2025

Integrating HD: Are we special?

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LONG TERM CONDITIONS
RESEARCH GROUP

Clinical
Nurse for 15 years, 7 years as neurodegenerative research nurse

Academic
PhD researcher at University of Southampton (UK)
Integrate-HD study, HD European and international projects

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Guest lecturer at IPCB (Portugal)

Voluntary
Portuguese HDA

INTEGRATE-HD

University of Southampton

Long-Term Conditions-Values and Needs

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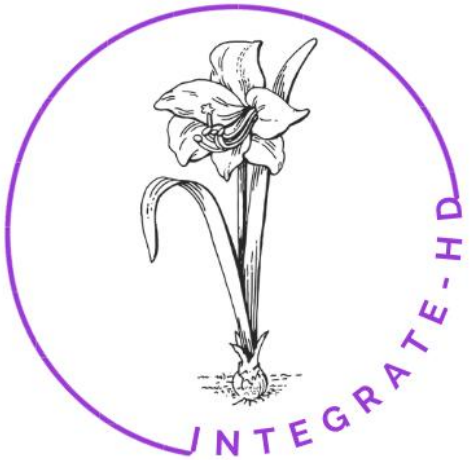
NIHR | Applied Research Collaboration Wessex

SOAR Southampton Academy of Research

What do I research?

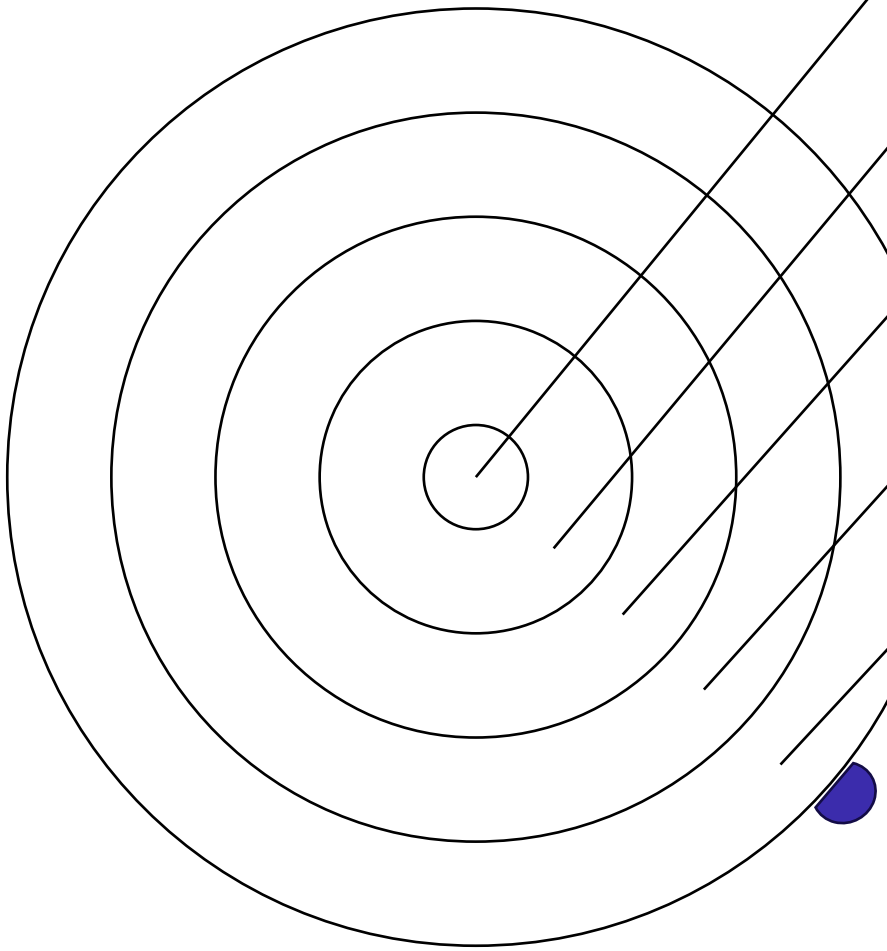
- Characterizing an *integrated care model* from the perspective of service users living with HD
- Identifying the most important *person-centered care outcomes* from care integration



1. What good care looks like?
2. How do we measure it?

Picture edited from source https://matt.might.net/articles/phd-school-in-pictures/

How do I research?



Work done in other neurological conditions

Literature review

How far are we from ideal

Survey

People's needs

Interviews

Success from people's perspective

Consensus workshops

New Model

Integration

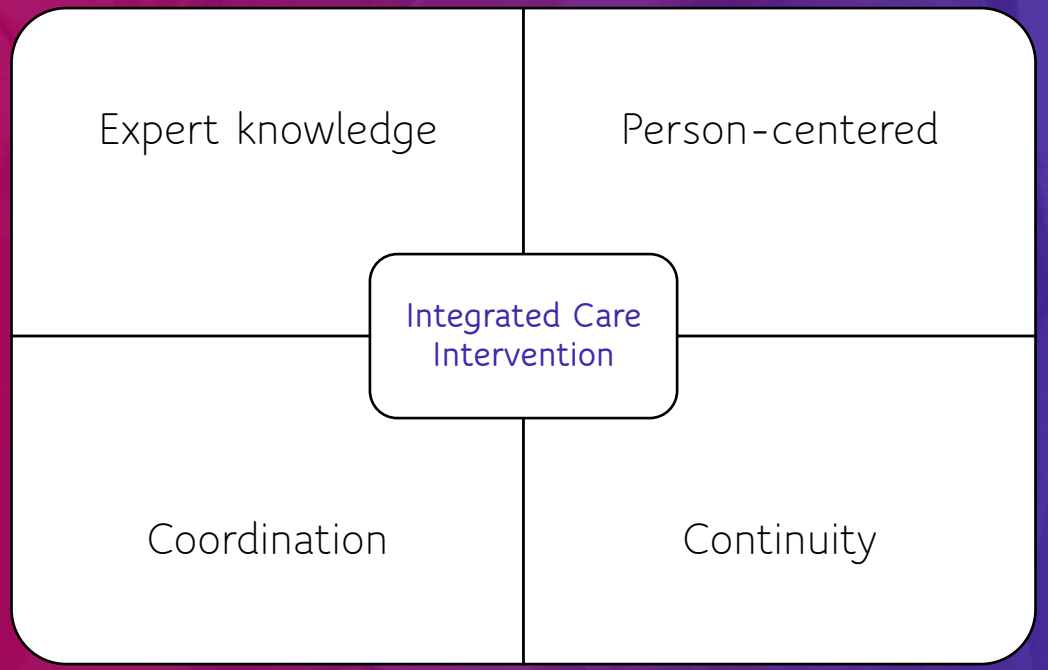
Integrated care model that responds to the needs of those living with Huntington's Disease

What have I found?

In the literature

No research in Huntington's disease

Mismatch between what people need and what is measured in studies



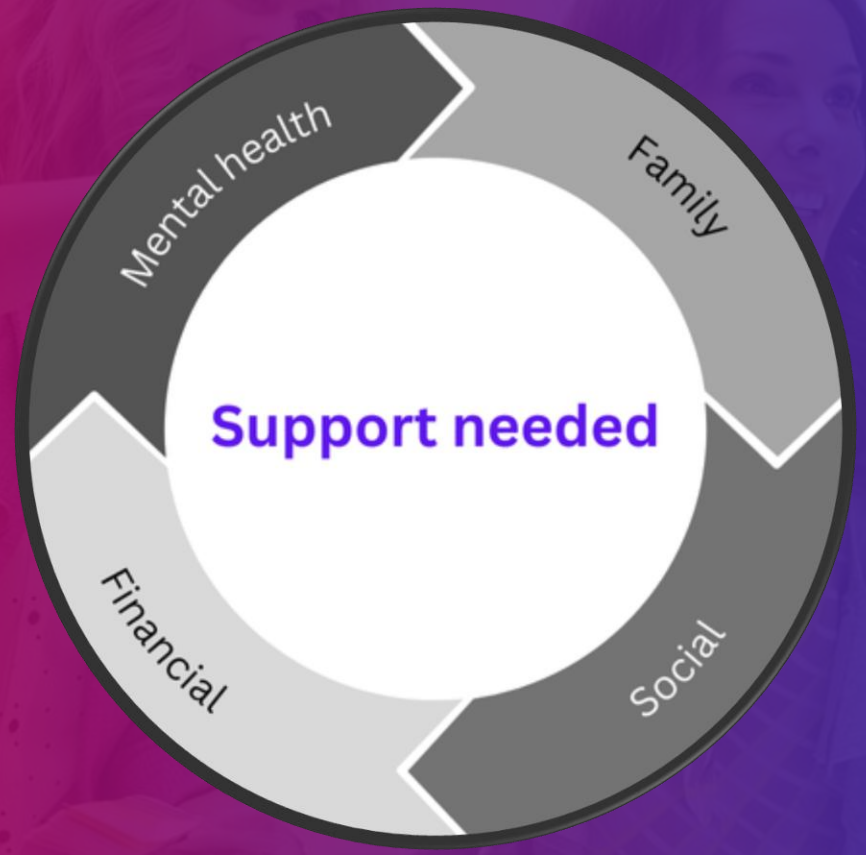
What have I found?

In the survey

Fragmented care, carers feeling ignored and “post-code lottery”

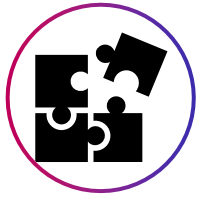
GPs and social workers involved in care BUT not knowledgeable

People with a care coordinator had a much better experience, BUT only 19% had access



Bartolomeu Pires et al. (2025). Co-design of a new integrated care model with people affected by Huntington's Disease. Manuscript submitted for publication. School of health sciences, University of Southampton.

What have I found?



Good looks like:

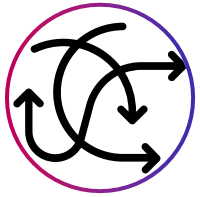
Expert knowledge

Person-centered care

Coordination

Continuity

Family-centered care



Caveats in care:

Vulnerability

Proactive care approach

Responsability without power

Advocacy, empowerment or workload?

Choice or negelct?

Integrated care

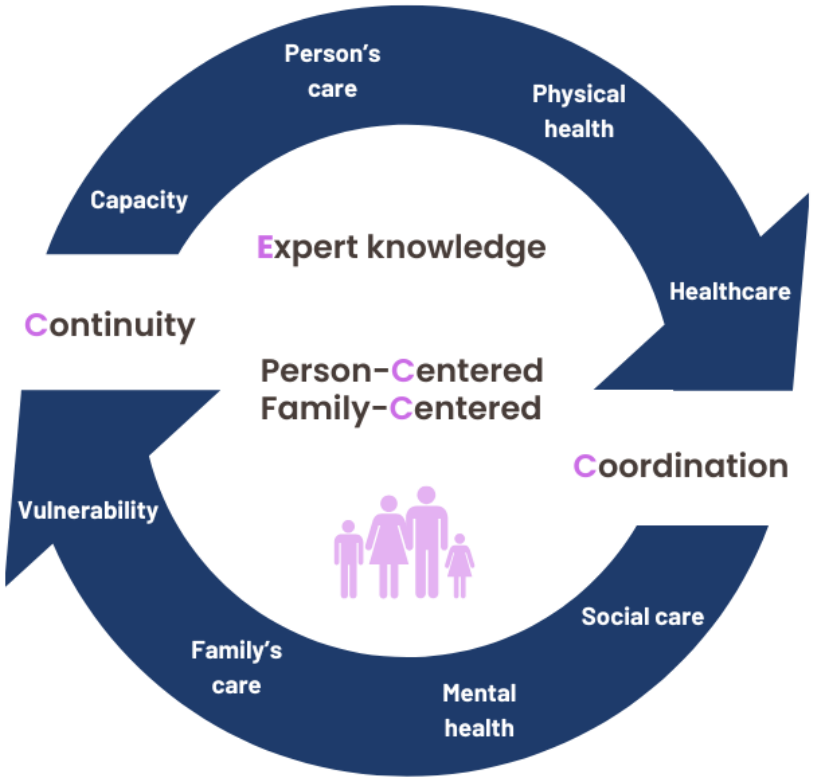
Complex needs

Resources needed

4 bridges

- Understanding people's capacity and people's vulnerability in managing care;
- Identifying individual and family care needs;
- Recognizing the necessity of both physical and mental health treatment;
- Establishing relational continuity across health and social care.

EC4Neuro model



Bartolomeu Pires et al (2025). Submitted for publication.

EC4Neuro model

What's it for?

"Hanging fruit"	Expert Knowledge	Coordination	Continuity	Person-centered care	Family-centered care
Low	Professionals consult with nearest HD expert team. Inter-professional HD education.	Social worker appointed and reachable. Identifiable HD expert teams.	Regular appointments and follow-ups. Regular follow-ups at the GP with referral to HD experts when needed. GP identifies and electronically records people at risk and caregivers.	Appointments are person-centered and needs-based. Signposting to community resources. Longer GP appointments (double slot). Care plan reviewed regularly. Non-pharmacological therapies offered. Individual care plan.	1:1 appointment for the informal carer (with expert team or GP). Family kept updated and involved with the care plan.
Intermediate	Social worker integrated in expert team.	Care coordinator available.	Mental health team accessible and with HD link pin. Social workers hold cases for longer. Appointments with same GP.	Self-referral system to expert team. Roadmap booklet/app/resource to help people navigate living with HD.	Social worker supports family across the lifespan. Caregivers training provided. Professionals involved with the HD community (for example developing activities with children at risk). Formal carers supporting with household tasks.
High	24-hour expert helpline. Expert multidisciplinary team available. Core team of GPs particularly trained and involved with PwHD. NICE guidelines development.	Raise public awareness. Upskill professional workforce. Increase funding to healthcare, social care and research.	Centralized electronic records between sectors. Patient passport/QR code/key medical history accessible.	Care settings fitting people's needs: home-based care, day-care and long-term care for adults with complex neuro needs. Robust care pathway.	HD hub caring for people at risk to advanced stages with non-pharma activities (including social worker). Informal caregivers considered part of the workforce (financial remuneration)

EXAMPLE 1
LOW HANGING FRUIT

Expert knowledge	• Who's the closest expert in HD? Professionals consult with nearest HD expert team
Coordination	• Appoint a named social worker to this individual or family
Continuity	• GP identifies and records electronically people at risk and informal caregivers • Invite person for a regular appointment
Person-centered	•"What would make a real difference to you?" •Focus clinical appointments on people's needs
Family-centered	• Invite the informal caregiver for an individual appointment.

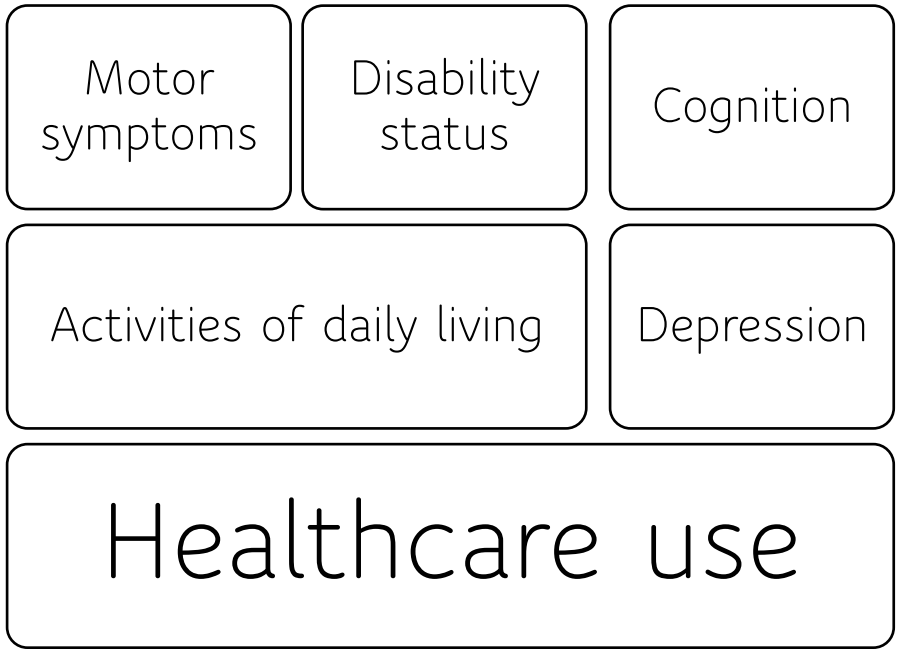
EXAMPLE 2
INTERMEDIATE HANGING FRUIT

Expert knowledge	• Embed a social worker in the HD expert team
Coordination	• Appoint a care coordinator responsible for this individual's or family's care
Continuity	• Offer appointments with the same GP
Person-centered	• Create a roadmap/app to help people navigate HD (what to expect and how to prepare)
Family-centered	• Let formal carers support with housechores so that the informal carer can spend quality time with the individual with HD

How do we know changes are working for people?

How to measure if care is integrated?

HOW CARE INTEGRATION IS USUALLY MEASURED



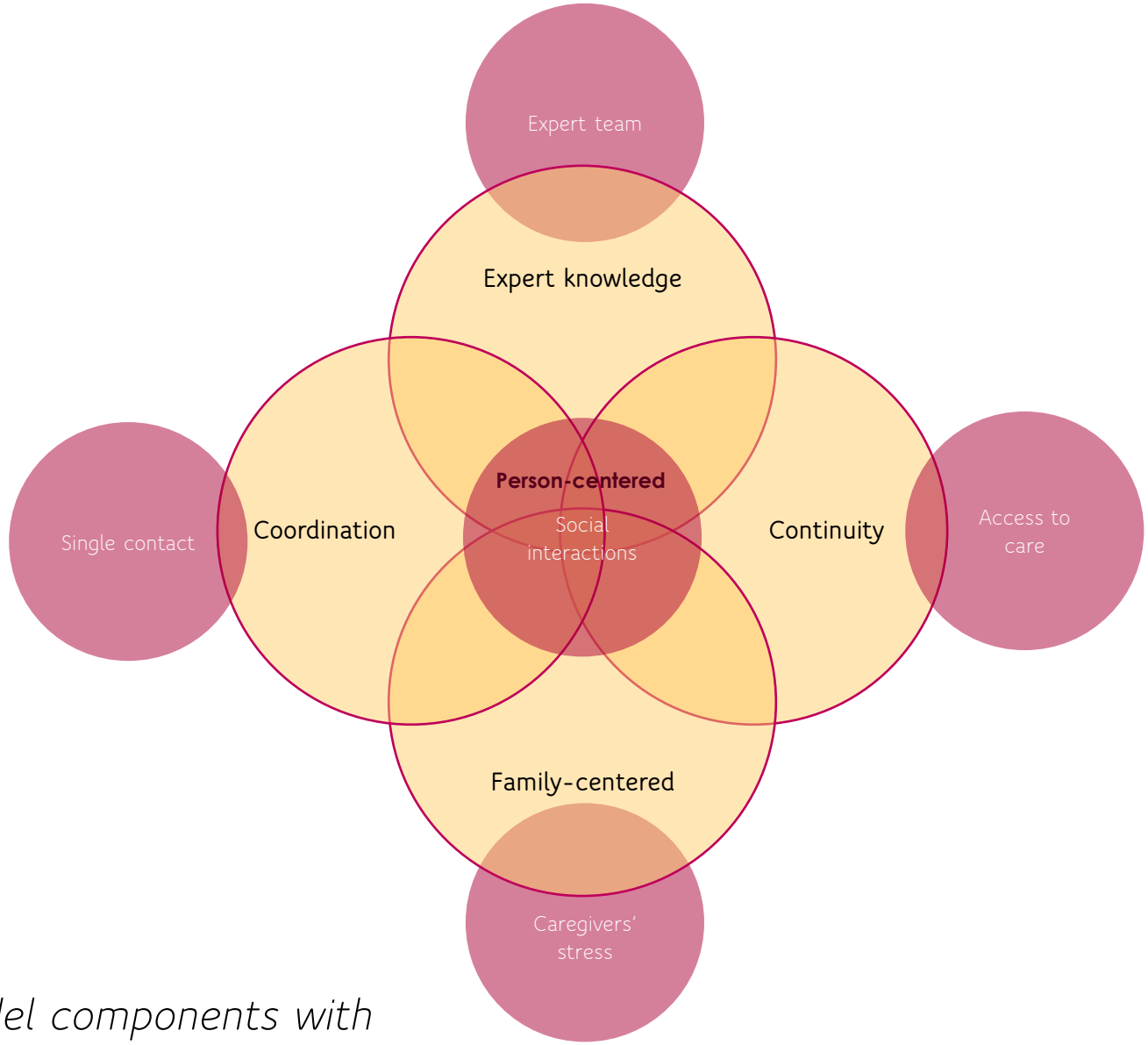
Community/soci	22	40	7	12	16	23	16	27	3	17	3		35	4	4	22	11	24	20	9	0	0	11	9	18
Home maintenar	42	21	10	4	15	35	13	28	18	15	17		10	0	3	20	7	5	21	14	0	0	20	25	16
Response time	23	20	8	19	6	18	4	2	11	16	7		11	0	0	18	35	7	9	21	23	0	7	12	5
Crisis episodes	21	39	11	16	5	20	8	18	19	5	20		10	4	0	21	20	6	11	24	16	0	14	30	6
Access to care	3	5	5	26	3	21	2	3	21	3	19		12	0	0	1	5	15	8	15	0	0	9	8	7
Access to expert	2	11	16	1	2	1	1	25	4	2	1		1	0	2	5	13	9	7	1	0	2	3	3	1
Access to a neur	18	12	25	31	1	2	14	29	26	4	21		13	4	13	19	18	19	53	22	7	17	2	11	19
Access to own m	47	19	22	54	8	22	30	30	22	26	31		47	0	0	24	25	26	28	23	0	16	21	16	11
Single point of co	16	1	17	10	4	10	3	20	23	18	8		36	0	1	3	6	2	5	25	0	0	10	13	12
Knowing who to	17	2	18	24	10	19	5	21	6	1	6		14	4	12	4	22	18	4	26	12	12	1	5	2
Financial suppor	20	38	21	6	11	16	12	15	24	19	9		15	0	0	2	3	3	18	11	13	0	26	26	13
Referrals proces	24	45	20	25	12	24	15	33	25	23	25		46	0	0	25	16	23	29	27	15	0	8	17	14
Length of time re	19	44	23	15	14	25	11	1	5	10	24		37	0	0	17	9	25	19	28	14	0	12	14	15
Possibility of sel	48	13	26	23	7	26	17	36	27	24	32		38	0	0	7	12	22	15	10	22	0	13	24	4
Personal choice	5	3	24	18	9	27	18	14	28	25	22		39	4	0	14	21	27	23	6	3	13	6	18	17
Empowerment /	26	4	9	20	13	28	20	34	29	27	33		40	1	0	26	17	10	24	29	4	8	19	19	20
Family anxiety an	28	22	6	8	20	29	24	10	20	28	35		16	2	18	11	4	28	14	3	2	7	25	20	21
Family needs	27	18	3	3	21	30	27	26	1	12	34		18	0	0	12	8	29	13	8	8	9	28	22	22
Carer' Stress anc	25	23	13	7	22	31	28	9	30	13	4		17	4	11	6	2	30	12	7	0	10	22	15	3
Carers' needs-ba	4	24	14	9	23	14	7	23	31	30	10		41	0	0	15	23	20	17	30	0	10	27	29	8
Carers involved i	30	10	28	11	24	15	29	16	16	31	28		2	0	0	27	24	31	22	16	0	10	24	7	10
Person-centered	29	9	29	5	17	13	6	32	32	32	23		31	0	5	23	26	11	26	2	1	1	15	4	23
Burden	31	43	12	40	25	32	45	37	33	33	45		49	4	0	28	41	55	54	31	0	0	36	33	24
Patient's Depres	14	37	30	27	26	12	31	8	34	9	36		25	0	0	8	10	33	31	32	0	0	16	27	25
Mental well-bein	15	16	4	13	27	11	22	12	35	8	12		18	4	0	9	15	34	32	17	0	2	18	28	26
Access to couns	39	17	27	22	28	17	32	13	36	11	30		12	4	0	10	37	35	10	4	17	2	23	21	27
Level of indepen	40	8	15	21	18	33	23	31	7	34	16		43	0	0	13	28	4	33	33	18	3	31	6	28
Quality of life	1	15	1	2	30	34	25	38	2	29	13		19	4	0	16	19	1	1	19	19	3	35	1	9
Safety/risk mana	35	42	31	29	31	3	9	39	8	6	37		44	0	0	30	29	36	34	34	20	3	29	31	29
Non-pharmacolo	33	36	32	17	32	36	26	40	37	36	26		26	0	6	41	31	37	36	35	0	0	34	23	30
Activities of daily	24	50	2	32	44	37	21	41	38	37	27		27	0	0	32	33	38	37	36	24	0	41	38	31
Equipment (e.g.,	46	35	33	33	19	38	19	19	14	38	15		3	0	0	33	1	21	38	37	0	0	33	32	32
Respite	32	25	34	14	29	39	34	11	39	39	11		4	4	0	34	40	16	3	38	25	0	30	34	33
Advanced life de	38	26	35	28	36	40	10	22	17	40	38		30	0	0	38	44	39	39	12	0	4	37	36	34
Death experience	36	48	36	35	37	41	48	42	40	41	39		42	0	0	39	47	40	30	13	0	5	49	37	35
Bereavement sup	27	49	37	34	33	42	49	17	41	42	40		45	0	0	40	49	41	51	20	4	0	50	42	36
Continuity of car	11	27	19	36	38	43	33	6	42	14	14		28	4	7	31	32	17	25	39	5	6	40	10	37
Social care profe	12	14	38	37	45	44	35	43	43	43	18		43	0	14	42	27	42	40	40	0	0	42	39	38
Joined-up health	13	6	39	30	35	5	36	35	15	44	41		44	0	15	29	14	8	6	41	6	12	4	2	39
Communication	49	7	40	38	39	8	38	44	44	22	2		29	3	19	45	36	43	43	43	0	14	32	40	40
Duplication of in	50	53	41	39	54	45	53	45	45	47	54		20	0	20	54	38	44	46	44	0	0	51	41	41
Local profession	9	34	42	41	34	7	46	46	46	48	42		5	0	0	46	39	45	35	45	0	0	38	35	42
Social worker far	45	46	43	42	49	46	44	47	47	49	50		6	0	0	35	30	46	27	46	0	0	39	43	43
Social worker wit	46	33	44	43	48	47	41	48	48	45	51		34	0	8	47	42	32	42	47	9	0	5	44	44
Rapport with pro	43	41	45	44	46	48	40	24	49	35	29		31	0	17	36	43	47	47	48	0	0	47	45	45
HD perceived kn	6	28	46	45	47	9	43	49	50	21	43		21	4	0	48	45	48	48	49	0	16	46	46	46
Professionals' u	10	31	47	46	42	6	39	50	9	7	5		22	4	16	49	34	14	49	50	0	1	45	47	47
Home-appointm	46	32	48	47	40	4	37	7	51	46	44		7	0	0	43	48	49	16	51	10	0	43	48	48
Live at home as l	7	30	49	48	41	49	47	4	10	50	46		8	0	9	44	50	13	2	5	0	15	48	49	49
Care settings ap	8	42	50	49	50	50	42	5	52	20	47		33	0	0	50	51	50	41	42	0	0	44	50	50
Distance travelle	0	47	51	50	43	51	50	51	53	51	48		32	0	0	37	52	51	44	52	0	0	53	51	51
Distance travelle	0	29	52	51	51	52	51	52	54	52	49		9	0	0	51	53	52	45	53	11	0	54	52	52
Research availab	0	52	53	52	52	53	52	53	55	53	52		23	0	0	52	46	53	50	18	0	0	17	53	53
Public awarenes	0	0	54	53	53	54	54	54	56	54	53		24	0	10	53	54	54	52	54	0	0	52	54	54
Other	0	0	55	55	55	55	55	55	12	55	55		0	0	0	0	0	12	55	55	0	0	55	0	55

Participant Name: [redacted]

[redacted]	More funding to the NHS, social care and research.
	Shared funding between health and social care, promoting cross-boundaries roles.
	Charities funded by the government as a multi-sectoral partner in care (formalize voluntary sector role)
	Increased staffing *ratios*
	Education of professional workforce: person-centred and multi-sectoral collaboration
	Compassionate culture
	Making Training Compulsary for Care workers
	The problem is that all the above is required

Ranking	Outcomes
1	Access to expert HD team
2	Access to care
3	Knowing who to contact
4	Having a single contact
5	Response time
6	Quality of life
7	Caregivers' stress
8	Financial support
9	Crisis episodes
10	Social interactions

Top 10 interventions and outcomes ranked in the Integrate-HD consensus workshops

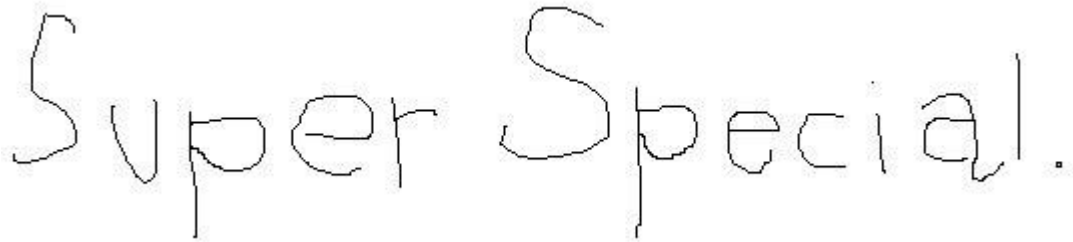


Venn diagram incorporating the EC4Neuro model components with some of the top ranked person-centered outcomes

Integrating HD:

Are we special?

2025



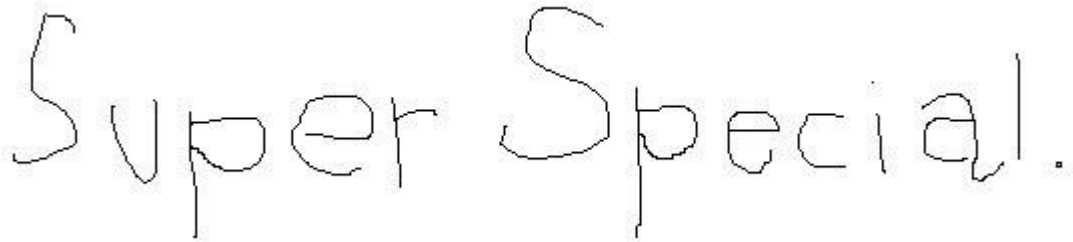
What is so special about Huntington's Disease care?

What is particular to Huntington's Disease care?

Integrating HD:

Do we want to be special?

2025



WHICH DISEASES DO WE SHARE COMMONALITIES WITH?

WHAT IS IT WE HAVE IN COMMON WITH THEM?

What other diseases have similar care needs to people living with Huntington' Disease?

How much do we share with other diseases?

Neurological conditions

- People that experience stigma: 84%
- Medical professionals disbelief people's symptoms severity: 85%
- Doctors don't know enough about the disease, GPs: 85%; Specialists: 57%
- People report mental health impacted: 35%

Invisible issues:
European Federation of Neurological Associations

1. It is important to have tools and measurements that capture people's symptoms
2. Support patients and caregivers to describe their symptoms more accurately
3. **Better education and training for healthcare professionals**
4. Health literacy is needed across education, employment and society
5. **People need psychotherapy** or counseling to support managing living with the disease
6. **Informal caregivers need financial support** to manage caring responsabilities but also high-quality care services to participate in employment

How much do we share with other diseases?

Progressive neurological conditions

People living alone in the community:

- Parkinson's disease 33%
- Motor Neuron Disease 33%
- Huntington's Disease 38%

Care inequality:
DeNPRU project, policy recommendations

1. Knowing the numbers to better plan
2. Improve care access through **giving people a care coordinator**
3. Provide flexible **coordinated care** (comission services)
4. **Educate the care workforce** e.g., professionals assessing care packages
5. Improve access to **financial support** e.g., reduce bureocraucy and make it easier for people
6. Strengthen **commmunity response**, e.g., work with community groups to reduce isolation
7. Support **informal carers**. Encourage professionals to involve carers
8. Review **research** priorities, e.g., ask living situation in studies, direct funds towards managing complex symptoms

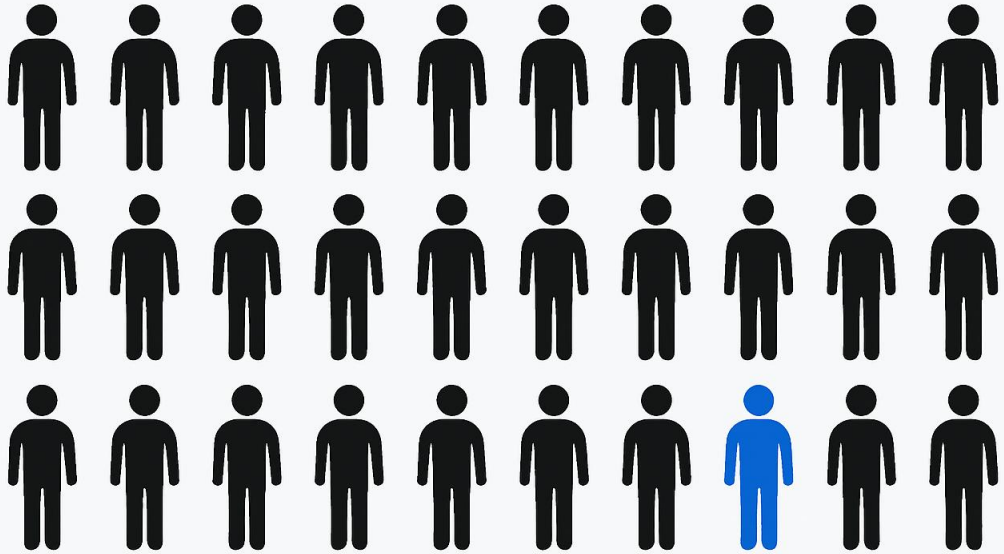
How much do we share with other diseases?

Rare diseases

- Adult rare diseases person with access to a care coordinator: 12%
- Access to a specialist centre: 32%

Care fragmentation:
CONCORD project

1. Lower cost of attending appointments
2. Electronic records immediately accessible to staff
3. **Expert lead consultant**
4. Access to a **care coordinator**
5. **Specialist centre** or clinic available
6. Formalised **care plan**
7. Meetings between care professionals to discuss care (**coordinated care**)



This content has been created by an AI language model and is intended to provide general information.

43% of the world lives with a neurological condition

1% of the world lives with a progressive neurological condition

6% of the world lives with a rare condition

3% of the world lives with a rare neurological disease:

~260 million people worldwide

Challenge

How do we get these needs ackowledged and acted on by decision-makers and managers?

What can we do next to improve care?

2025

We are more likely to improve care if we show how much we resemble other diseases.

Health equity.

Health equity

Credits +

Overview | Data and evidence | Response

Equity is the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation). Health is a fundamental human right. **Health equity is achieved when everyone can attain their full potential for health and well-being.**

Health and health equity are determined by the conditions in which people are born, grow, live, work, play and age, as well as biological determinants. Structural determinants (political, legal, and economic) with social norms and institutional processes shape the distribution of power and resources determined by the conditions in which people are born, grow, live, work, play and age.

People's living conditions are often made worse by discrimination, stereotyping, and prejudice based on sex, gender, age, race, ethnicity, or disability, among other factors. Discriminatory practices are often embedded in institutional and systems processes, leading to groups being under-represented in decision-making at all levels or underserved.

Progressively realizing the right to health means systematically identifying and eliminating inequities resulting from differences in health and in overall living conditions.

Fact sheets +

Questions and answers +

Database and tools +

Technical work +

World Health Organization

Donate

Health Topics | Countries | Newsroom | Emergencies | Data | About WHO

Home / Health topics / Health equity

WITHOUT RESOURCES, "SELF-MANAGEMENT" IS JUST NEGLECT.

Health equity

Credits +

Overview | Data and evidence | Response

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People's living conditions are often made worse by discrimination, stereotyping, and prejudice based on sex, gender,

- Fact sheets +
- Questions and answers +
- Database and tools +
- Technical work +


Next steps

More information

Literature review article

https://onlinelibrary.wiley.com/doi/abs/10.1111/hex.13948

Survey short report

https://www.hda.org.uk/news/integrate-hd-survey-unveiling-care-challenges-for-the-huntingtons-disease-community/

Survey article

https://journals.sagepub.com/doi/full/10.1177/18796397241288449

Equity

https://www.who.int/health-topics/health-equity#tab=tab_1

DeNPRU research

https://ore.exeter.ac.uk/articles/report/Living_alone_with_a_progressive_neurological_condition_a_neglected_inequality_DeNPRU_Exeter_report_2025/29813489/1

CONCORD research

CONCORD: CoOrdiNated Care of Rare Diseases | Faculty of Population Health Sciences

EFNA surveys

SURVEY RESULTS: Assessing diagnosis and care pathways of people living with neurological disorders - EFNA

THANK YOU!

Share the cockpit and set the course

Long-Term Conditions-Values and Needs

THE UNIVERSITY OF SYDNEY

NIHR | Applied Research Collaboration Wessex

SOAR Southampton Academy of Research

NHS University Hospital Southampton NHS Foundation Trust

University of Southampton

LUMC Leiden University Medical Center

MS Society

GENETIC ALLIANCE UK

PARKINSON'S UK

THE NEUROLOGICAL ALLIANCE

EFNA EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

EHDN EUROPEAN HUNTINGTON'S DISEASE NETWORK

Advancing Research, Conducting Trials, Improving Care

HD VOICE

Huntington's Disease Association

HDYO

ASSOCIAÇÃO PORTUGUESA DOS DOENTES DE HUNTINGTON APDH

EUROPEAN Huntington Association

PhD PPI group

Thank you.

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