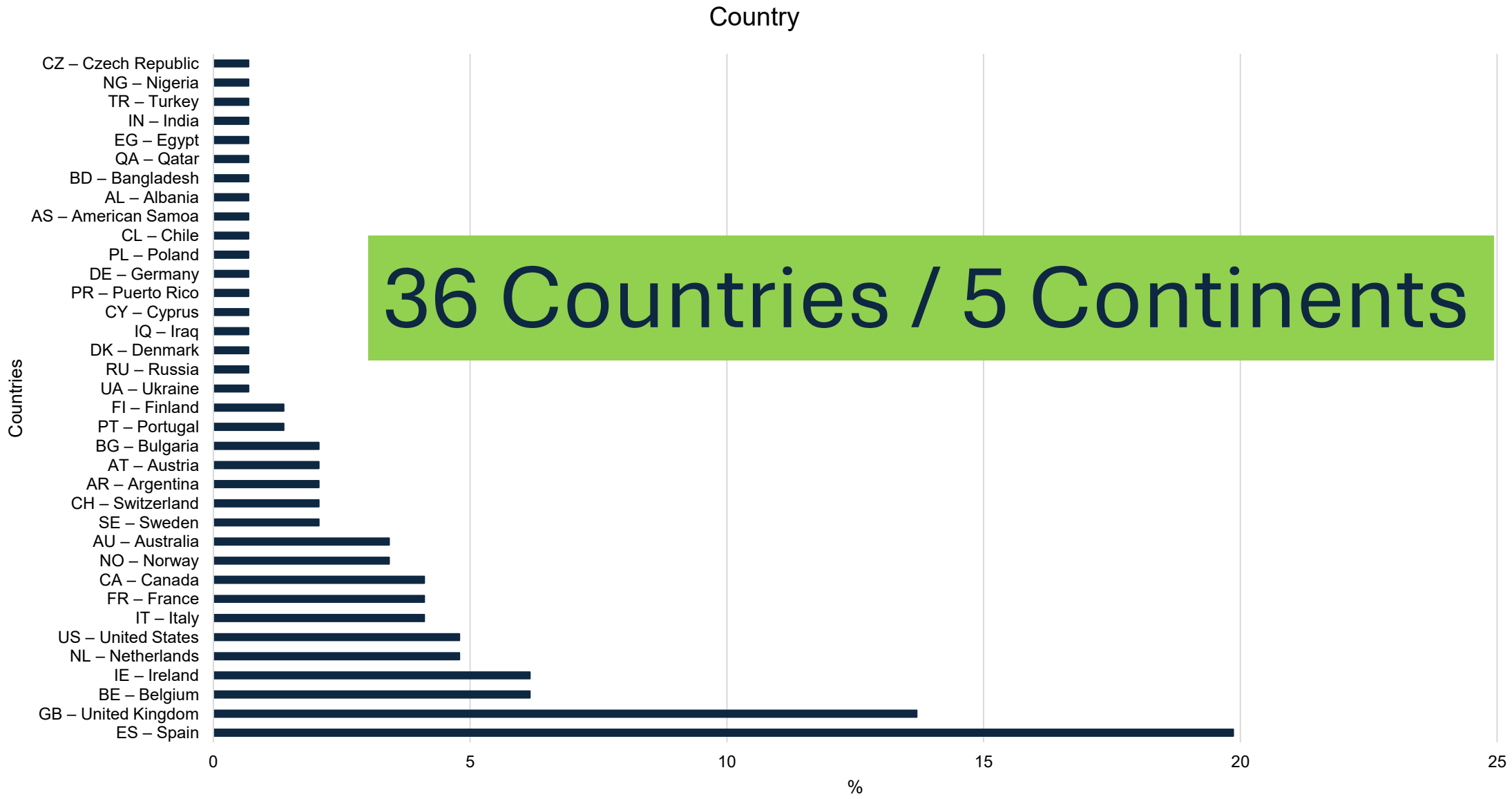
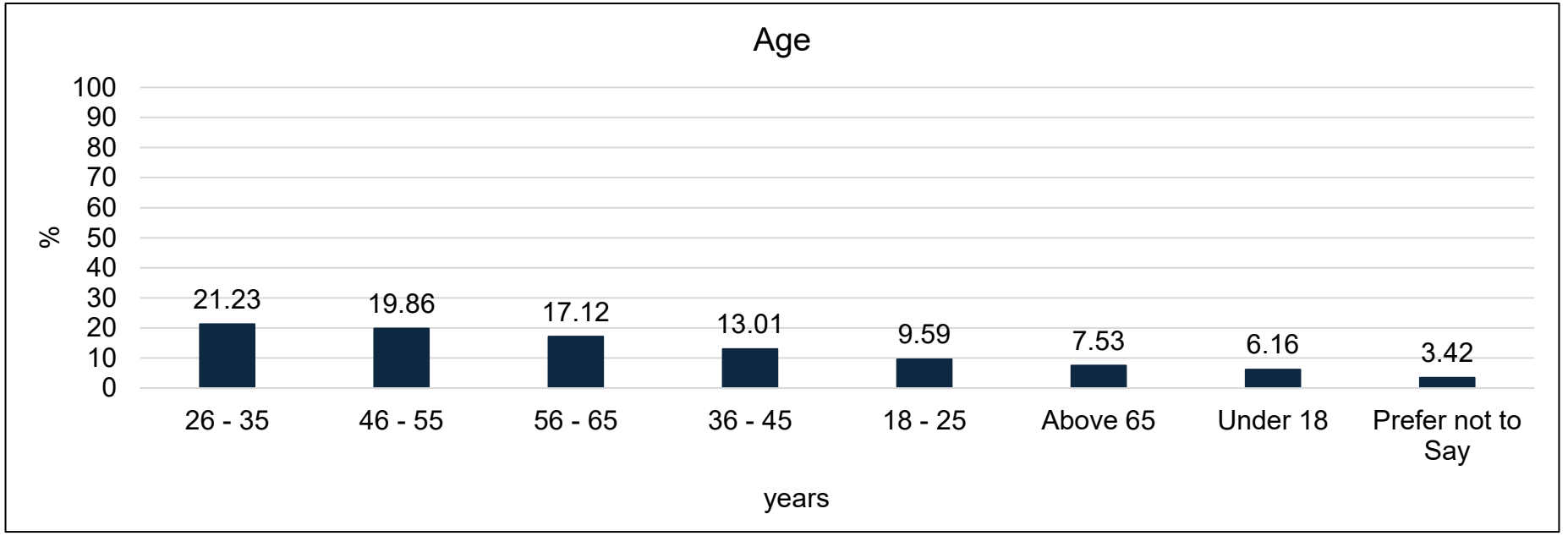
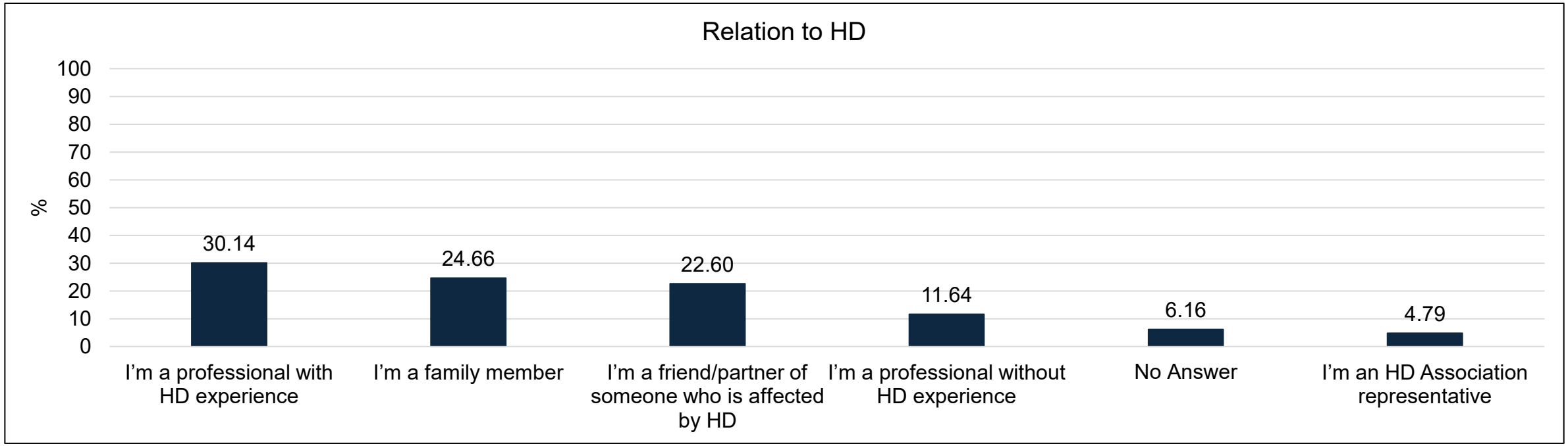
Real-life Experiences for Better Care

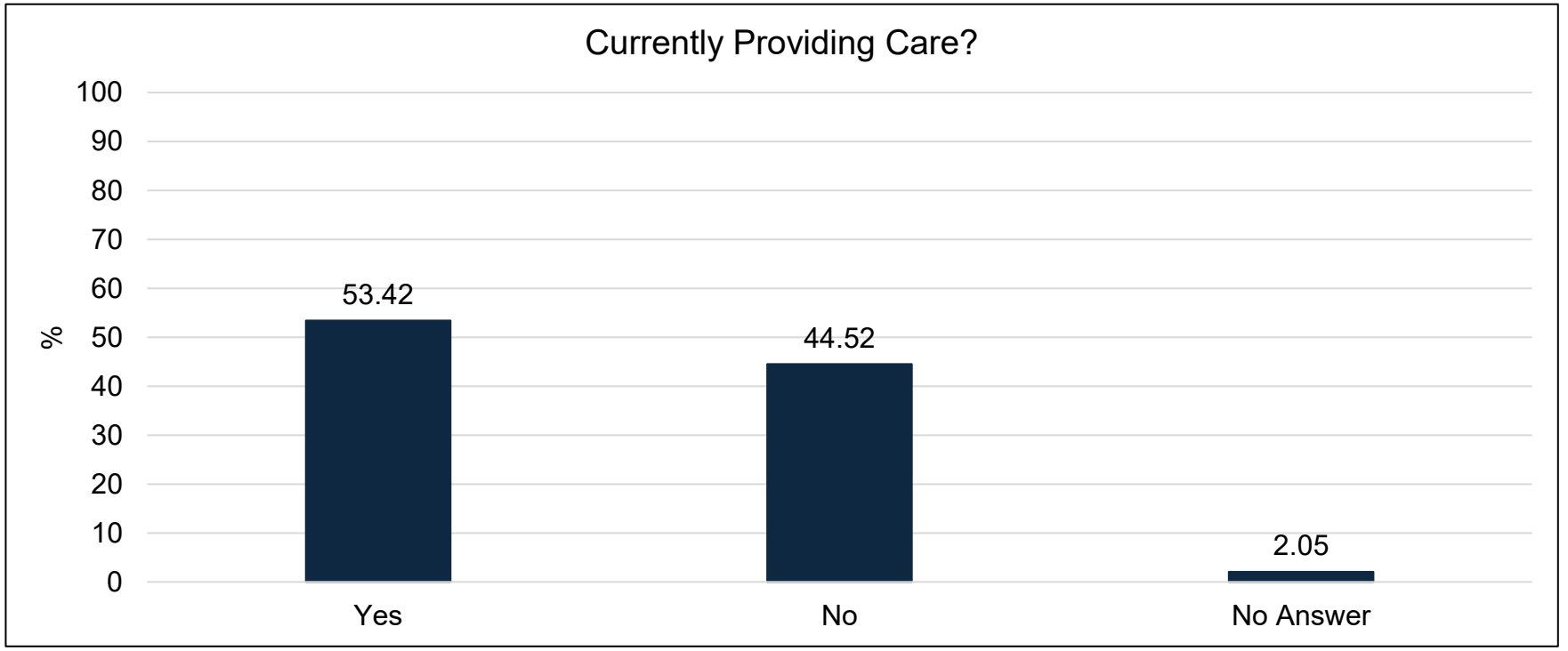
First 100 days: 146 users

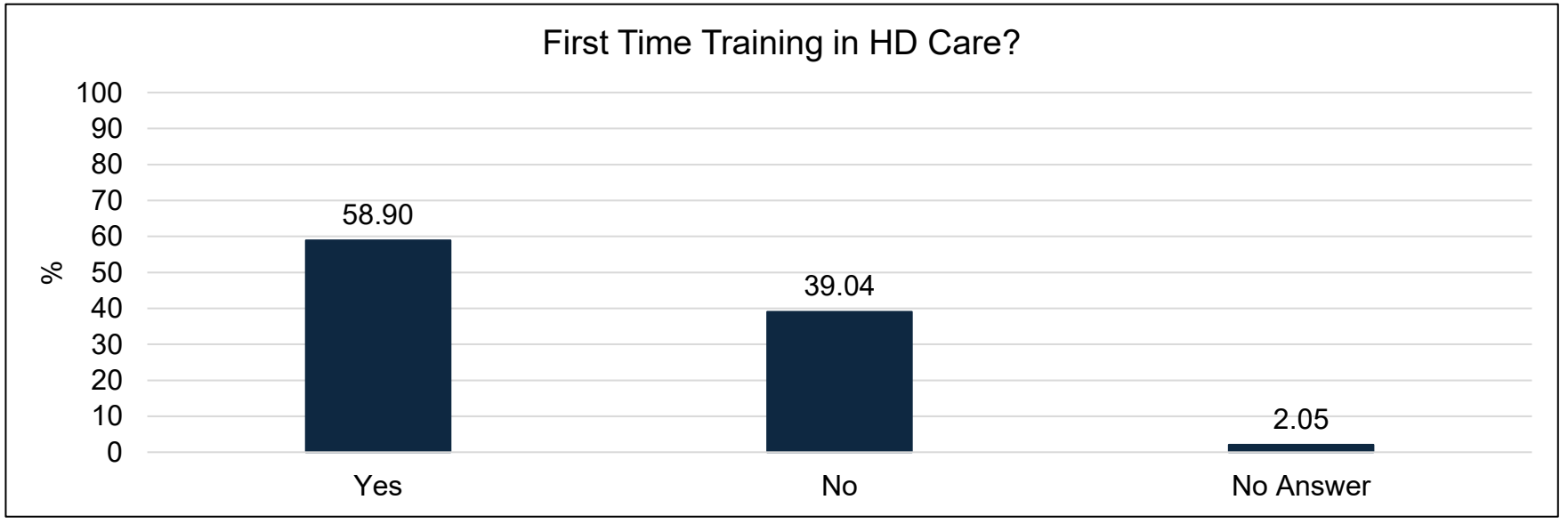
(28th May 2025 - 5th September 2025)


Country
CZ – Czech Republic
NG – Nigeria
TR – Turkey
IN – India
EG – Egypt
QA – Qatar
BD – Bangladesh
AL – Albania
AS – American Samoa
CL – Chile
PL – Poland
DE – Germany
PR – Puerto Rico
CY – Cyprus
IQ – Iraq
DK – Denmark
RU – Russia
UA – Ukraine
FI – Finland
PT – Portugal
BG – Bulgaria
AT – Austria
AR – Argentina
CH – Switzerland
SE – Sweden
AU – Australia
NO – Norway
CA – Canada
FR – France
IT – Italy
US – United States
NL – Netherlands
IE – Ireland
BE – Belgium
GB – United Kingdom
ES – Spain
Countries
0
5
10
15
20
25
%
36 Countries / 5 Continents


Age
100
90
80
70
60
50
40
30
20
10
0
%
21.23
19.86
17.12
13.01
9.59
7.53
6.16
3.42
26 - 35
46 - 55
56 - 65
36 - 45
18 - 25
Above 65
Under 18
Prefer not to Say
years


Relation to HD
100
90
80
70
60
50
40
30
20
10
0
%
30.14
24.66
22.60
11.64
6.16
4.79
I'm a professional with HD experience
I'm a family member
I'm a friend/partner of someone who is affected by HD
I'm a professional without HD experience
No Answer
I'm an HD Association representative


Currently Providing Care?
100
90
80
70
60
50
40
30
20
10
0
%
53.42
44.52
2.05
Yes
No
No Answer


First Time Training in HD Care?
100
90
80
70
60
50
40
30
20
10
0
%
58.90
39.04
2.05
Yes
No
No Answer

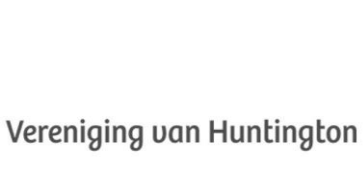

MOVING
FORWARD


EUROPEAN Huntington Association


РЕДКИЕ ЛЮДИ
Вместе ради жизни


Huntington Liga vzw


Landsforeningen for Huntingtons sykdom


Vereniging van Huntington


AHF
ASSOCIATION HUNTINGTON FRANCE
Vivre avec la maladie


FEPAEH
FEDERACIÓN ESPAÑOLA DE PERSONAS AFECTADAS POR LA ENFERMEDAD DE HUNTINGTON


Asociación Corea de Huntington Española


ASOCIATIA HUNTINGTON - ROMÂNIA


Riksförbundet
Huntingtons sjukdom


LIGUE HUNTINGTON
FRANCOPHONE BELGE


HUNTINGTON
O.N.L.U.S.
LA RETE ITALIANA DELLA MALATTIA DI HUNTINGTON


YTAN
Digitalt stöd unga anhöriga


Roche


PTC
THERAPEUTICS


NOVARTIS


EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS


HORIZON


#RAREis...
A program by AMGEN

Belgium (Wallonia) December 2022

Sweden December 2023

Belgium (Flanders) December 2022

Czech Republic May 2025

Norway May 2023

France September 2023

Italy February 2025

Spain October 2021

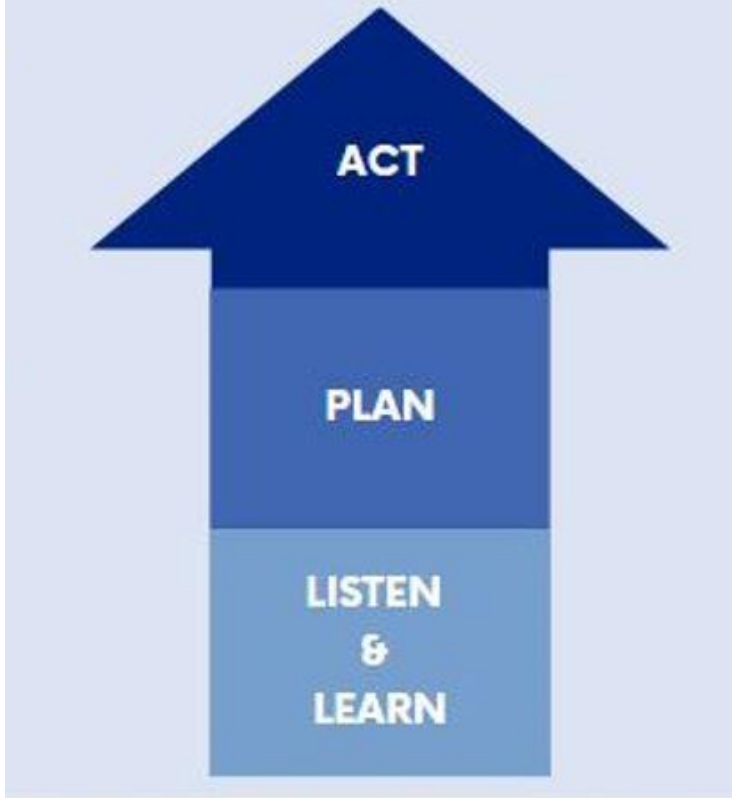
Russia July 2021

The Netherlands 2023

Romania April 2024

OUR MISSION

WITH THE LOCAL ASSOCIATIONS



OUR MAIN GOALS

- BRING THE HD COMMUNITY TOGETHER
- OFFER TAILORED SUPPORT TO SPECIFIC GROUPS IN THE HD COMMUNITY
- PROVIDE ADEQUATE AND RELIABLE INFORMATION
- EDUCATE FAMILIES AND PROFESSIONALS ON HD AND RESEARCH
- INCREASE CLINICAL TRIAL READINESS

Collaborations & Online Presence

🌍 Collaborations with Associations in 10 European countries:
Belgium, Czech Republic, France, Italy, Netherlands, Norway, Romania, Russia, Spain, Sweden

📝 8 Country-Specific Surveys | 805 Respondents

💻 Online Presence:

- 1 Webpage (11 languages) | 2076 visitors (1st Semester 2025)
- Facebook | 150 Followers (1st Semester 2025)
- Instagram | 220 Followers (1st Semester 2025)
- Podcast (Norwegian and Italian) | 233 listeners
- Newsletter (monthly) | 7550 Recipients | Open Rate 52.3% (1st Semester 2025)

Events & Sessions

🎓 Research Webinars:

- 5 Webinars | ~540 registrants

 Training Course “Let Us Talk”: Communication Skills for Healthcare Professionals

- 3-day online course | 111 attendees

👥 Local Meetings:

- 4 Meetings in Spain | 242 attendees
- 1 Meeting in Norway | 16 attendees

🗣️ Online Sessions:

- 11 Sessions “One Disease, Multiple Stories” | ~550 registrants
- Other Online Sessions (genetic testing, holiday challenges, reproductive options)

Campaigns & Support

📢 Social Media Campaigns:

- My HD Research Experience | Russian
- 30th Anniversary of the HD Gene Discovery | Spanish
- Why Should I Care About HD Research? | Swedish
- Lifestyle Tips for HD Families | English/Spanish/Norwegian/Russian

🤝 Online Psychological Support:

- Spain | 16 people
- Romania | 20 people

Outputs & Recognitions

📚 Outputs

- Article in the Journal of Personalized Medicine | «Perceptions about Research Participation among Individuals at Risk and Individuals with Premanifest Huntington's Disease: A Survey Conducted by the European Huntington Association»
- 12 conference papers
- 8 oral presentations and 12 poster presentations
- Book: Chronicle of a Fortune Foretold

🏆 Awards & Recognitions

- 2021 | EFNA Grant Award for Personalized Health and Social Care (Let Us Talk)
- 2022 | Top-scoring poster at the European Conference on Rare Diseases and Orphan Products, EURORDIS (Let Us Talk)
- 2023 | RAREis Global Advocate Grant (Horizon Therapeutics) (Lifestyle Tips for HD Families)
- 2024 | RAREis Global Advocate Grant (Amgen) (One Disease, Multiple Stories)

Support the EHA
Join Our Teaming Project

Help us make a difference for the Huntington's disease community!
Join the European Huntington Association Teaming Group and **contribute just €1 per month** to support our initiatives, projects, and advocacy efforts.
Every small contribution helps improve the lives of people and families affected by HD.

www.teaming.net/
europeanhuntingtonassociationprojects

Did you know you can support the EHA's projects with just **€1 per month**? By joining our **Teaming** group, you contribute to initiatives that empower and connect the HD community across Europe. Every small donation helps us create meaningful projects, organize events, and reach more families affected by HD.

https://eurohuntington.org/
https://huntington-academy.org/
https://ehamovingforward.org/

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ruth@eurohuntington.org