

Fabry Disease and the Heart

Work from Birmingham

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Conflicts of
Interest: None

Disclaimers and Disclosures

- I have received honoraria for talks, teaching and travel bursaries from:
 - Amicus Therapeutics
 - Sanofi
 - Takeda
 - Chiesi
 - Kidneys for Life

Topics

Atrial work

- ECGs in patients
- Cell model of Fabry Disease

Exercise capacity

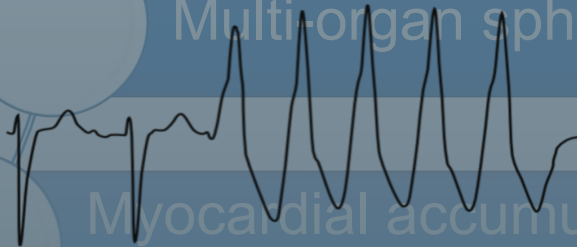
- Peak oxygen capacity on exercise testing

Fabry Disease

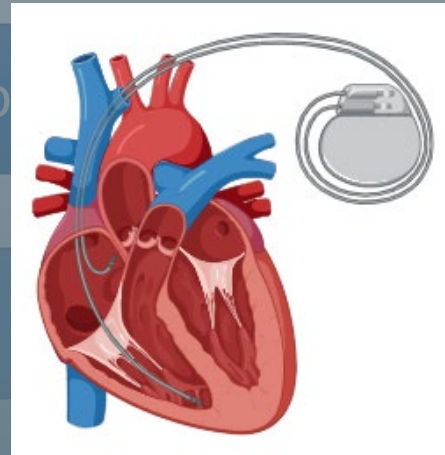
Rare X-linked lysosomal storage disorder

Prevalence of arrhythmia is very high

Multi-organ sphingolipid



Myocardial accumulation
fibrosis



Hypothesis

ECHOCARDIOGRAPHY PARAMETERS

Indexed LA Volume Increase

LA GLS Impairment

Primary atrial involvement

Atrial changes happen early

Prior to LVH

Undiagnosed AF

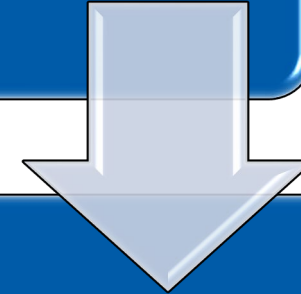
Stroke - 25% under 30 years

Roy 2025 *CJCO*

FIN Meeting
26/4/25

Aims

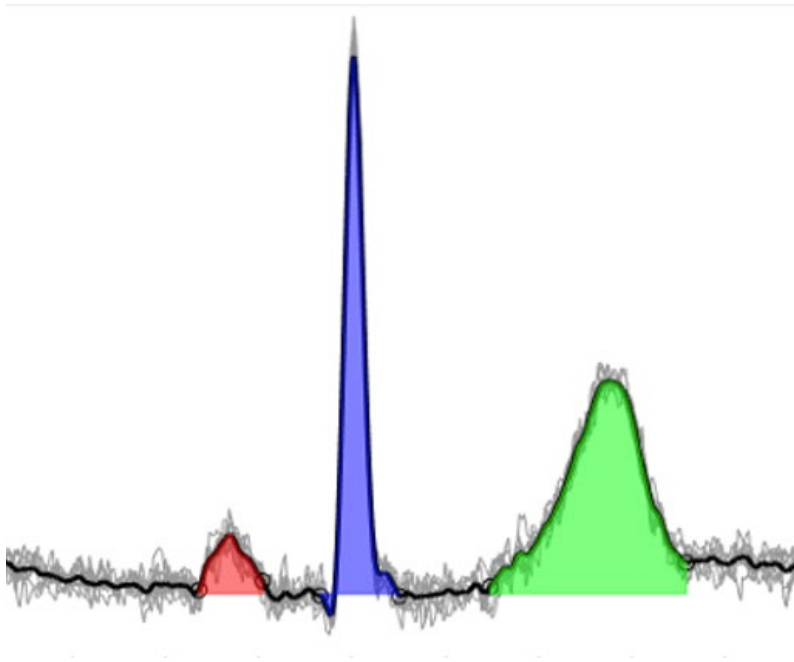
Identify early atrial ECG
changes in patients Fabry
Disease



Understand if these
reflect changes in
Fabry atrial cells

Methods

ECGs of adults with Fabry




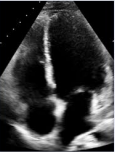
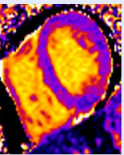


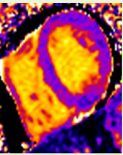

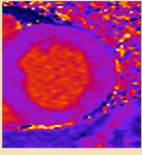
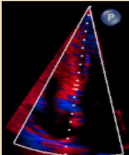

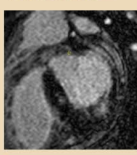
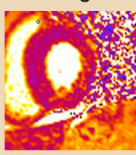

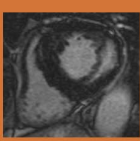
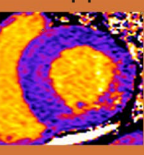






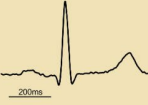





Stem cells derived atrial cardiomyocytes with a Fabry mutation

Confirm enzyme deficiency and Gb3 accumulation

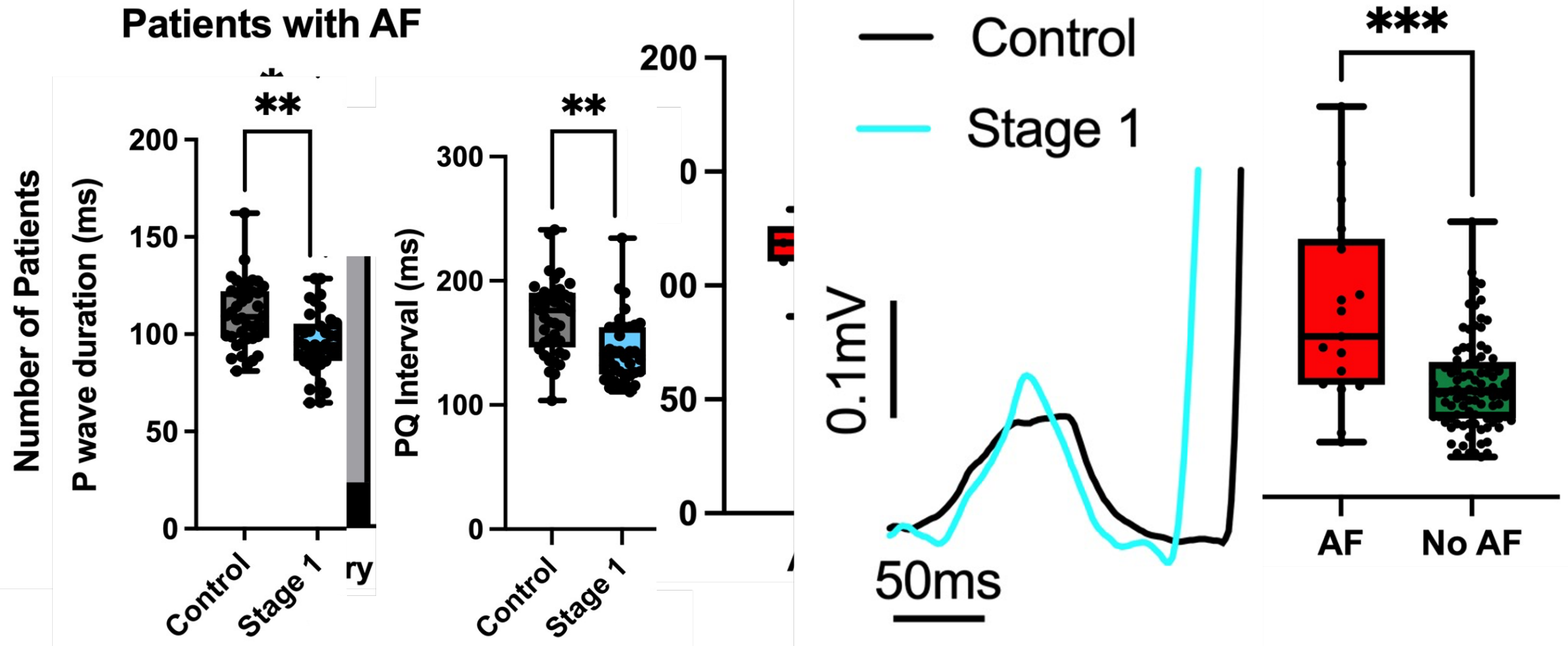
Functional experiments



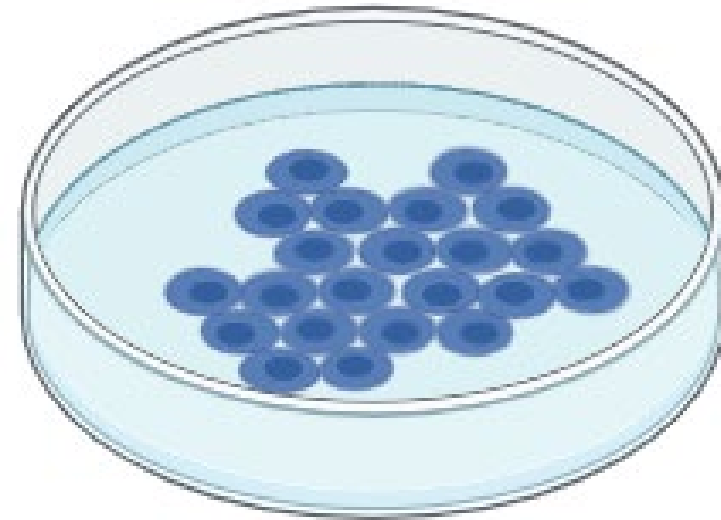
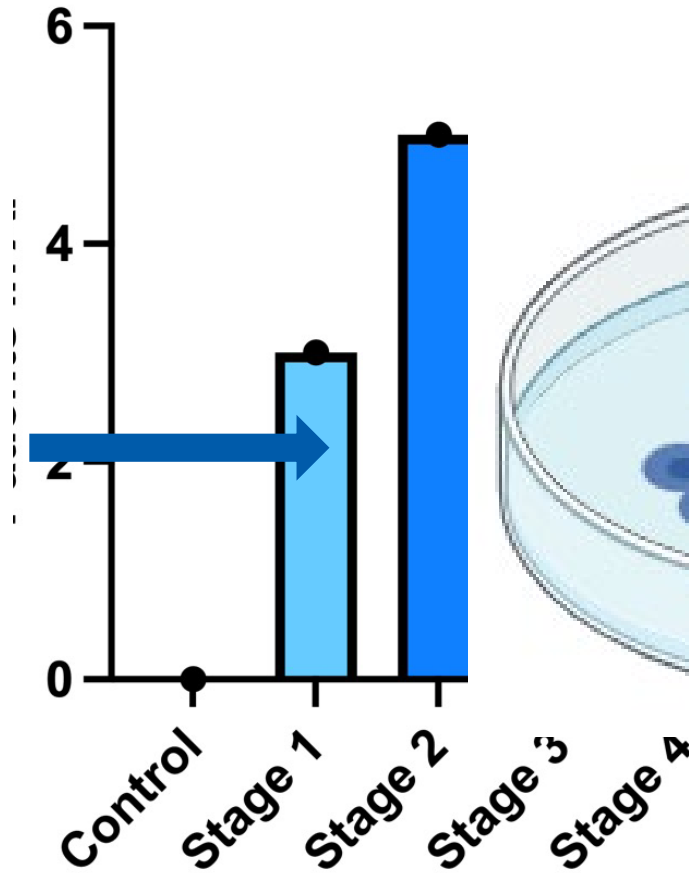
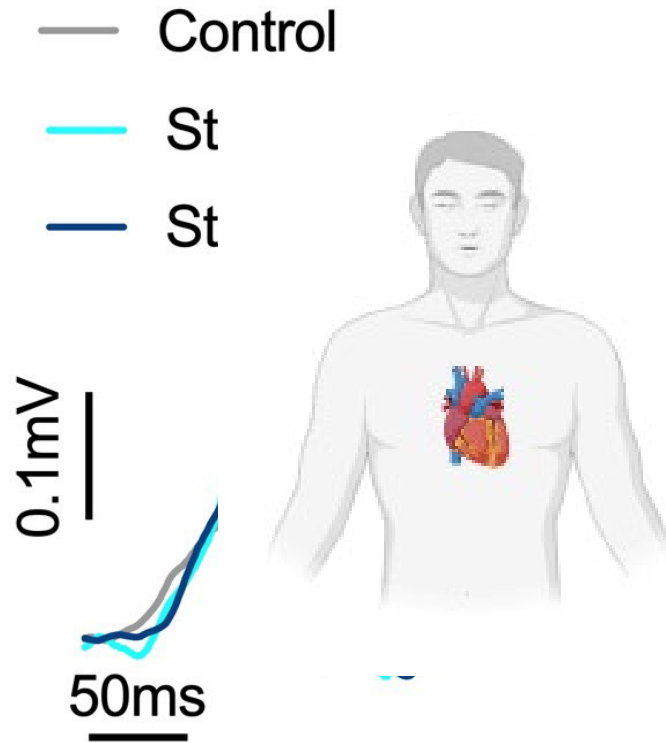
Staging

CONTROL	STAGE 1	STAGE 2	STAGE 3	STAGE 4
<div> <div>Normal GLS</div>  </div> <div> <div>Normal LV function</div>  </div> <div> <div>Normal T1</div>  </div>	<div> <div>Normal GLS</div>  </div> <div> <div>Normal LV function</div>  </div> <div> <div>Normal T1</div>  </div>	<div> <div>Impaired GLS</div>  </div> <div> <div>Low T1</div>  </div> <div> <div>Early diastolic dysfunction</div>  </div>	<div> <div>LVH</div>  </div> <div> <div>Focal LGE</div>  </div> <div> <div>Focal high T2</div>  </div>	<div> <div>Systolic dysfunction</div>  </div> <div> <div>Diffuse LGE</div>  </div> <div> <div>Pseudo-normalised T1</div>  </div>
<div>  <div>Normal biomarkers</div> </div> <div>  <div>Normal ECG</div> </div>	<div>  <div>Normal biomarkers</div> </div> <div>  <div>Normal ECG</div> </div>	<div>  <div>Mild cardiac symptoms</div> </div> <div>  <div>Borderline biomarkers</div> </div> <div>  <div>PQ prolongation</div> </div>	<div>  <div>Moderate cardiac symptoms</div> </div> <div>  <div> <div>↑ Troponin</div> <div>↑ NT-proBNP</div> </div> </div> <div> <div>LVH</div> </div>	<div>  <div>Severe cardiac symptoms</div> </div> <div>  <div>Arrhythmias</div> </div> <div>  <div> <div>↑ Troponin</div> <div>↑ NT-proBNP</div> </div> </div>

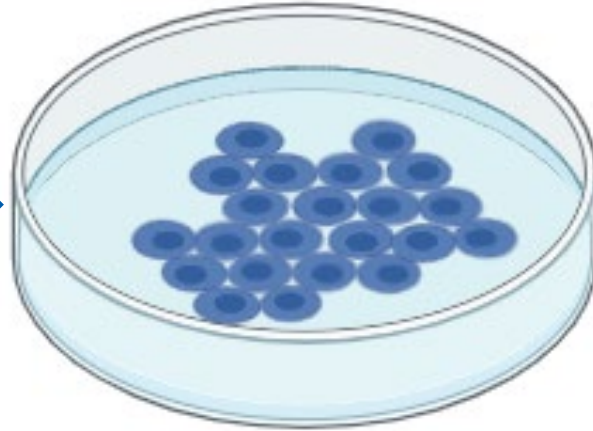
Early P-Wave changes in "phenotype negative" Fabry



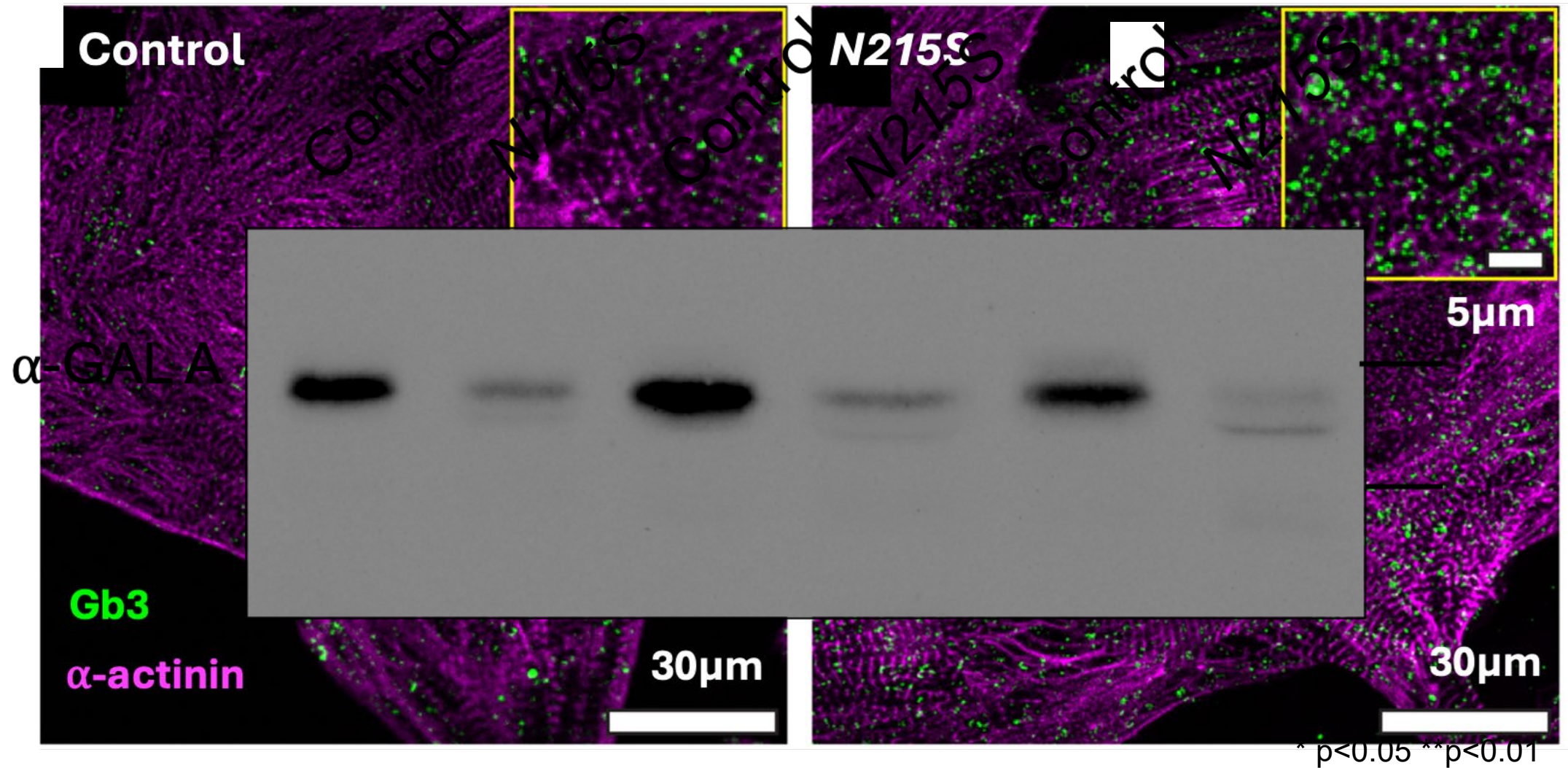
Take homes



Next steps



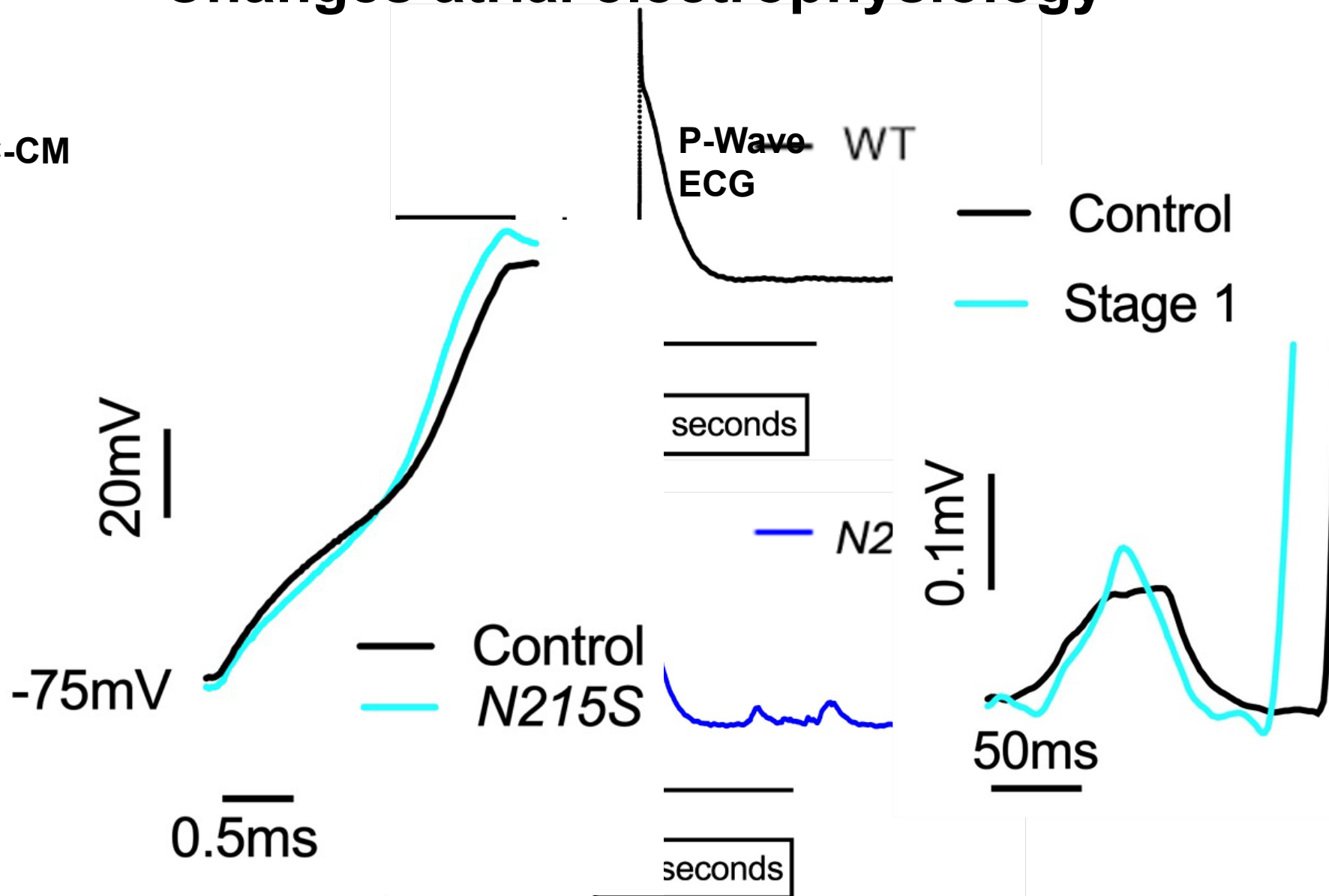
Stem cell model



* $p < 0.05$ ** $p < 0.01$

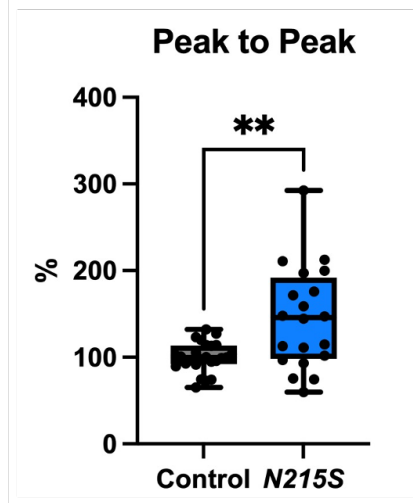
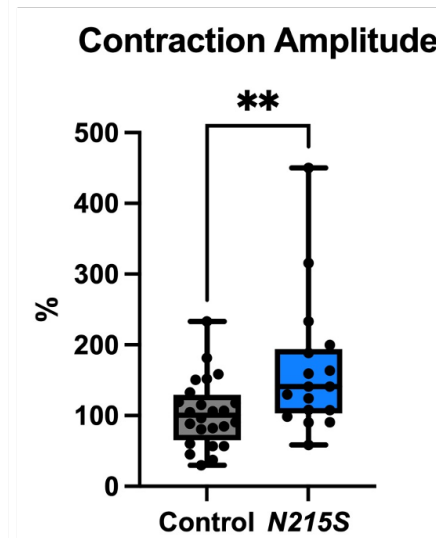
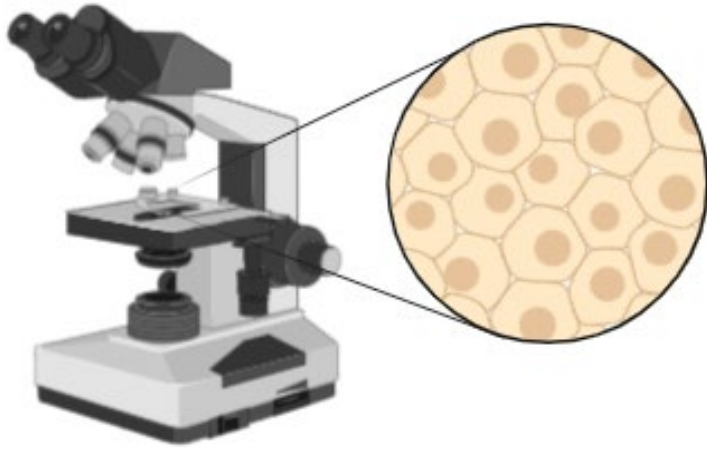
Changes atrial electrophysiology

Atrial iPSC-CM
Upstroke

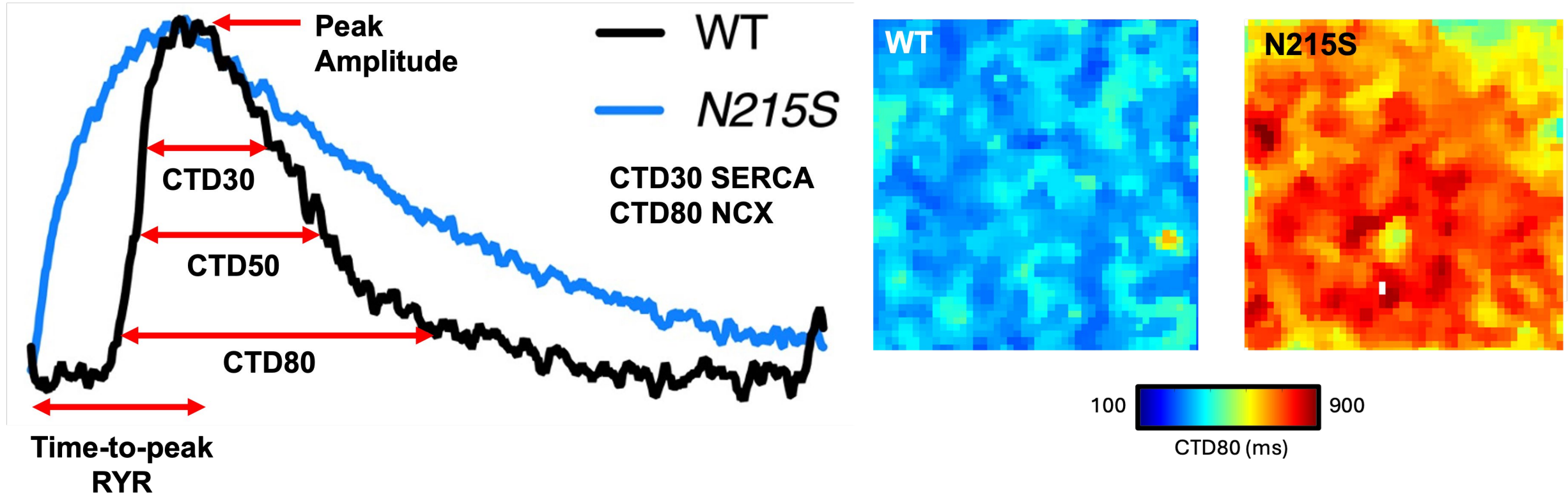


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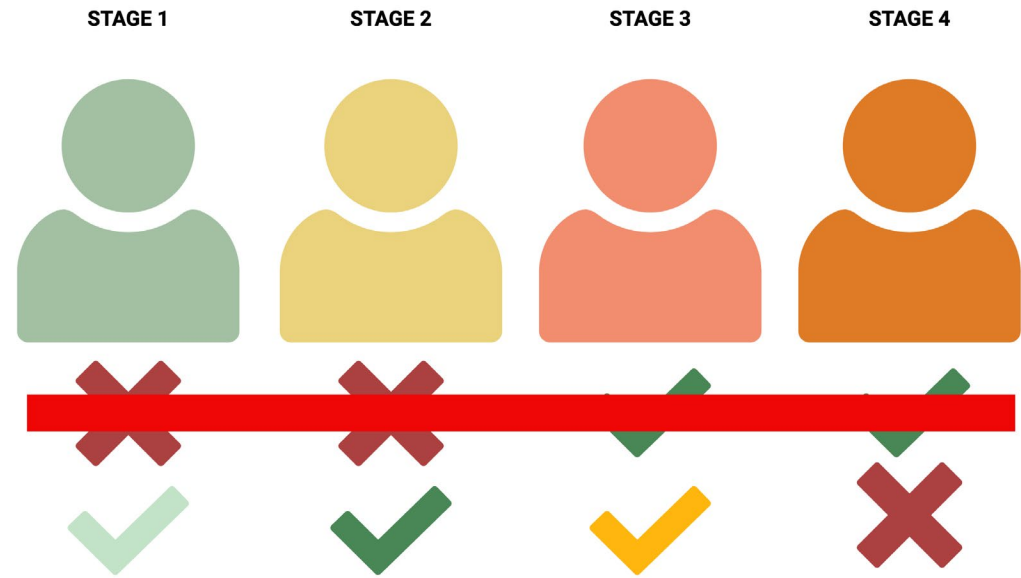
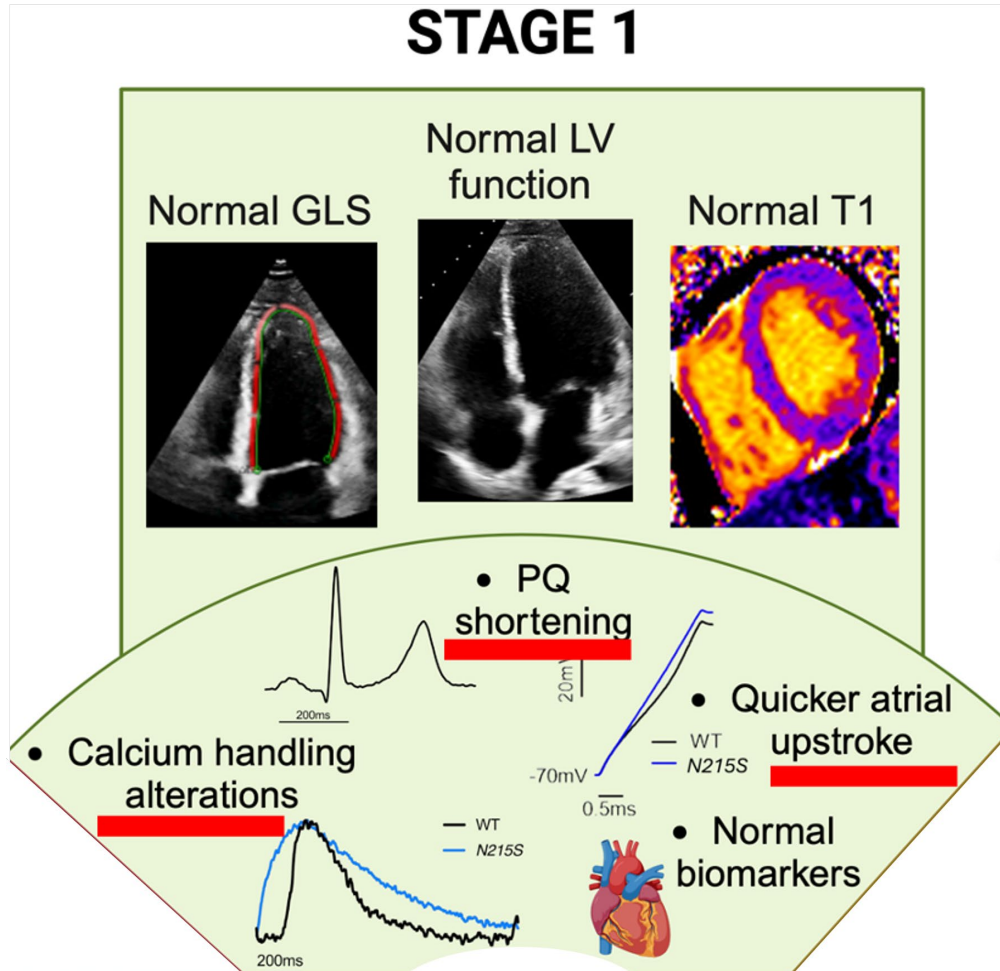
Changes in atrial muscle contraction



Changes in movement of calcium



Conclusions

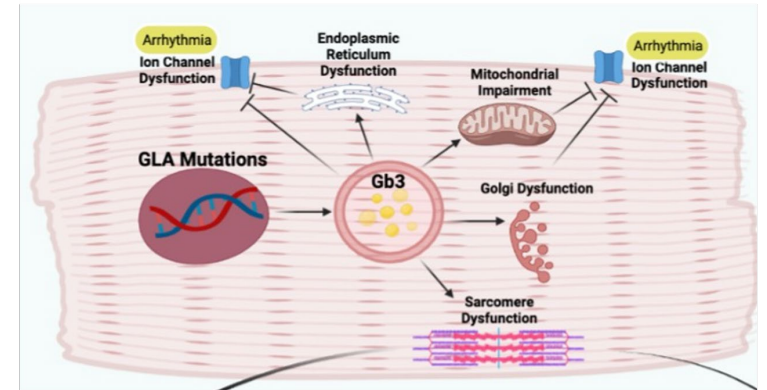
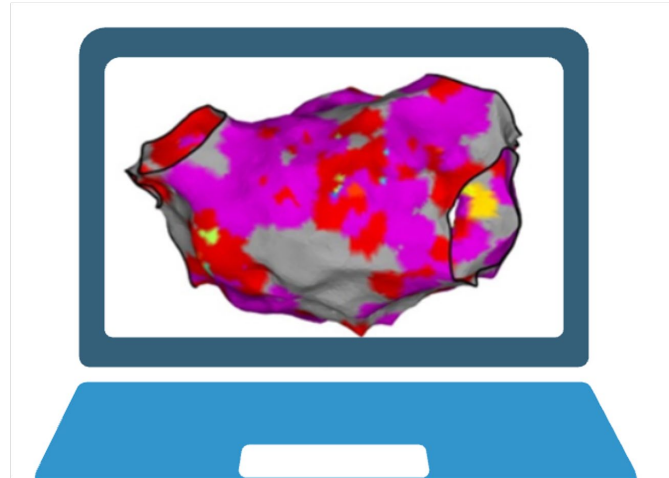


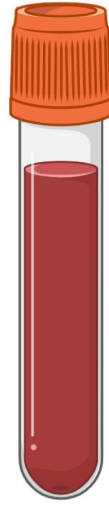
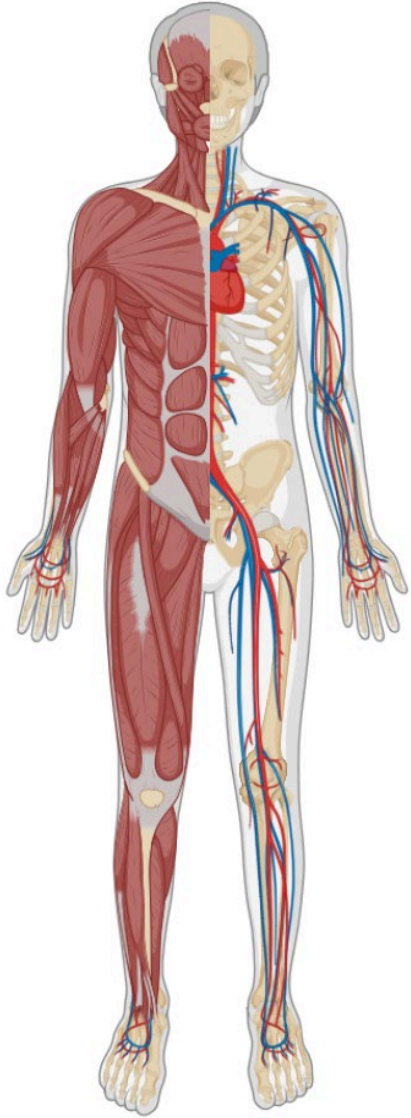
Future Direction

Therapy

Computer model

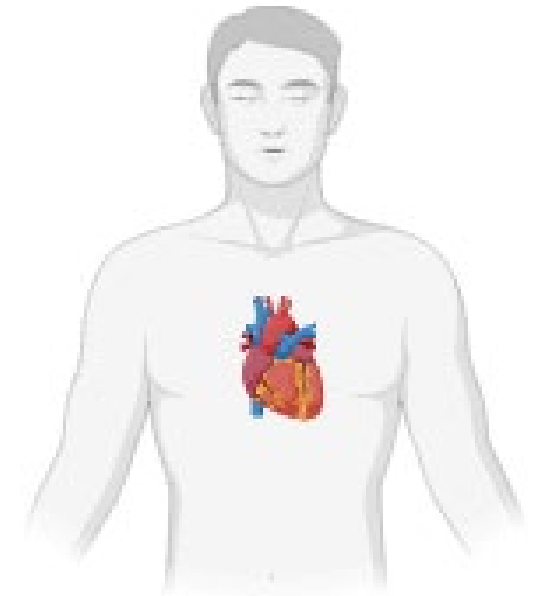
Mechanisms





Exercise Intolerance

Common



Hypothesis

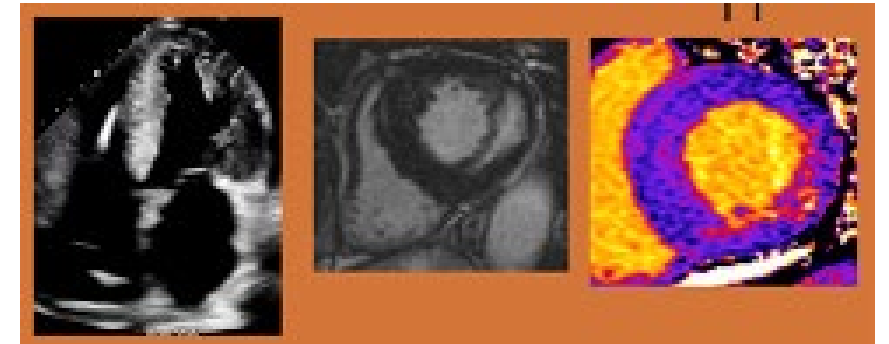
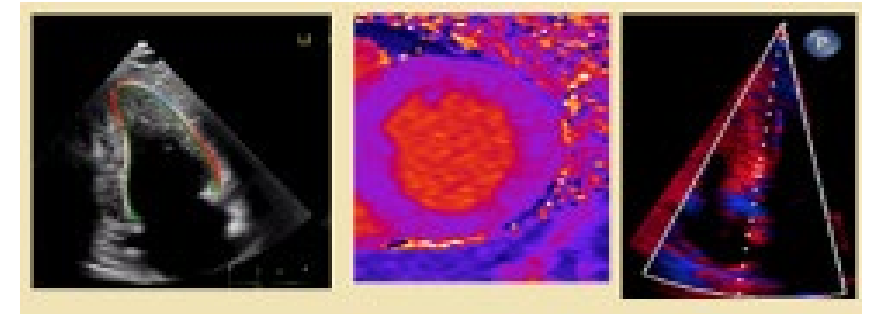
Exercise limitation is evident early in accumulation phase

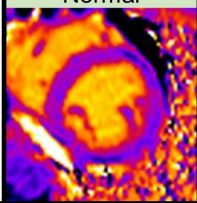
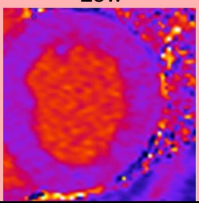
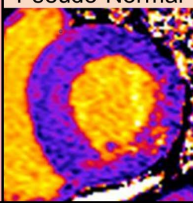
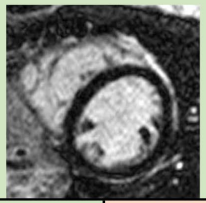
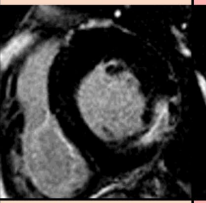
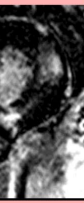






Progressively worsens with later phases



Exercise capacity worsens with cardiac disease stage in Fabry



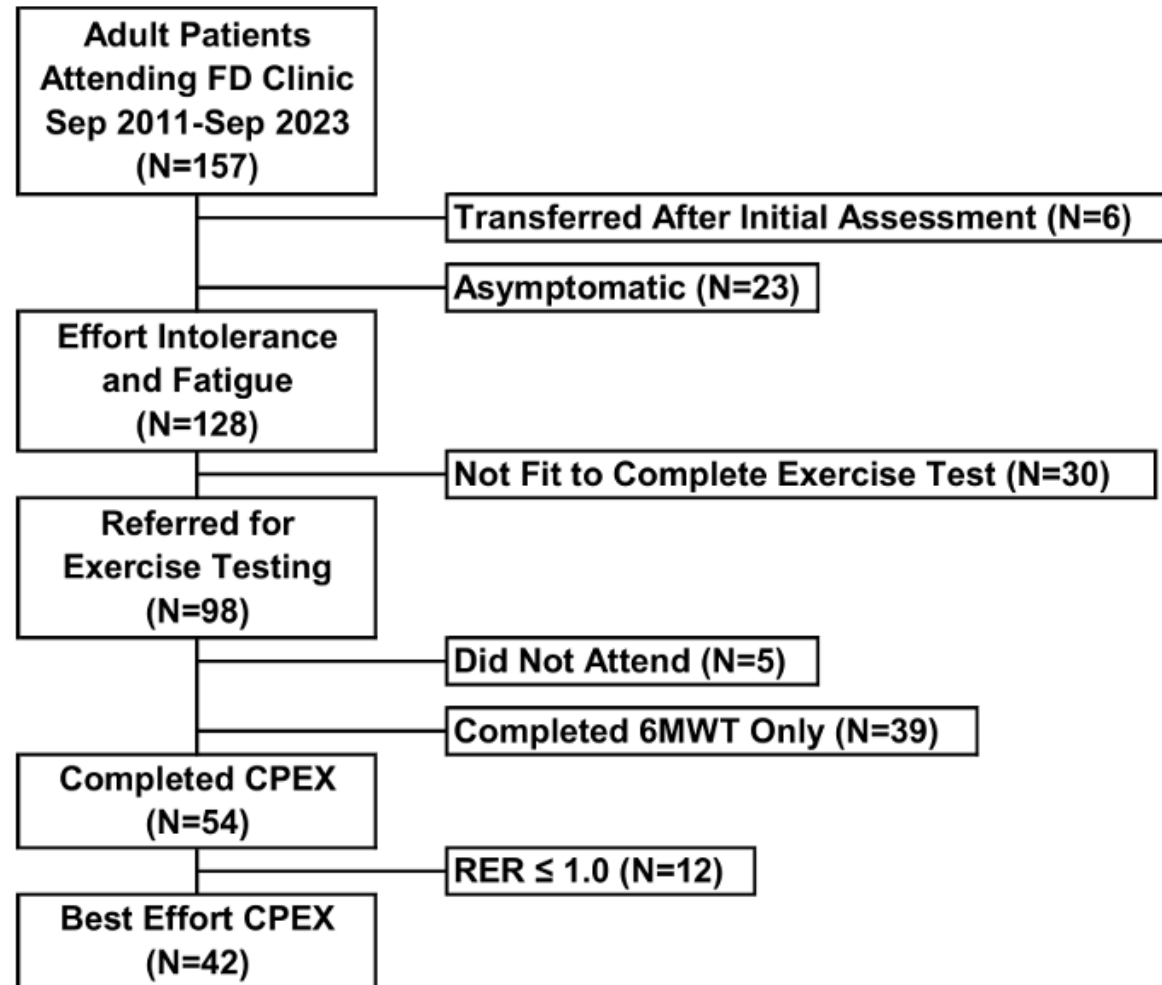
	Cardiomyopathy Phase			
	Phase 1	Phase 2	Phase 3	Phase 4
CMR/TTE Parameters				
T1 Mapping	Normal	Low		Pseudo-Normal
				
LGE	None	Focal	Diffuse	
				
LVH	Absent	Borderline	Moderate	Severe
				
LV GLS	<-17%	≥-17%		
LV EF	≥55%			<55%
Diastolic/Systolic Dysfunction	Normal	≥Grade I Diastolic Dysfunction		Systolic Dysfunction
ECG Parameters				
PR Interval	Normal	<120 / >200ms	>200ms	
ST Segment	Normal		Abnormal	
T-Wave	Normal		Inversion	
Arrhythmias	No			Yes
Biochemistry				
HS Troponin	Normal	Borderline ^a	>14 / 16ng/L ^b	
NT-proBNP	Normal	Borderline ^a	>400 ng/L	

Methods

Data collection of Fabry cohort undergoing exercise testing

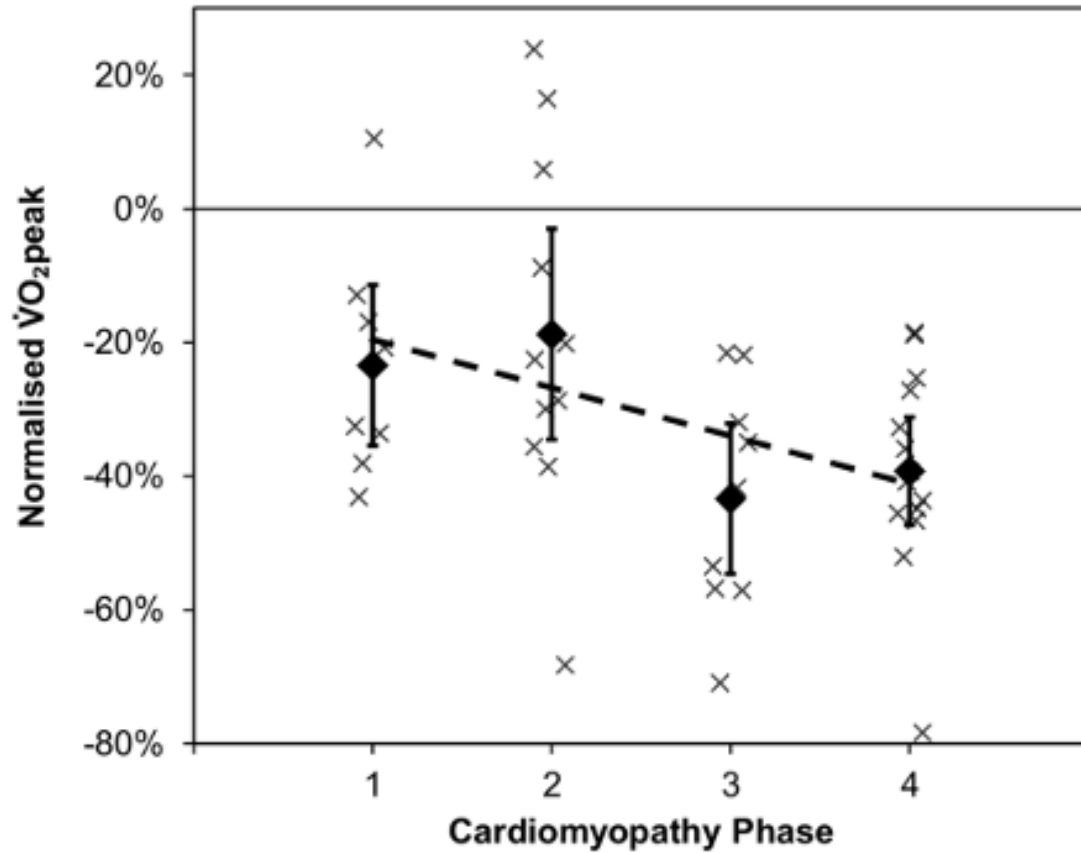
Cardiopulmonary Exercise test

$\dot{V}O_{2peak}$ measured on CPEX

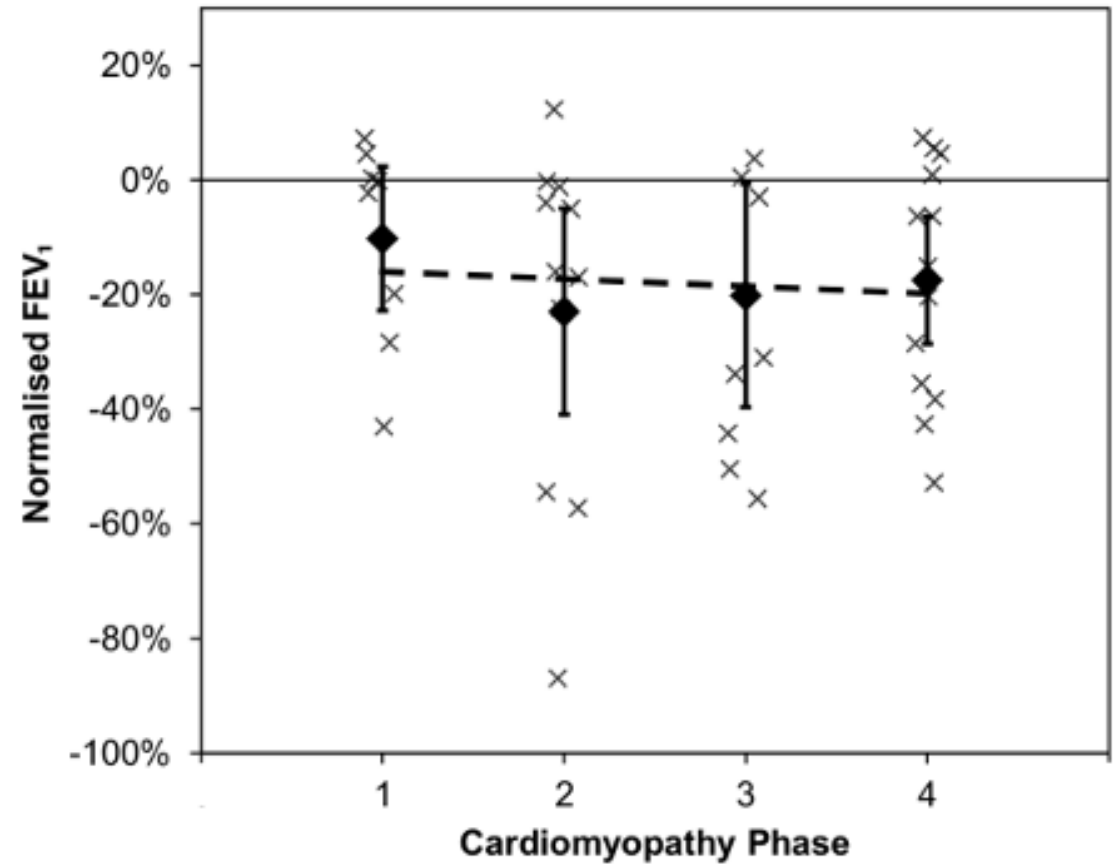


Roy et al 2025 *Heart*

B Normalised $\dot{V}O_{2peak}$



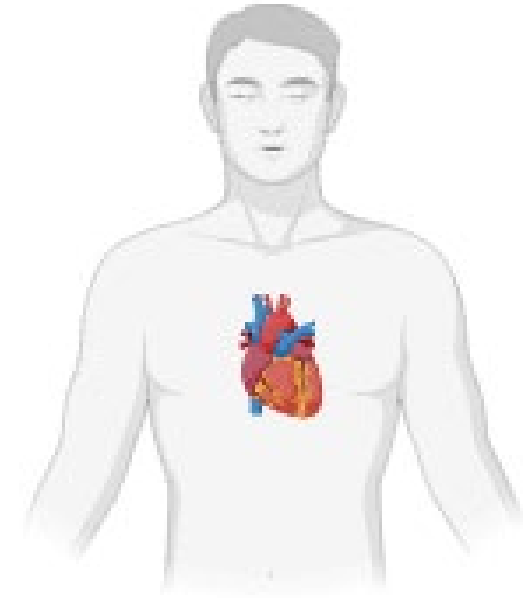
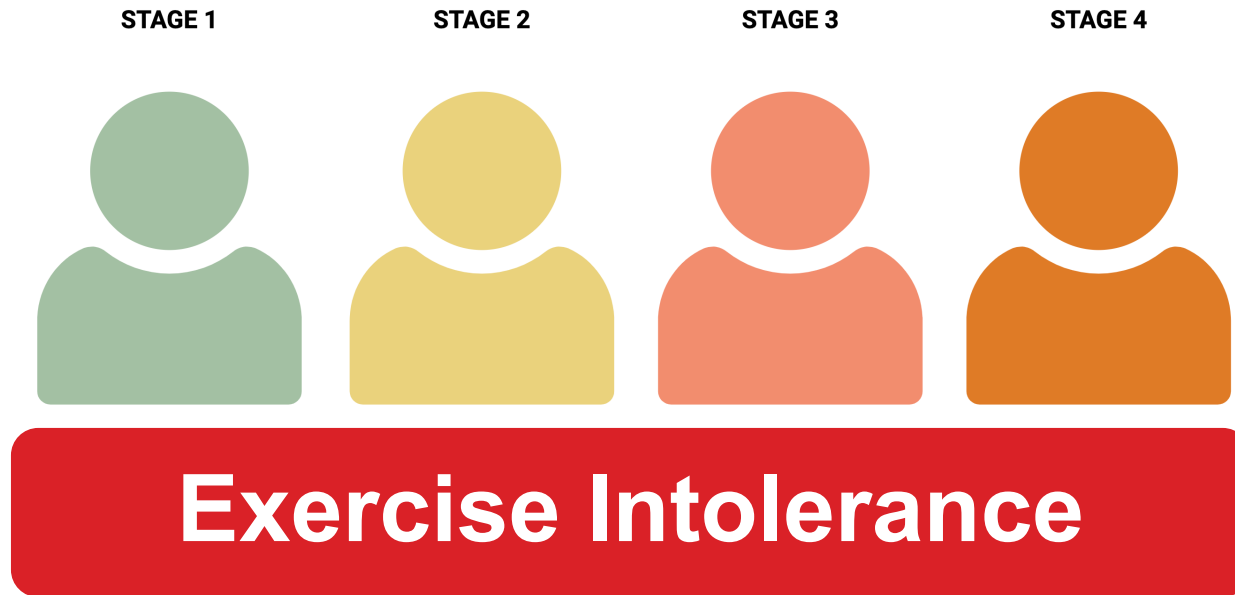
D Normalised FEV₁



Roy et al 2025 *Heart*

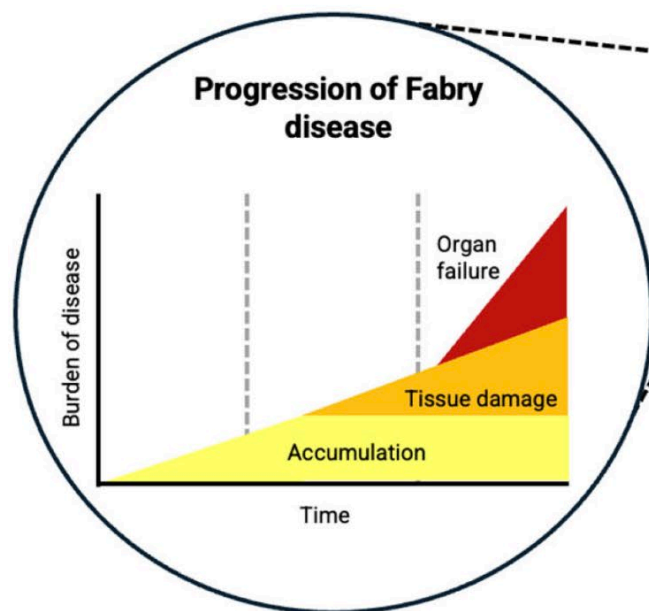
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Conclusions





Future direction



Heart

Accumulation of sphingolipid in cardiac myocytes

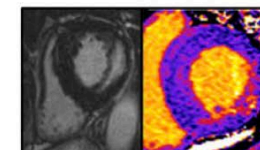
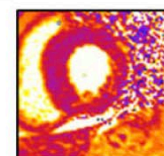
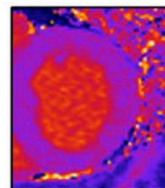
Tissue inflammation, left ventricular hypertrophy

Inflammation, fibrosis, organ dysfunction

Low T1 on cardiac MRI

Left ventricular hypertrophy
Raised T2 suggestive of myocardial oedema

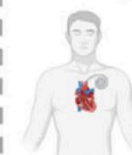
Late gadolinium enhancement
Pseudonormalised T1



Asymptomatic



Symptomatic heart failure
HFpEF



Advanced cardiomyopathy
HFpEF
Arrhythmia

Kidney

Accumulation of sphingolipid in podocytes and renal tubular cells

Podocyte injury, irreversible glomerular damage

Organ dysfunction

Asymptomatic
Normal or supranormal GFR



Proteinuria
Decline in GFR



End stage renal failure requiring dialysis +/- transplantation



Therapeutics

?

SGLT2 inhibitors

?

GLP-1 agonists *

* Especially in patients with type 2 diabetes or BMI >27

?

Non-steroidal MRAs

? IL-6 inhibitors / Colchicine

Thompson et al 2025 *Biomedicines*

FIN Meeting
26/4/25

Acknowledgements

University of Birmingham

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University of Oxford

Ben Davies

Queen Elizabeth Hospital Birmingham

Professor Rick Steeds

Professor Tarekegn Geberhiwot

Professor Jonathan Townend

Funders

British Heart Foundation, Metchley Park Fellowship



Thank you

References

1. Roy A, Thompson SE, Hodson J, van Vliet J, Condon N, Alvior AM, et al. Changes in peak oxygen consumption in Fabry disease and associations with cardiomyopathy severity. *Heart*. 2025;111(5):230-8.
2. Thompson SE, Roy A, Geberhiwot T, Gehmlich K, Steeds RP. Fabry Disease: Insights into Pathophysiology and Novel Therapeutic Strategies. *Biomedicines*. 2025;13(3).
3. Roy A, Thompson SE, Hodson J, Win KZ, Alvior AM et al. Utilization of Transthoracic Echocardiography and Biochemical Markers in Detecting Cardiomyopathy in Fabry Disease, *CJC Open* 2025,

Conflicts of
Interest: None

Ageing & Fabry disease

Patrício Aguiar

Reference Center in inherited metabolic disorders

ULS Santa Maria, Lisbon, Portugal

Disclosures

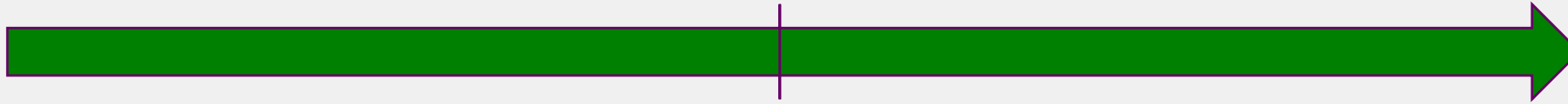
I have the following financial relationships to disclose:

- Grant / research support from Takeda.
- Honoraria from Takeda, Sanofi-Genzyme, Biomarin, Ultragenyx, Alexion, Chiesi and Amicus.

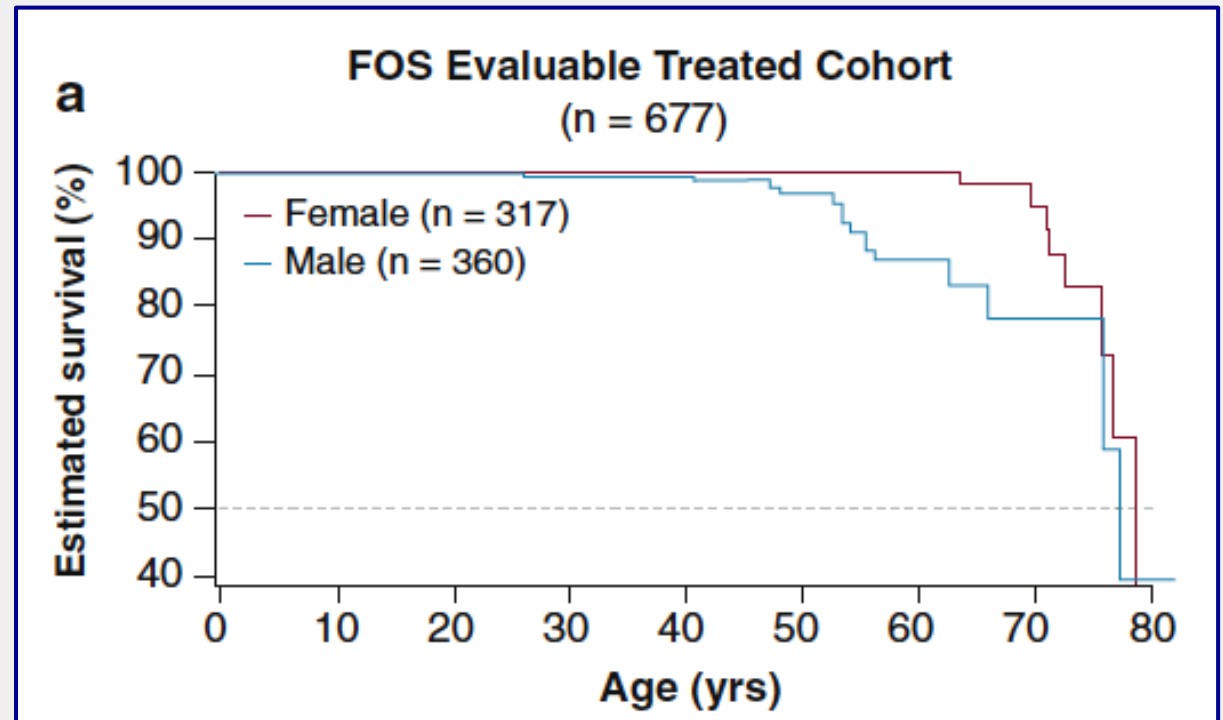
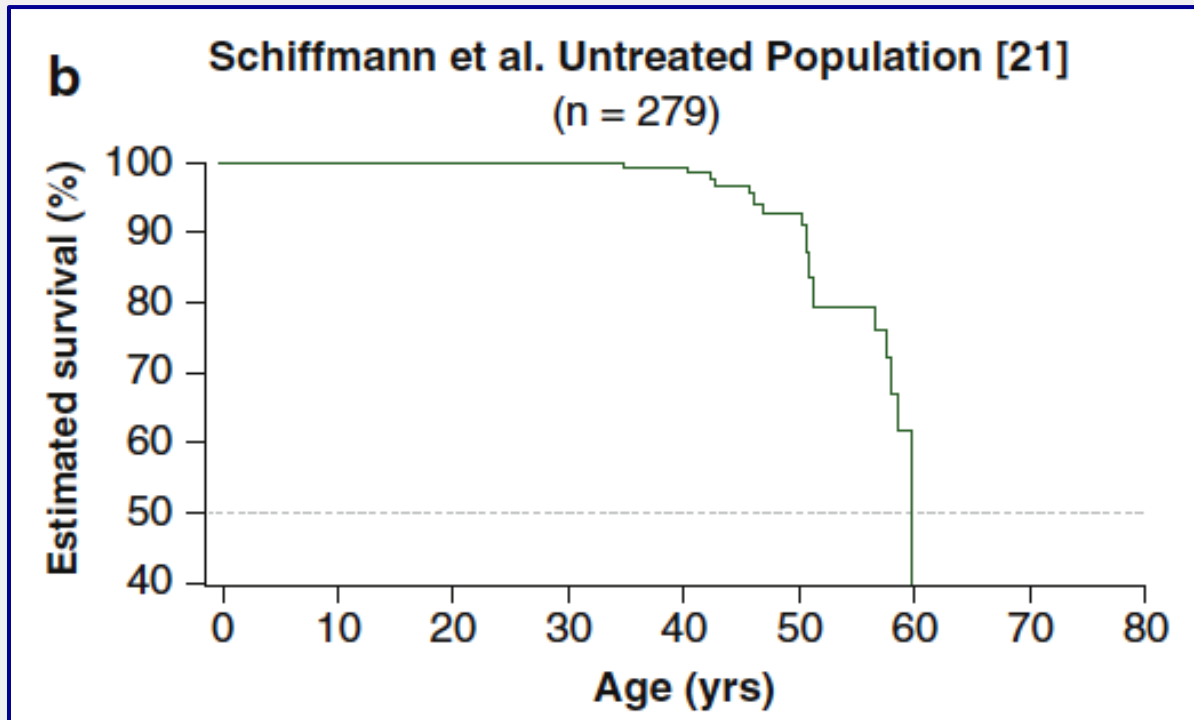
Fabry disease is changing: lifespan



Fabry disease is changing: lifespan



Improved health care and overall survival



Fabry disease is changing: epidemiology and phenotype

Table 1 Studies of prevalence of Fabry disease

Methods	Source	Ascertainment period	Total number of cases	No. per 100000	Country and reference
Birth prevalence (number of postnatal plus prenatal enzymatic diagnoses divided by number of births)	Two centres holding all enzymatic analyses in Australia	1980-1996	36	0.85	Australia [34]
Birth prevalence (number of cases born within a certain period divided by total number of live births in the same period)	All the laboratories making pre- and postnatal diagnoses of LSDs in The Netherlands	1970-1996	27	0.21	The Netherlands [33]
Prevalence of obligate carriers	By family history, from the UK AFD register	1980-1995	60	0.29	UK (females only) [26]
Prevalence	Records from regional genetic units and enzyme reference laboratories; records from individual doctors	1980-1995	98	0.27	UK (males only) [425]
Birth prevalence (number of cases born within a certain time period divided by total number of live births in the same period)	Two main reference centres for diagnosis of sphingolipidoses by enzyme analysis of patients under 5 years suspected of LSD	1997-2002	1	0.015	Turkey [426]
Birth prevalence (number of postnatal plus prenatal enzymatic diagnoses divided by number of live births) in north Portugal	One centre providing all pre- and postnatal diagnoses of LSDs in Portugal	1982-2001	1	0.12	North Portugal [427]
Neonatal screening	Northern Italy	2004-2006	12	30	Italy [35]
Neonatal screening	Taiwan	2006-2008	73	80	Taiwan [36]

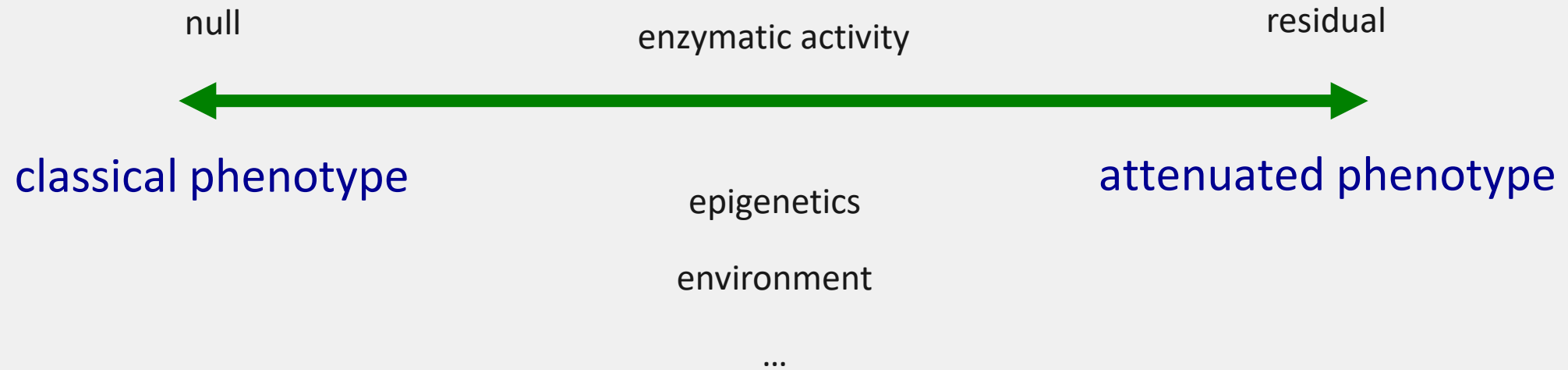
1 : 117.000

rare disorder (?)

1 : 1250



Fabry disease is changing: epidemiology and phenotype



Founder effect of Fabry disease due to p.F113L mutation: Clinical profile of a late-onset phenotype Molecular Genetics and Metabolism 129 (2020) 150–160

Olga Azevedo^{a,b,c,*}, Andreas Gal^d, Rui Faria^e, Paulo Gaspar^f, Gabriel Miltenberger-Miltenyi^{b,c,g}, Miguel F. Gago^{b,c,h}, Fátima Diasⁱ, Alice Martinsⁱ, Jorge Rodrigues^j, Pedro Reimão^k, Olga Pereira^l, Sónia Simões^m, Emilia Lopesⁿ, Maria José Guimarães^o, Nuno Sousa^{b,c}, Damião Cunha^{b,c}

Fabry disease is changing: clinical trials

2001

SAFETY AND TOLERABILITY OF RECOMBINANT α -GALACTOSIDASE A		CTOSIDASE A	
		RECOMBINANT α -GALACTOSIDASE A GROUP (N=29)	PLACEBO GROUP (N=29)
CHRISTINE DOMINIQUE P. GE LOUIS CA	CHARACTERISTIC		
	Age (yr)		
	Mean	32.0±9.4	28.4±11.4
	Range	16–48	17–61
FOR THE INTERNATIONAL COLLABORATIVE FABRY DISEASE STUDY GROUP			

2017

Oral pharmacological chaperone migalastat		
	Migalastat n=36	ERT n=21
Age (years)±SEM (min, max)	50.5±2.3 (18, 70)	46.3±3.3 (18, 72)
randomised phase III ATTRACT study		
Hughes DA, et al. <i>J Med Genet</i> 2017; 54 :288–296.		

Fabry disease patients are getting older



Age is the most important prognostic factor in Fabry disease



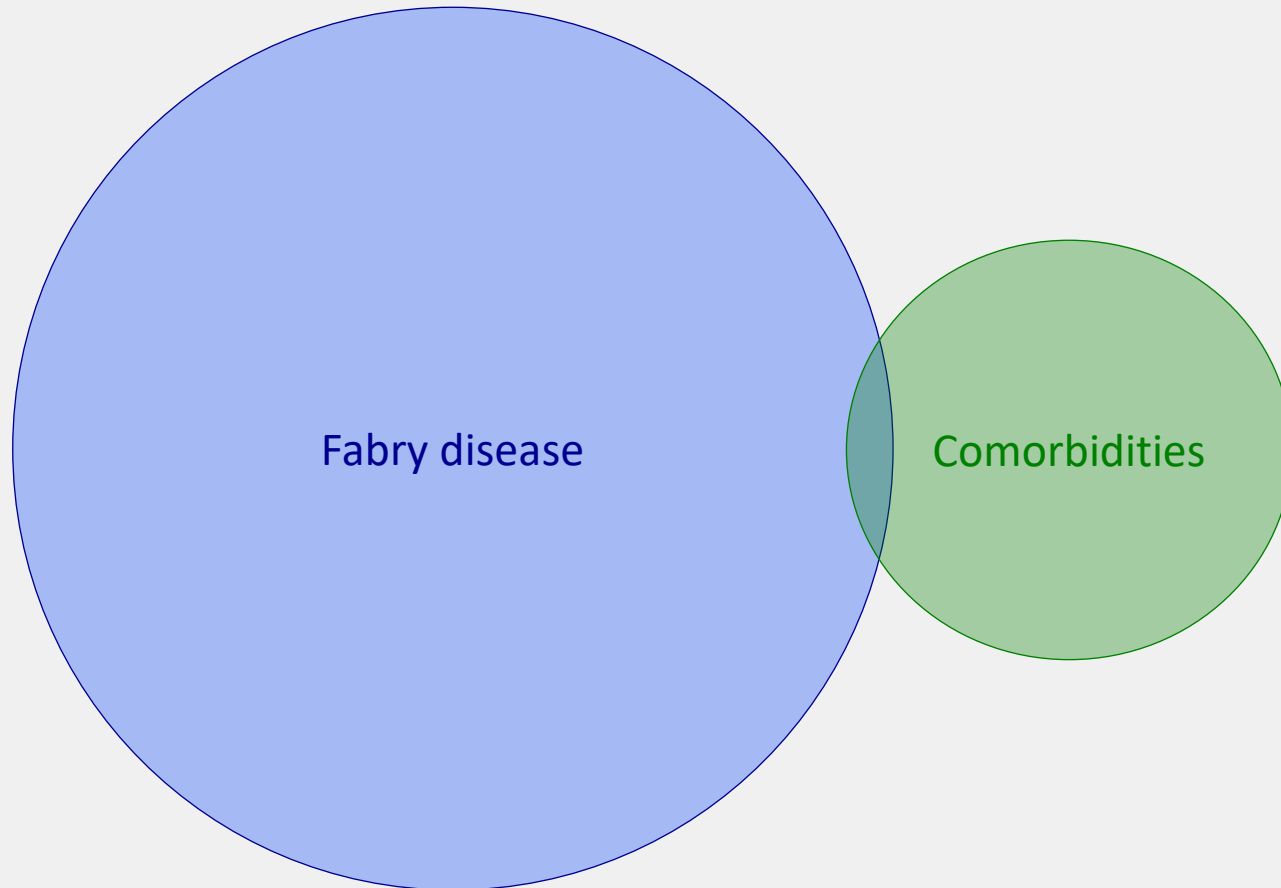
Ageing & Fabry disease: challenges

- Comorbidities and phenotype modulation
- Health-related QoL in older people with Fabry disease
- Natural history of attenuated phenotypes and how to evaluate QoL
- Multidisciplinary team changes
- Disease-specific treatment objectives and ageing
- Lifespan and causes of death in Fabry disease
- Research needs

Challenges: comorbidities

General health status

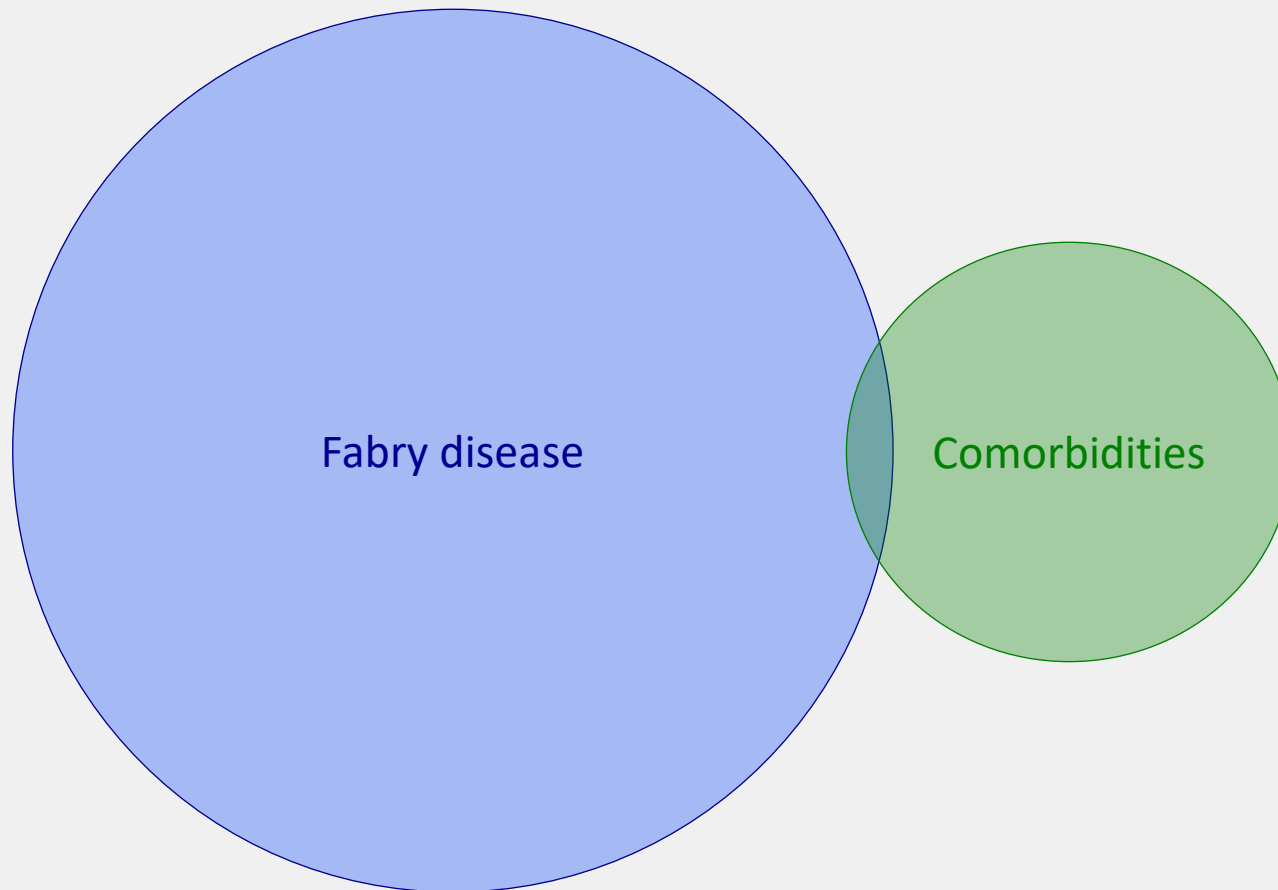
young patients



Challenges: comorbidities

General health status

older patients



Challenges: comorbidities and phenotype modulation

Pain



age

Challenges: comorbidities and phenotype modulation

Stroke risk

Estimation of Stroke Risk in Patients with Fabry Disease Using a Machine Learning Model

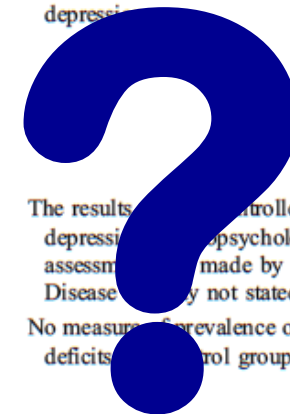
Staci Kallish, DO,¹ Giorgio P Biondetti,² John L Jefferies, MD, MPH, Patrício Aguiar, MD, PhD, Matthew W Nelson, PharmD, Joseph D Giuliano, Joseph W Zabinski, PhD, Costas Boussios, PhD, Gary Curhan, MD, ScD, Jigar N Bandaria, PhD, Richard E Gliklich, MD, David Warnock, MD

Key characteristics associated with elevated risk in FD patients shared roughly 70% similarity with those present in non-FD patients

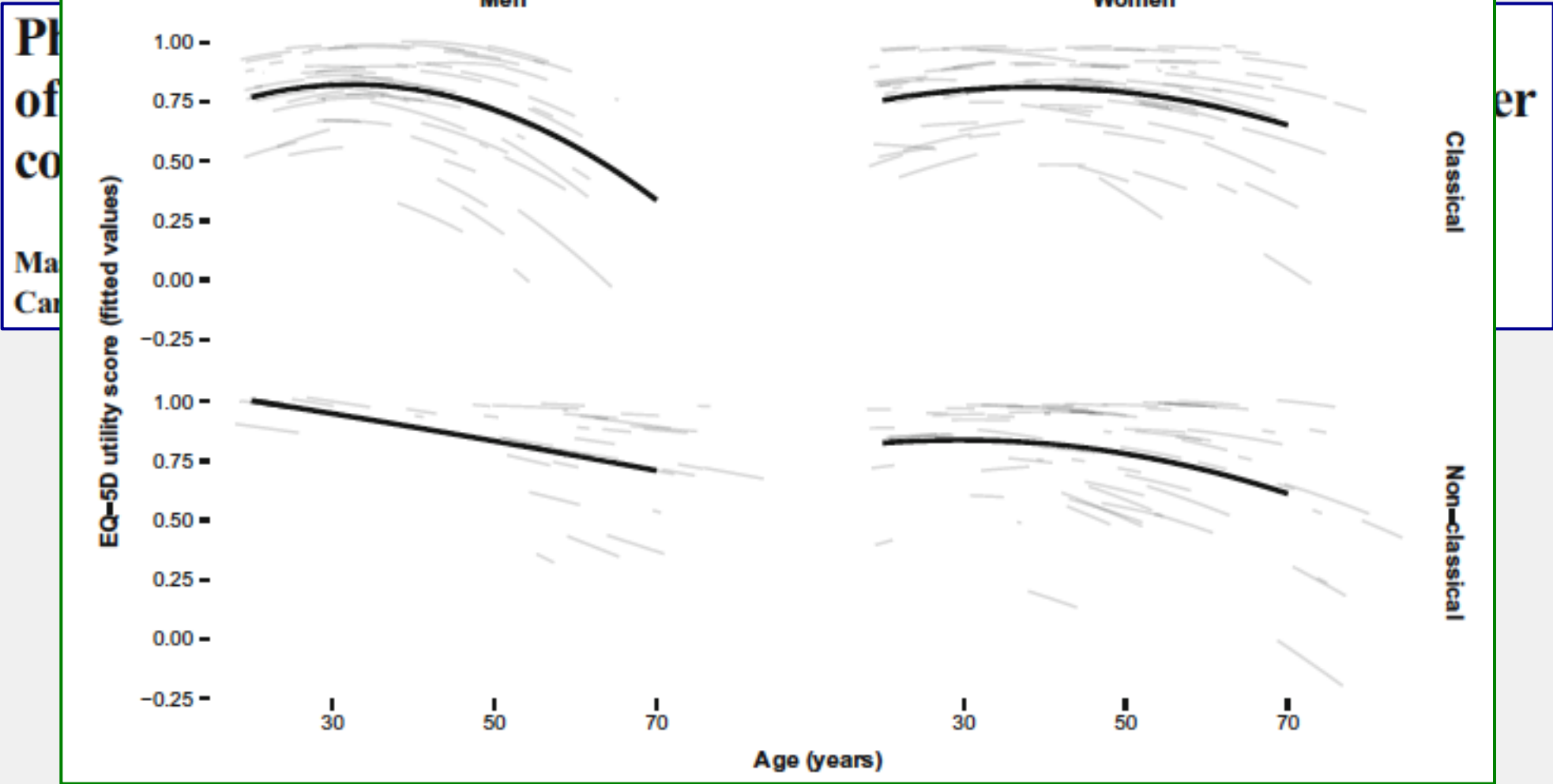
Challenges: comorbidities and phenotype modulation

Risk of dementia

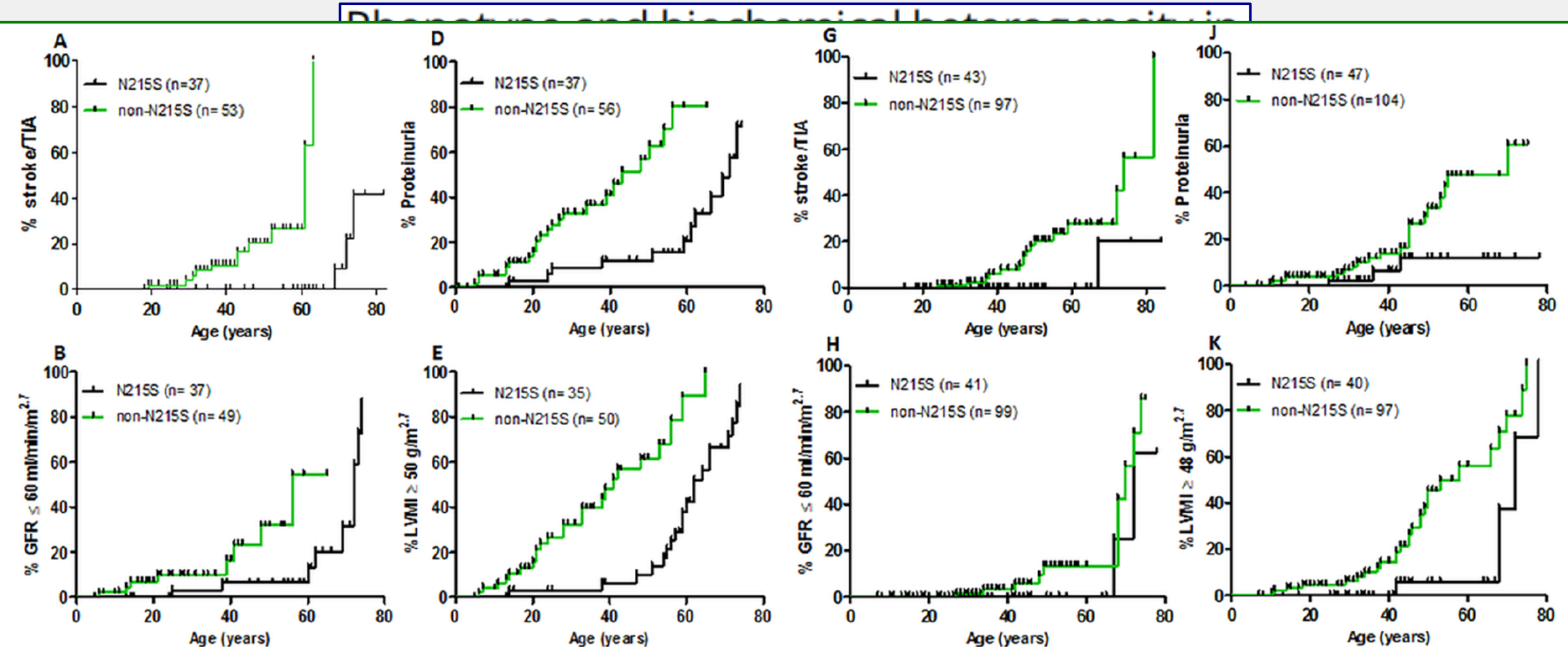
Authors	N	Age (years)	Sex	Tests performed	Type of analysis	Stroke (n)	Impaired cognitive domains	Limitations
Low et al. (2007)	21 P, 46 C	Mean 40.2 Range 20–62	2 F 19 M	MMSE, NUCOG	Group comparisons healthy vs. patient	9/14, MRI in 14/ 21 P	Language	Too broad and too few <i>N</i> -tests. No measure of premorbid or present intellectual functioning. Depression not examined
Segal et al. (2010)	16P	Mean 29 Range N/A	9 F 7 M	Comprehensive <i>N</i> -battery	<i>N</i> -test results were compared to age-based norms	1	Psychomotor speed, attention and executive functions	No measure of premorbid or present intellectual functioning. Children and adults grouped in analysis
Schermyly et al. (2011)	25 P, 20 C	Mean 36.5 Range 21–56	15 F 10 M	RAVLT, WMS-R, TAP, TMT, Part A + B, and WCST	Group comparisons healthy vs. patient	5	Attention and executive functioning (became non-significant after controlling for depression severity)	No measure of premorbid intellectual functioning
Elstein et al. (2012)	6P	Mean 41.3 Range 25–63	4 F 2 M	Mindstream's computerised cognitive battery for mild impairment	The results were compared to Norms from Mindstream's program	2	Psychomotor speed	The results are not controlled for depression
Sigmundsdottir et al. (2014)	17 P, 15 C	Mean 46.6 Range 25–60	5 F 12 M	Comprehensive <i>N</i> -battery	Group comparisons healthy vs. patient	4	Psychomotor speed and executive functions (only males)	The results are not controlled for depression. Psychological assessment was made by telephone. Disease severity not stated
Wadley et al. (2015)	54, 216 C	Mean 55.7 Range 46–72	37 F 17 M	NINDS-CSN, CERAD	Group comparisons healthy vs. patient	6	No significant difference between patient and control group. No significant gender difference	
Lelieveld et al. (2015)	25 P	Mean 37.9 Range N/A	15 F 10 M	MMSE, AVLT, WMS-R, TMT part A + B	Comparisons between baseline and 8-year follow-up	N/A	N/A	
Current study	41 P, 80 C	Mean 47.2 Range 20–75	29 F 12 M	Comprehensive <i>N</i> -battery	Observed scores compared to regression based reference data	7	Psychomotor speed, attention and executive functions	Fixed categorisation of tests in cognitive domains



Challenges: health-related QoL



Challenges: attenuated phenotypes



Challenges: attenuated phenotypes

- Is the phenotype related to FD itself or ageing / comorbidities
- How can we measure health-related QoL: heart failure QoL scales (?)
- What is the lifespan of attenuated phenotypes (?)

Challenges: multidisciplinary team

young patients

- Primary care / GP
- Diagnostic laboratory
- Geneticist
- Psychologist
- Social worker
- Reproductive medicine
- Specialist nurse
- Patient advocacy
- Rehabilitation
- Palliative / pain care

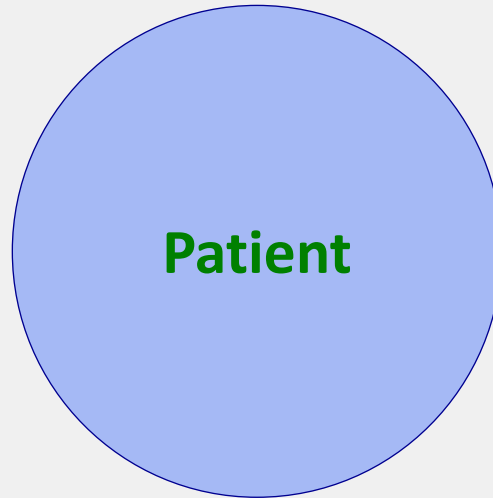


- Coordinator Paediatrician / Internist
- Cardiologist
- Nephrologist
- Neurologist
- Ophthalmologist
- ENT
- Dermatologist
- Psychiatrist
- Gastroenterologist
- Rheumatologist

Challenges: multidisciplinary team

old patients

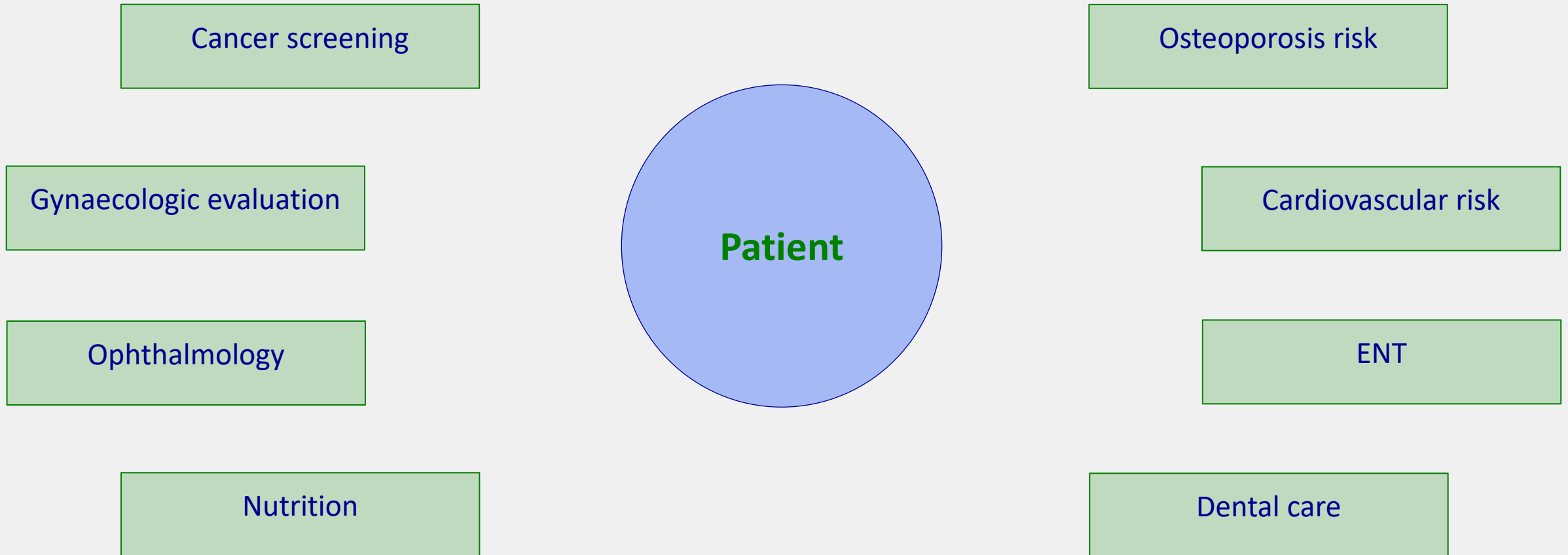
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- ENT
- Dermatologist
- Psychiatrist
- Gastroenterologist
- Rheumatologist

Challenges: multidisciplinary team

old patients



Challenges: disease specific treatment

Clinical trials

Treatment	Clinical trial	Population	Mean age (range)	Age inclusion criteria
Agalsidase- α	Schiffmann R ¹	26 males	34.0 ()	≥ 18 yo
Agalsidase- β	Eng C ²	58 patients (2F)	32.0 (16 – 48)	≥ 16 yo
Migalastat	FACETS ³	24M, 43F	40.0 (16 – 68)	16 – 74 yo
	ATTRACT ⁴	25M, 32F	48.9 (18 – 72)	16 – 74 yo

No evidence in elderly

1 - Schiffmann R et al. JAMA (2001); 285: 2743-2749.

2 – Eng C et al. N Engl J Med (2001); 345: 9-16.

3 - Germain DP et al. N Engl J Med (2016); 375: 545-55.

4 - Hughes DA et al. J Med Genet (2017); 54(4): 288-296.

Challenges: disease specific treatment

Clinical trials

Treatment	Clinical trial	Median age (range)	Age inclusion criteria
Agalsidase-α	Schiffmann R ¹	34.0 ()	≥ 18 yo
Agalsidase-β	Eng C ²	22.0 (16 – 48)	≥ 16 yo
Migalastat	FACETS ³	30.0 (16 – 68)	16 – 74 yo
	ATTRACT ⁴	38.9 (18 – 72)	16 – 74 yo

Adjunctive treatments

heart failure

antiarrhythmic

cardiac devices

antiproteinuric

pain killers

antiplatelets / anticoagulants

1 - Schiffmann R et al. JAMA (2001); 285: 2743-2749.
2 – Eng C et al. N Engl J Med (2001); 345: 9-16.
3 - Germain DP et al. N Engl J Med (2016); 375: 545-55.
4 - Hughes DA et al. J Med Genet (2017); 54(4): 288-296.

Challenges: causes of death in Fabry disease

up to 2001

Cause of death	Number of deaths in male relatives					Number of deaths in female relatives					Overall number of deaths				
	Age at death (years)					Age at death (years)					Age at death (years)				
	0-20	21-50	>50	Unknown	Total	0-20	21-50	>50	Unknown	Total	0-20	21-50	>50	Unknown	Total
Cardiac	0	22	8	1	31	0	1	11	0	12	0	23	19	1	43
Renal	0	29	14	7	50	0	5	2	0	7	0	34	16	7	57
Cerebrovascular	0	5	5	2	12	0	6	8	2	16	0	11	13	4	28
Respiratory	0	0	1	0	1	0	0	0	0	0	0	0	1	0	1
Malignancy	0	2	1	0	3	0	4	5	1	10	0	6	6	1	13
Infection	0	3	0	2	5	0	0	1	0	1	0	3	1	2	6
Multisystemic	0	0	0	0	0	0	0	1	0	1	0	0	1	0	1
Other	0	7	3	6	16	0	4	5	7	16	0	11	8	13	32
Total	0	68	32	18	118	0	20	33	10	63	0	88	65	28	181

Challenges: causes of death in Fabry disease

2001 – 2007

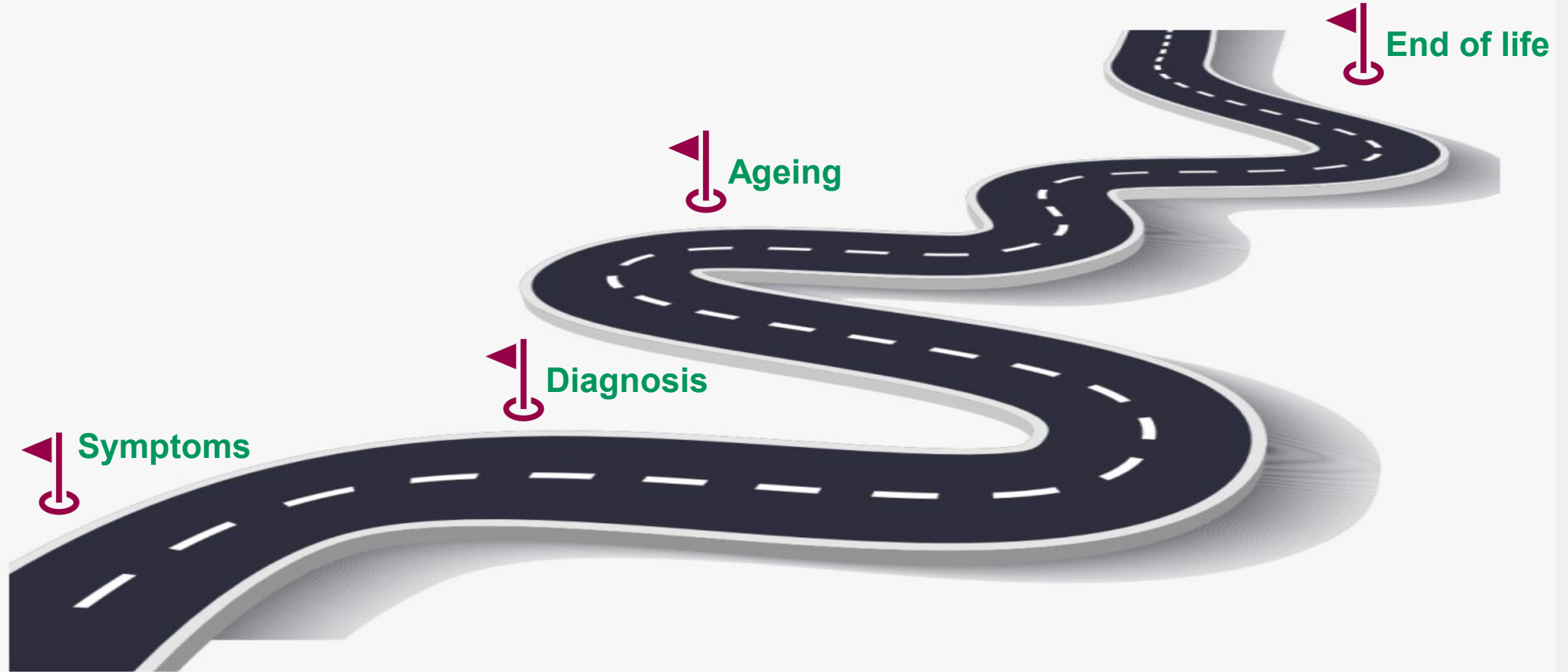
Cause of death	Received ERT at some time			Never received ERT			Overall		
	M	F	Total	M	F	Total	M	F	Total
Cardiac	10	2	12	2	2	4	12	4	16
Renal	3	0	3	0	0	0	3	0	3
Cerebrovascular	3	0	3	1	0	1	4	0	4
Respiratory	2	0	2	1	0	1	3	0	3
Malignancy	1	1	2	1	0	1	2	1	3
Infection	5	0	5	0	0	0	5	0	5
Multisystemic	2	2	4	2	0	2	4	2	6
Other	2	0	2	0	0	0	2	0	2
Total	28	5	33	7	2	9	35	7	42

Cardiac supportive care is essential

Research is an urgent need in old Fabry disease patients



(Not only) the end of a patient journey...



Take-home messages

- Due to different reasons Fabry disease patients are getting older
- The comorbidities may influence Fabry disease phenotype and decrease health-related QoL
- In patients with attenuated phenotypes, the influence of age in Fabry disease phenotype may be even of greater magnitude
- The evidence supporting disease-specific treatment in elderly patients with Fabry disease is scarce
- A holistic multidisciplinary team and adjunctive therapies are paramount in older patients with Fabry disease
- Research is an urgent need in this population

Thank you



Põe quanto És no Mínimo que Fazes

"To be great, be whole: nothing of yours exaggerate or exclude.

Be entire in everything. Give all of you in the least you do.

Hence on every lake the whole moon shines as it lives high."

Ricardo Reis, in "Odes"

**Turning Passion into Action:
Sustainable futures for Patient Organizations
Annual FIN Expert Meeting**






Vanessa Ferreira, PhD MBA

Head of Patient and Public Involvement and Engagement



Where are you on the funding journey?" (Show of hands)

Ask participants to raise their hands to indicate:

-  **Green:** We've successfully applied for multiple funding calls
-  **Yellow:** We've tried applying but still learning.
-  **Red:** We're just starting and haven't applied yet.

 Follow-up: Share briefly a tip or a challenge faced.

Diverse funding opportunities

- Public grants – national & regional-, EU funding programs,
- Pharma & biotech,
- Private foundations and charities e.g. Wellcome Trust, Bill & Melinda Gates),
- Corporate Social responsibility (CSR) programs,
- Crowdfunding & community fundraising,
- Membership fees & subscriptions,
- Donations & legacy giving,
- Events & campaigns,
- Service-based income e.g. consultancy,
- EU & Global networks (Global Genes)



Quick interactive game

How many:

- "Has applied for EU funding"
- "Has collaborated with pharma"
- "Knows what a Work Package is"
- "Has been rejected for funding (and learned from it!)"
- "Knows what Lump Sum is"
- "Recently started the first steps related to EU funding and/or other"

Share your best tip

Write in a sticky note

- “What’s one thing you wish you knew before applying for funding?”
- “What’s your best advice for building partnerships?”



The Nobel Prize in Physiology or Medicine 1981

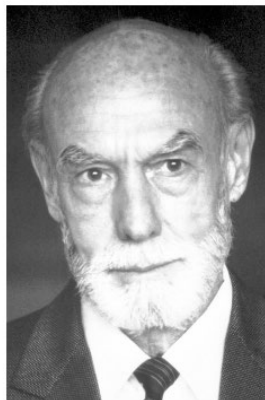


Photo from the Nobel
Foundation archive.
Roger W. Sperry

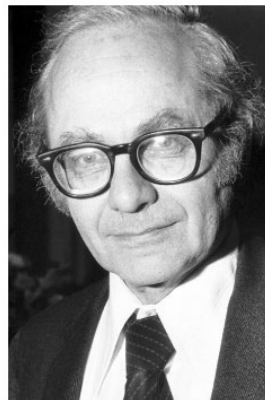


Photo from the Nobel
Foundation archive.
David H. Hubel

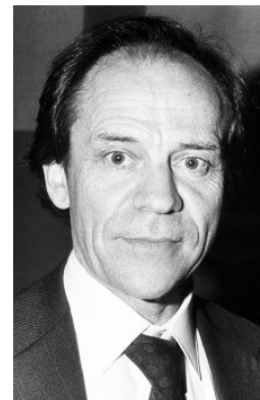


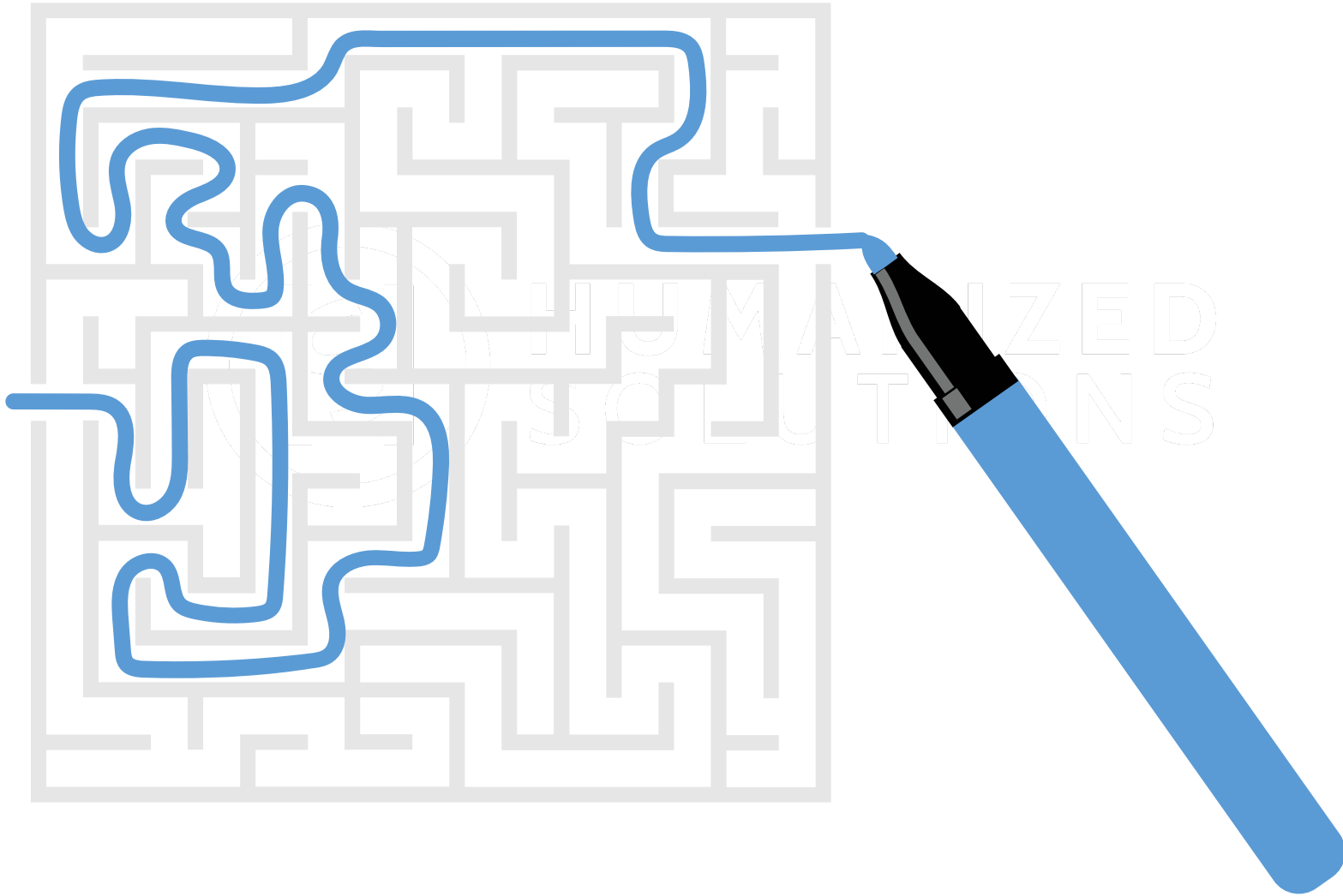
Photo from the Nobel
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Torsten N. Wiesel



1981



1996



CDG

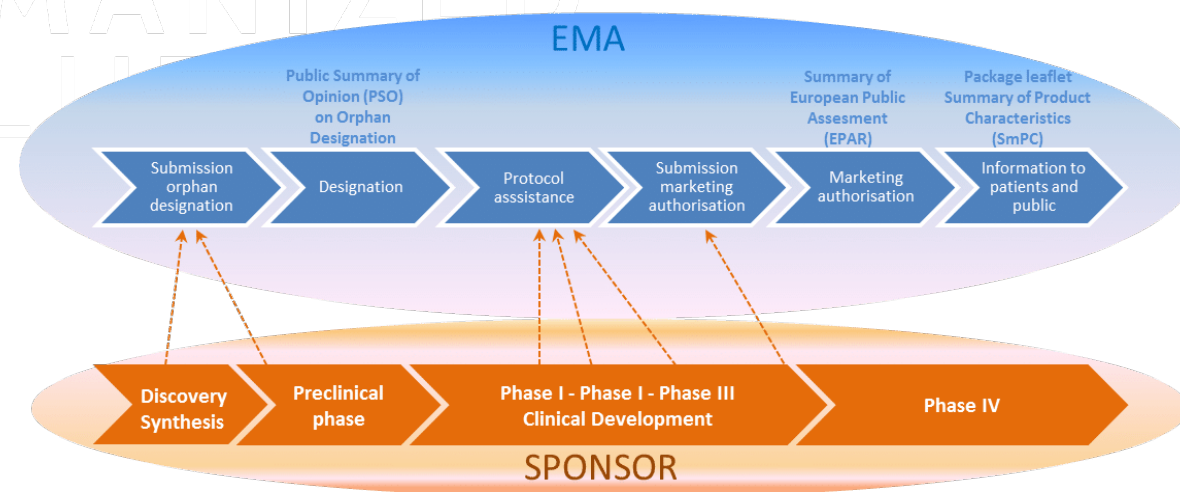






2010

Orphan Drug Regulatory Journey in the EU





Biology and PhD

APCDG (2010-2024)

World Conference on CDG
(2013-2023)

Co-founder, Patient advocacy, Senior researcher at CDG & Allies

at FCT NOVA (2016-)

Mentor Degree, Master, PhD students, Post Docs

World CDG Day (2016-)

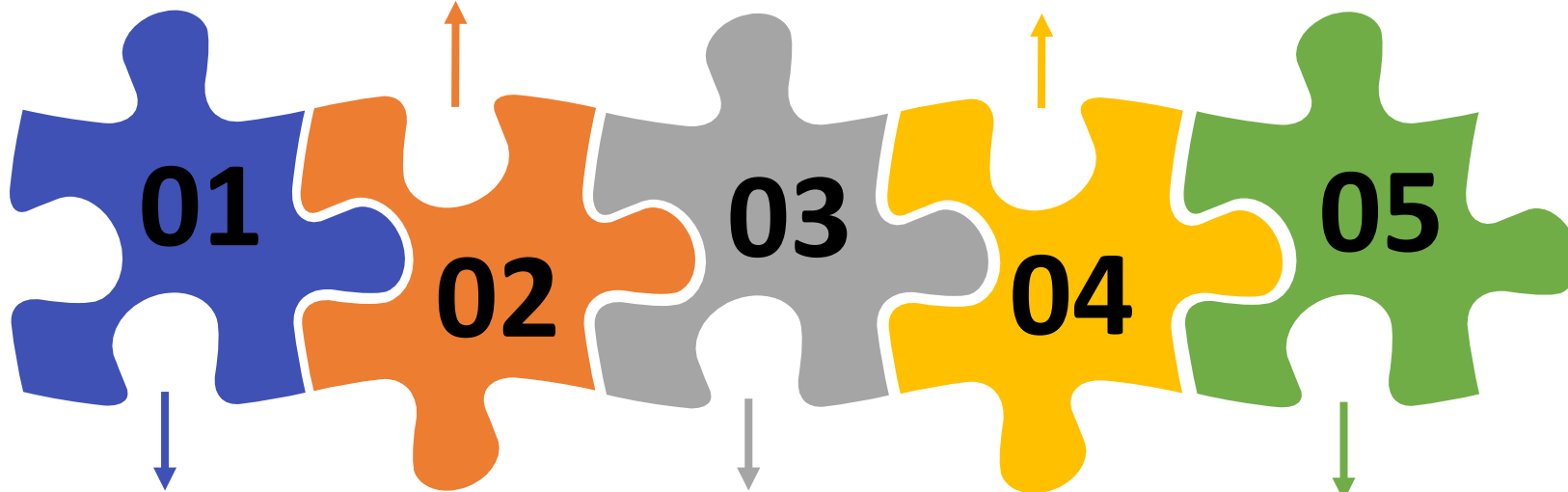
World CDG Org (2020-)

People



Vanessa

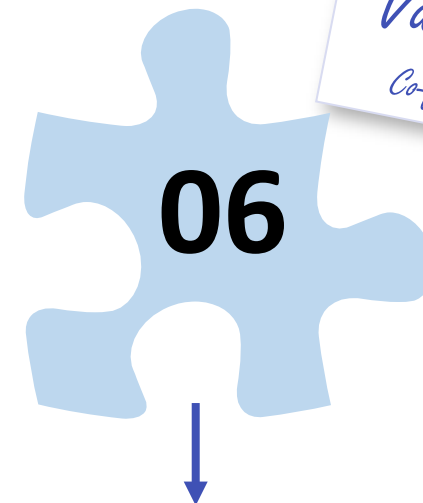
Co-founder



Family experience

Pharma industry
(2011-2020)
MBA (2011-2013)

Training in Coaching (2020);
Since 2021:
Coaching program for "Health Empowerment &
Wellbeing: A Coaching Program to Elevate Patient
and Citizen Involvement in Healthcare".
Consultant Patient Advocacy
Mentor at
Universidad Europea Madrid (UEM)



Humanized Solutions (2022-)
EUPATI Fellow (2023)
Adjunct Professor UEM (2024-)

Personal journey: From passion and goodwill to understanding the need for strategy and financial sustainability.



People Ce

DOUBT

The reality of leading an association isn't just  —it's also about structure and resources.

What I would tell the Vanessa of 2010



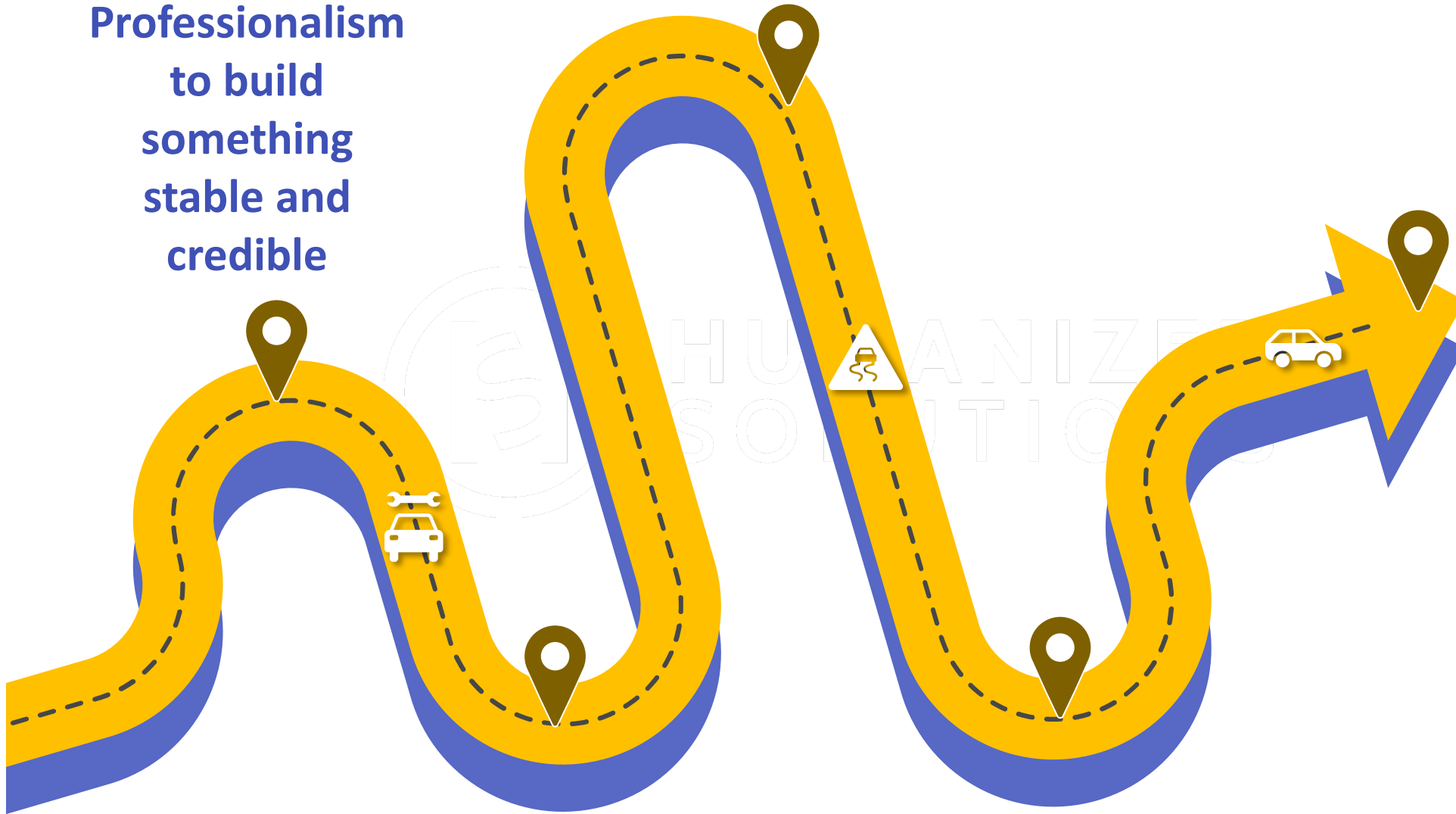
Passion & Goodwill starts the journey, but strategy and sustainability keep it going.

How to transform the CDG patient group into a recognized, professional entity — moving beyond the perception of being just a group connected by shared experiences?

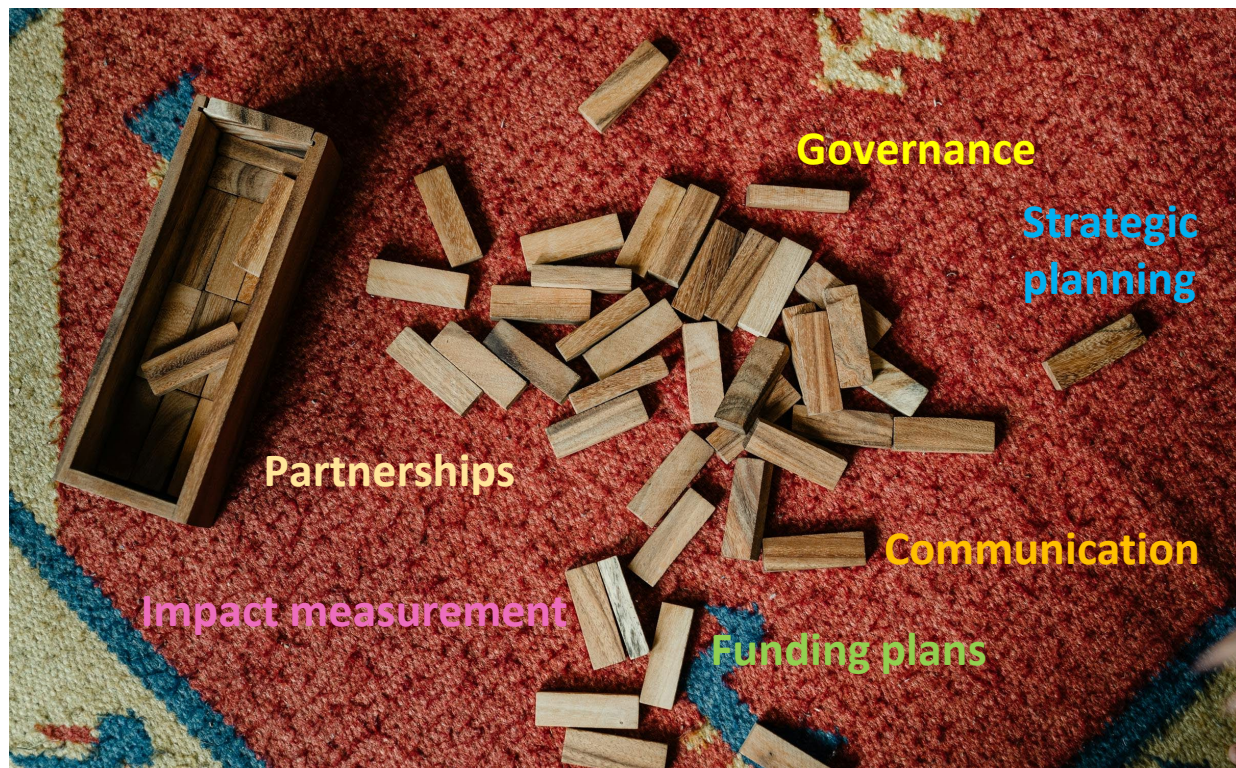


Passion & Goodwill starts the journey, but strategy and sustainability keep it going.
Professionalism is one key component.

**Professionalism
to build
something
stable and
credible**



From passion to mission: The power of professionalization to become sustainable



Passion and goodwill open doors, but professionalism turns ideas into action, secures your place at the table, and leads to real achievements.

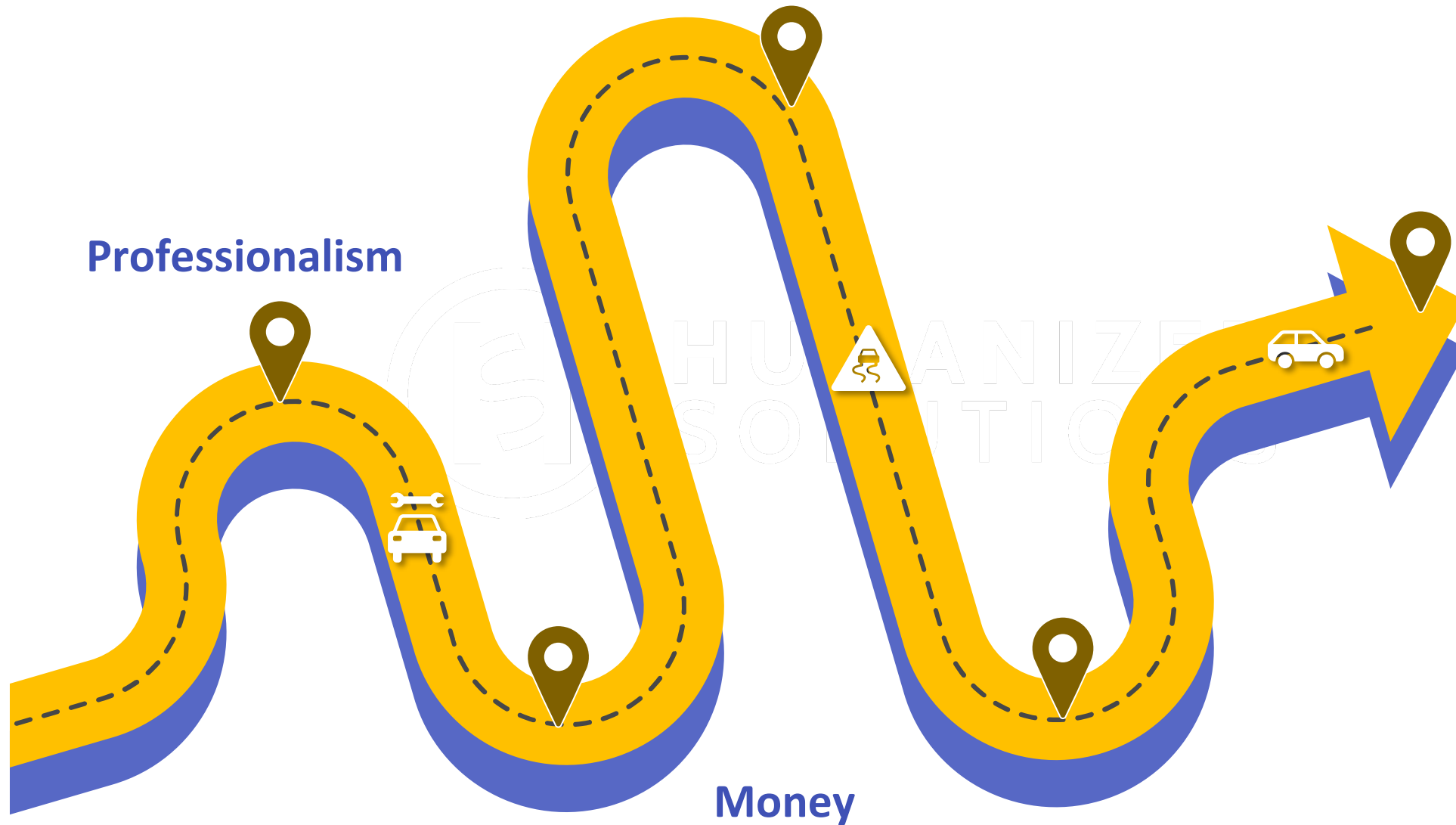
The importance of being seen as professional to secure funding and partnerships.

 Credibility	 Trust for funding	 Sustainable growth	 Stronger partnerships
Be seen as reliable, organized, and serious by funders, researchers, and policymakers.	Funders and sponsors need to trust you have systems in place — governance, finance, clear goals.	Professional structure prevents burnout and keeps your mission alive long-term.	Professionalism opens doors to pharma, academia, and public institutions.

What I would tell the Vanessa of 2010



Professionalism gets you a seat at the table, and funding that sustains it.
Money, Money, Money: Funding is essential to turn purpose into impact

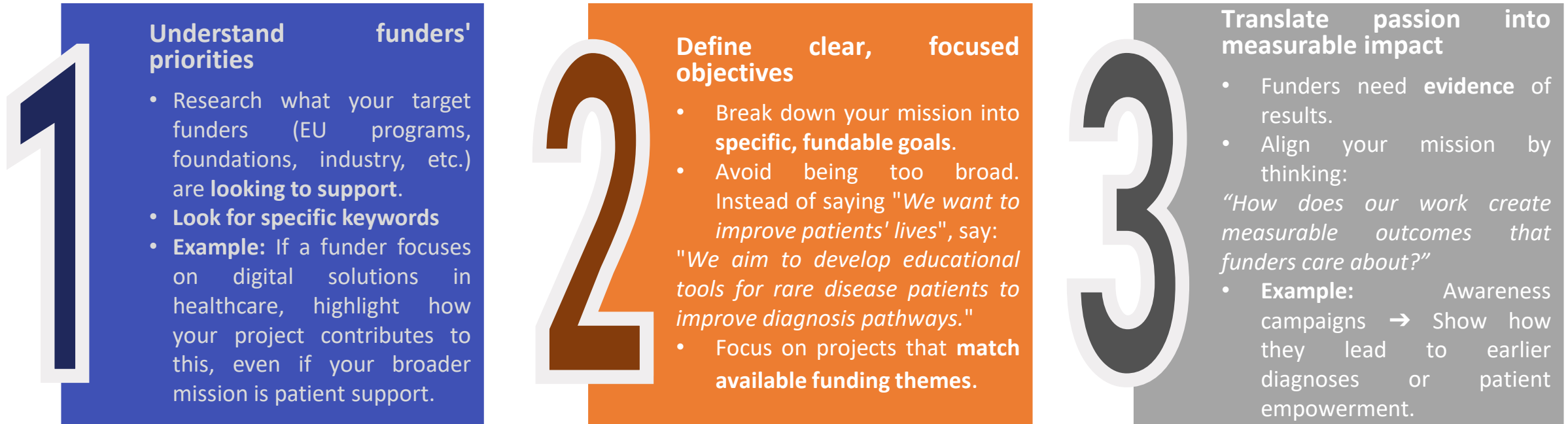


Money, Money, Money: Funding is essential to turn purpose into impact

 — *Innovation & New Projects* — *Growth & Expansion* — *Community Support & Services* — *Infrastructure & Stability* — *Education & Training* — *Engagement & Communication* — *Visibility & International Collaboration* — *Resources & Equipment* — *Partnerships & Networking* — *Advocacy & Awareness* — *Research & Innovation* — *Opportunity to Launch New Initiatives* Heart — Enhanced Patient Care & Human Impact

→ Ultimately, funding helps fulfill the mission: improving lives. → Focus your mission to align with funding goals.

Step by Step: How to focus your mission to align with funding goals



Step by Step: How to focus your mission to align with funding goals

4

Read the guides & Use the language of funders

- Adapt how you **present your mission** using terms funders recognize.
- Words like "*capacity building*", "*innovation*", "*public health impact*", "*cost-effectiveness*", "*stakeholder engagement*" resonate more than emotional appeals alone.

5

Stay true, but flexible

- You don't need to change your mission — just frame it **strategically**.
- Focus on the **parts of your mission that overlap with funders' goals**.
- Example: If your mission is broad patient advocacy, but the funding is for research collaboration, **emphasize how you facilitate patient involvement in research**.

6

Create a "Funding alignment map"

- List:
 - Your core activities
 - Funders' priorities
 - Find the **connection points**.
- Focus your applications and efforts where these align best.



Example:

- **Original mission:**
"Support families affected by rare diseases through advocacy, education, and community building."
- **Aligned for funding:**
*"We empower rare disease patients and families **by developing** innovative educational tools **and fostering** patient involvement in healthcare research — contributing to better health outcomes and system innovation."*



Aligning your mission with funding goals is about speaking the funder's language, focusing on impact-driven objectives, and showing how your passion delivers results in areas they care about.

Free resources and programs to gain or refresh necessary skills.

1. NGO Management Certificate – Harvard Kennedy School (Free Modules Available)

Focus: Leadership, fundraising, governance, strategic management for NGOs.

While full programs are paid, Harvard offers free online modules via edX and other platforms.

- [Harvard edX Courses](#)

2. Nonprofit Ready – Free Courses for NGOs

Over 500 free courses on topics like: Fundraising & Grant Writing, Financial Management, Governance & Board Development, Project Management.

Created specifically for nonprofits and NGOs.

- [Nonprofit Ready Courses](#)



Free resources and programs to gain or refresh necessary skills.

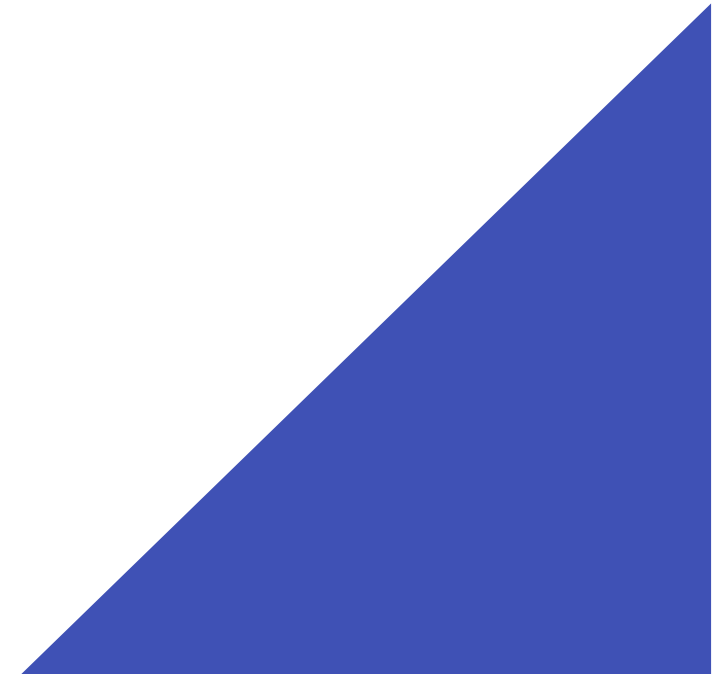
3. Coursera – Nonprofit Management Courses

Universities like Duke, Stanford, and UPenn offer courses such as:

- "Nonprofit Management Essentials"
- "Fundraising and Development"
- "Financial Management for NGOs"

Many courses are free to audit.

- [Coursera Nonprofit Courses](#)



Free resources and programs to gain or refresh necessary skills.

4. The Open University – Free NGO Courses

Topics include:

- "Introducing the Voluntary Sector"
- "Working in the Voluntary Sector"
- "Leadership and governance basics"

○ [OpenLearn Voluntary Sector Courses](#)

5. NGO Academy (by ERSTE Foundation & WU Vienna)

Free capacity-building programs for NGOs, including patient organizations, focused on leadership, impact measurement, strategy, and financial sustainability.

○ [NGO Academy](#)



Free resources and programs to gain or refresh necessary skills.

6. The Center for Nonprofit Management (CNM) – Free Webinars

Regular free sessions on nonprofit excellence:

- Grant writing
- Strategic partnerships
- Board governance

- [CNM Events](#)

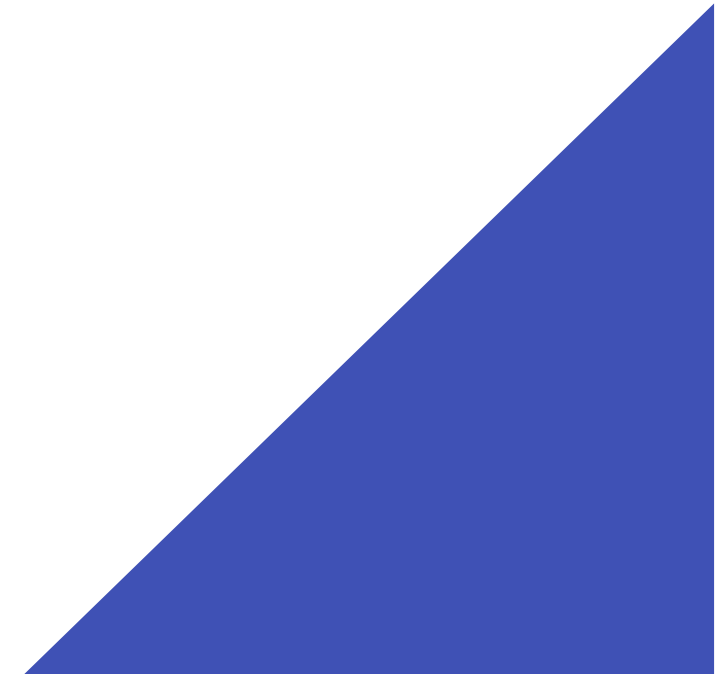
7. GlobalGiving – Accelerator for NGOs

A free virtual training program to help NGOs build skills in:

- Crowdfunding
- Storytelling
- Donor engagement

Upon completion, NGOs get permanent membership on GlobalGiving's platform.

- [GlobalGiving Accelerator](#)



Free resources and programs to gain necessary skills.

1. EIT Health

Programs designed to empower different target audiences including patient organizations and advocates to engage in healthcare innovation and entrepreneurship.

- [EIT Health Patient Innovation Bootcamps](#)
- [Women Entrepreneurship Programs](#)

2. EPF (European Patients' Forum) – [Capacity Building Programme](#)

Supports patient organizations in becoming more sustainable, influential, and professional through webinars, workshops, and mentoring.

- Topics: Governance, strategic planning, advocacy, communication, and fundraising.
- 

**Free resources
and programs
to gain
necessary
skills.**

3. PARADIGM – Patient Engagement Tools & Guidelines

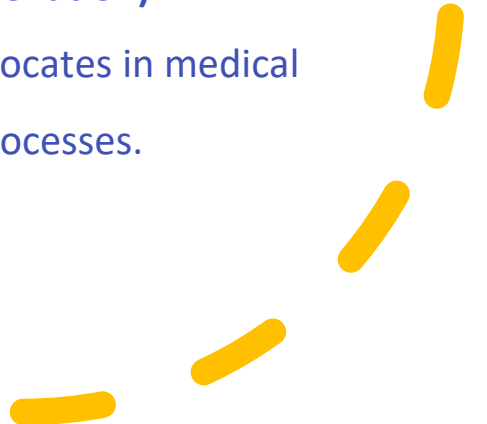
A set of free tools and frameworks to guide patient organizations on how to engage effectively with industry and researchers in medicines development.

Includes templates for agreements, metrics for impact, and best practices.

- [PARADIGM Toolbox](#)

4. EUPATI (European Patients' Academy on Therapeutic Innovation)

Offers free online courses and resources to train patient advocates in medical research, drug development, clinical trials, and regulatory processes.

- [EUPATI Toolbox](#)
 - [EUPATI Open Classroom](#)
- 

**Free resources
and programs
to gain
necessary
skills.**

5. Patient Focused Medicines Development (PFMD) Resources

Offers structured methodologies and tools to improve patient engagement and professional interaction with pharma and regulatory bodies.

- [PFMD Resources](#)

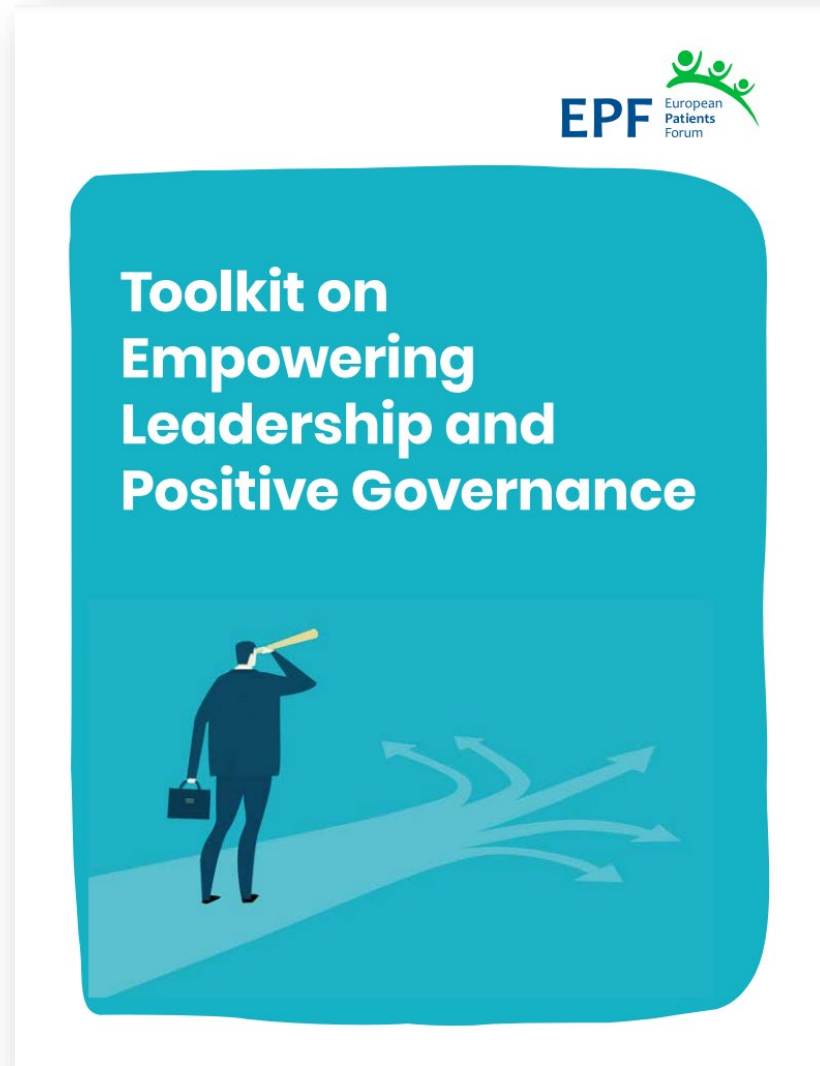
6. European Commission – Funding & Tender Portal Training

Free webinars and guides on how to participate in EU-funded projects (Horizon Europe, etc.)

Ideal for associations wanting to step into European funding frameworks.

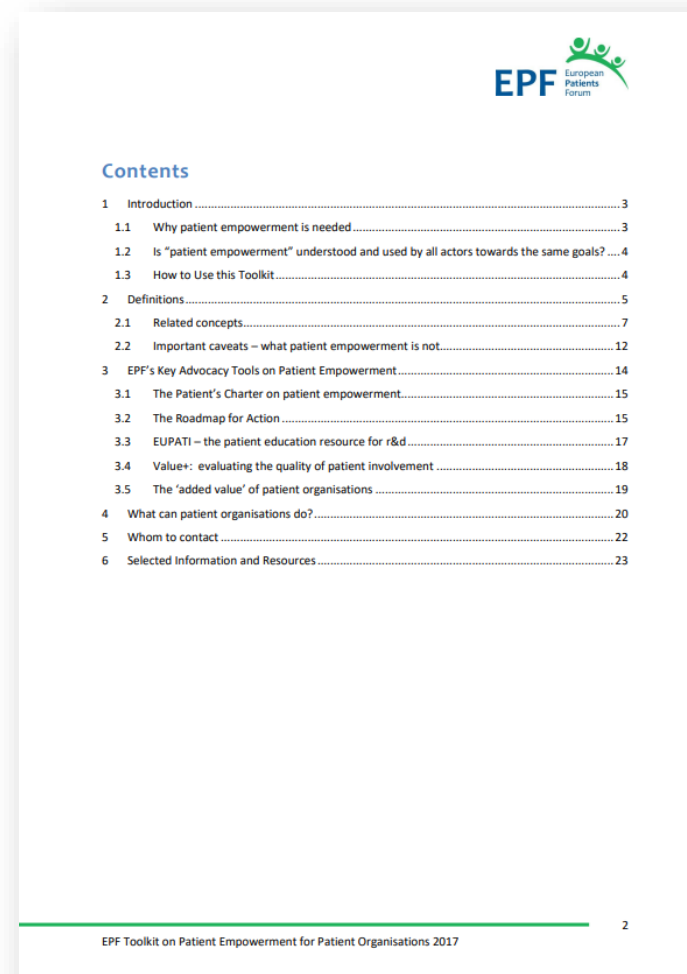
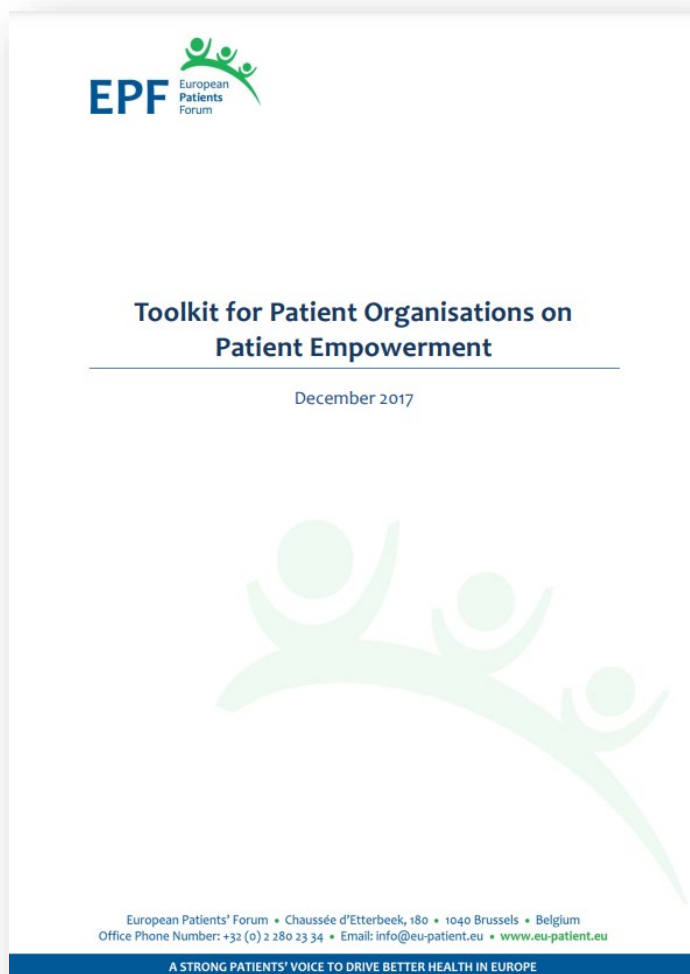
- [EU Funding & Tender Portal](#)
- 

Toolkit on Empowering Leadership and Positive Governance by the European Patients' Forum (EPF)



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Toolkit for Patient Organisations on Patient Empowerment by the European Patients' Forum (EPF)



Fundraising Toolkit for Patient Organisations by the European Patients' Forum (EPF)



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EPF
EPF

EPF TOOLKIT / FUNDRAISING FOR PATIENT ORGANISATIONS 3

Free resources and programs to gain necessary skills specifically for Rare Diseases.

1. EURORDIS Open Academy

Free training for patient advocates to engage in research, regulatory affairs, HTA (Health Technology Assessment), and market access.

- **EURORDIS Winter & Summer Schools**
- **Digital School**: Focus on digital skills, understanding of research, eHealth tools for patient organizations, and more.

2. Global Genes – RARE University & Toolkits

Free educational resources, toolkits, and webinars specifically for rare disease advocates and organizations.

Topics: Fundraising, governance, collaboration, research readiness.

- **Global Genes RARE University**

Free resources
and programs
to gain
necessary skills
for Rare
Diseases.

3. Rare Diseases International (RDI) – Advocacy & Policy Resources


Provides toolkits and webinars to strengthen patient organizations' roles in global advocacy, governance, and collaboration strategies.

- Members training: How to influence international actions through national advocacy
- Youth Leadership Programme
- RDI Advocacy and Policy Resources



4. Beacon Empowering Rare Disease Communities

Provides training, resources, and networking opportunities to help rare disease communities grow, professionalize, and drive meaningful change.

E.g., RareSummit, Patient Group Mentoring.

- Strategic planning and sustainability
 - Building capacity with AI
 - Networking with confidence masterclass
 - The Cambridge Rare Disease Showcase
- 

Share4Rare toolkit for Patient Advocacy

  Ref. Ares(2018)6664049 - 27/12/2018
D1.4 Toolkit for Patient Advocacy

DELIVERABLE:

Toolkit for Patient Advocacy (D1.4)

Document information

Programme	Innovation Action
Call identifier	H2020-ICT-2016-2017
Topic	Collective Awareness Platforms for Sustainability and Social Innovation
Project Title	Social media platform dedicated to rare diseases, using collective intelligence for the generation of awareness and advanced knowledge on this large group of diseases
Start of Project	1 January 2018
Duration	36 months
Project acronym	Share4Rare
Grant agreement number	780262
Number of the Deliverable	D1.4
WP / task related	WP1 / T1.5
Dissemination level	PU public
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Version	1.0
Number of pages	88
Lead partner	UPPMO
Author(s)	Omaira Gill, Dimitrios Athanasiou, Suzie-Ann Baker



Global Genes Rare Advocacy Exchange 2025



The calendar graphic displays eight sessions arranged in two rows of four. Each session is represented by a colored calendar icon with a date at the top, a title and speaker list in the center, and a time slot at the bottom. The sessions are as follows:

Date	Title	Speakers	Time
MAR 10	Kick-off and Keynote: When Leadership is Thrust Upon You	Zoe Manville, Rare Mom; <i>Portugal the Man Singer</i> Mel Dixon, Rare Mom; Cure DHDDS Kara Ryska, The Special Needs Mom Podcast; The Pathway to Peace Coaching Community	1-2:30pm ET
MAR 12	Harnessing Your Values to Fuel Your Leadership Strategy	Amy Brin, MSN, MA, Amy Brin Consulting Amber Denton, NBIA Disorders Association Lakeia Nard, Melanin Children Matter	1-2:30pm ET
APR 10	Thinking Outside of Your Inbox, Innovative Fundraising Opportunities	Jillian Arnold, Rare Mom; Advocate; Podcast Host; Author Kasey Woleben, Rare Mom; Rare Village Brittany Markham, Rare Mom, ASMD	2:30-4pm ET
MAY 8	From Conflict and Competition to Cooperation and Collaboration	Emily Amerson, Rare Parent, CTNNB1 Chandler Crews, Rare Individual; The Chandler Project Payal Patel, Rare Mom, DLG4 Sarah Shaffer, Rare Mom; Author	2:30-4pm ET
JUN 5	Interacting with FDA: PFDD and Listening Sessions	Charlene Son Rigby, Rare Mom; Global Genes Larry Bauer, Regulatory Drug Develop. Expert Robyn Bent, PFDD - CDER, FDA Dorothea Lantz, Rare mom, Prader-Willi; PWSA	1-2:30pm ET
SEP 18	Getting a Precise Diagnosis is Critical for Adults and Children	Effie Parks, Rare Mom, CTNNB1; Once Upon a Gene Podcast Michael Kruer, Phoenix Children's Shazia Lakhani, American Kidney Fund Lukas Lange, Probably Genetic	1-2:30pm ET
SEP 18	Rare Grief is a Sneaky Bitch: Grieving a RARE Diagnosis	Lisa Keefavuer, <i>Grief is a Sneaky Bitch</i> Book and Podcast Daniel DeFabio, Rare Dad; Global Genes Jessie Fein, Author; Podcaster; Mito Advocate Ronda Thorington, Rare Mom; Parent Coach	2:30-4pm ET
OCT 16	Knowing the Rights of Your RARE Child (or Yourself)	Benita Talati, Rare Individual; Disability Attorney Kelley Coleman, Rare Mom; Author Michele Erwin, All Wheels Up	12:30-2pm ET

Register Now At No Cost



"If I could go back..."

Let's take a moment to learn from each other!

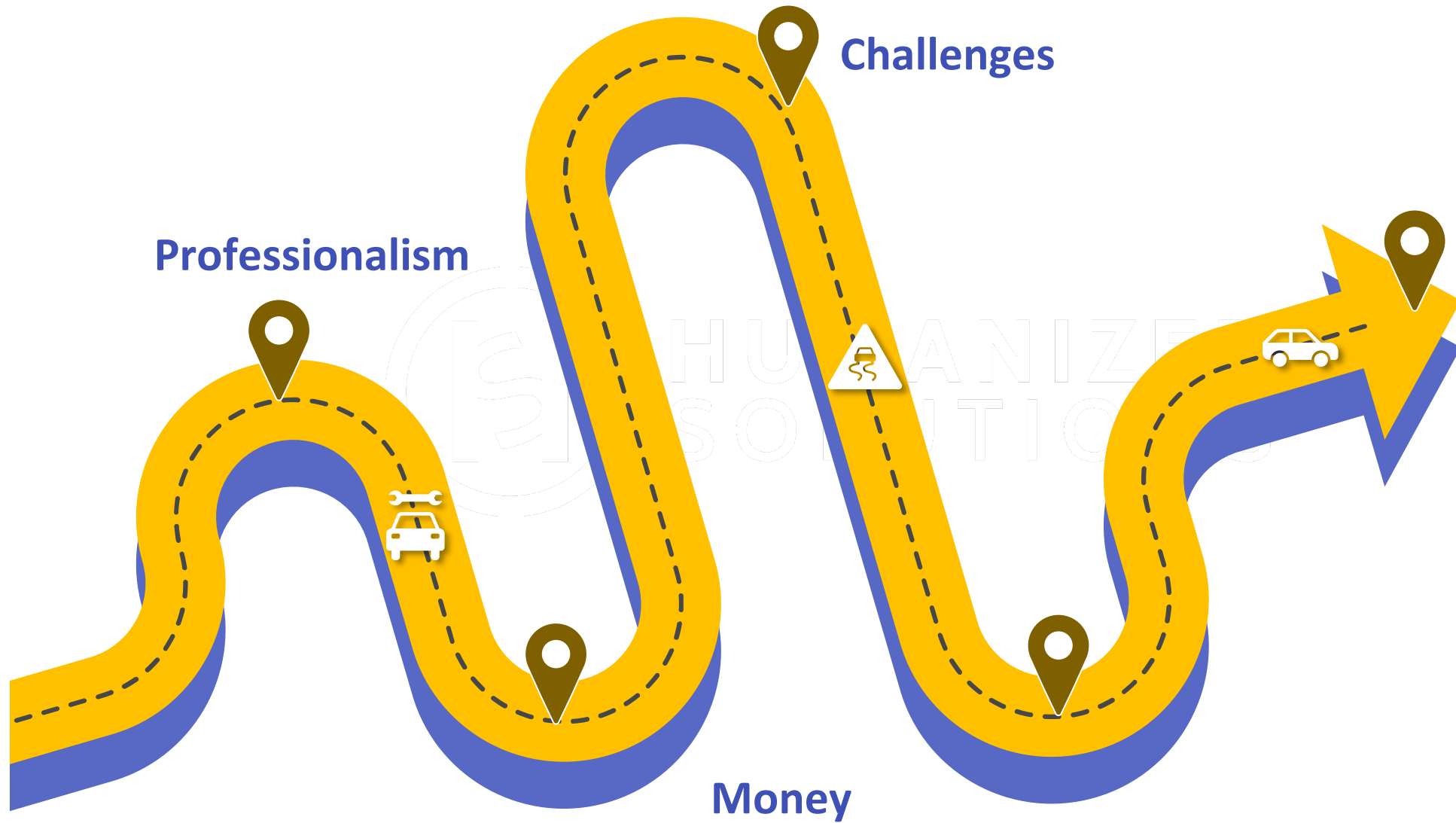
Using sticky notes, please answer the following questions based on your experience level:

◆ For experienced advocates (5+ years in a patient group or NPO):

- "If you could give advice to your younger self when you started your association, what would you do differently?"
- "What has been the key factor that kept your organization going over the years?"

◆ For new advocates (recently established associations):

- "What is the biggest challenge you're facing right now?"
- "What support or resource do you think would help you reach the next level in your organization?"







**Challenges when
researchers, medical
doctors, companies, want
to involve Patient Groups
in funding opportunities**





**Challenges when Patient
Groups engage with
researchers, medical
doctors, companies in
funding opportunities**

Lack of time, Resources and Funding

Financial risk and co-funding requirements

Some funding schemes require co-financing or upfront investment, which is not feasible for most small patient organizations. Cash flow issues can arise due to delayed payments from funders.

Difficulty finding consortia or partners

Complexity of Application Processes:

Funding applications, especially EU-level ones, are **highly technical**, requiring knowledge of administrative, legal, and financial procedures. Patient groups often lack experience in navigating these bureaucratic processes.

Legal and administrative barriers

Many patient groups are not legally structured to meet eligibility criteria for funding (e.g., being recognized as a formal entity under EU law). Lack of experience with contracts, VAT issues, and compliance rules.

Difficulty demonstrating impact
E.g., define clear KPIs

Lack of strategic focus

Lack of awareness of funding opportunities; Language and jargon barriers

Unclear role in funded projects

Sustainability after the project ends; Lack of training and support

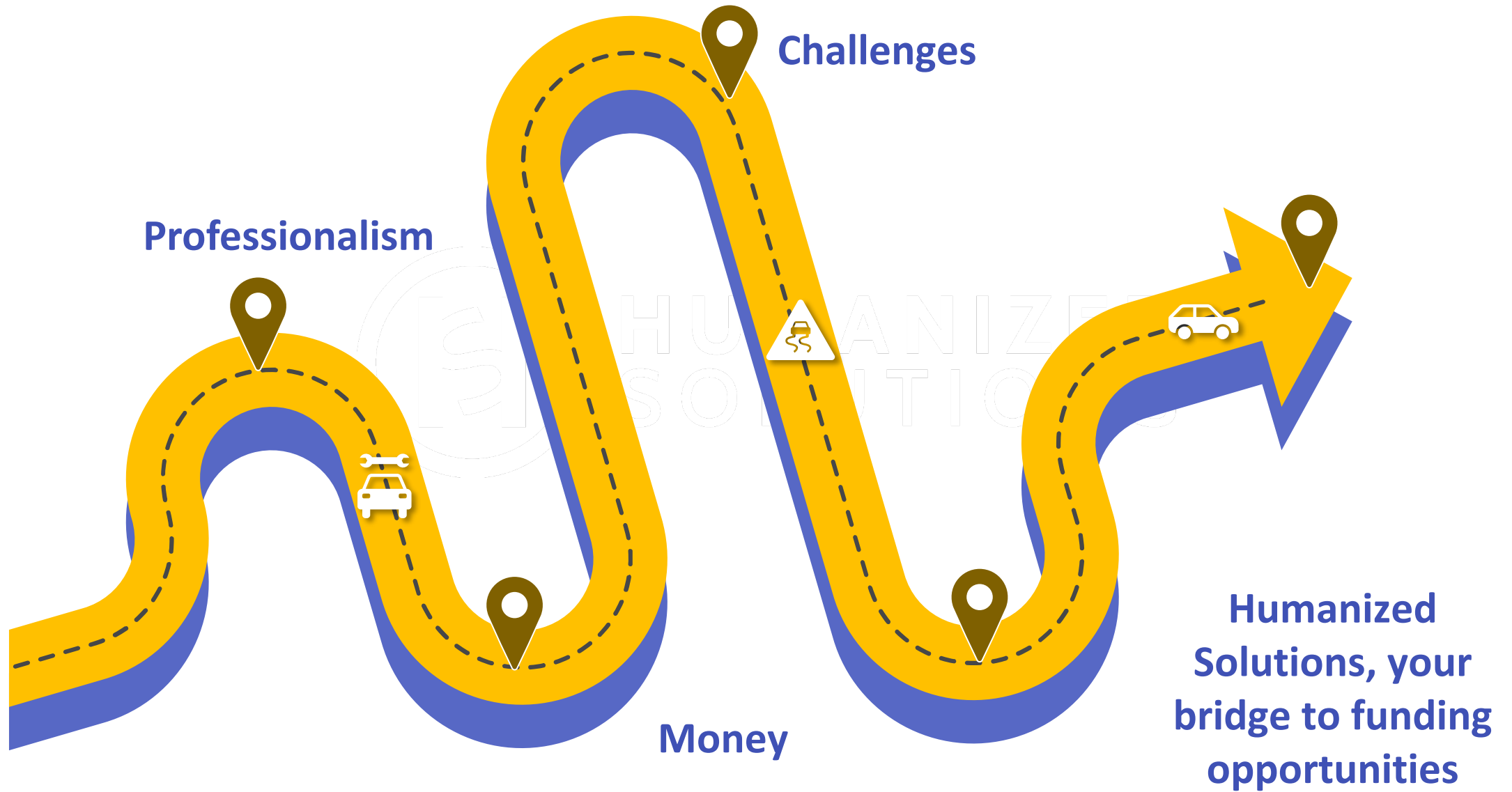
Limited human and technical resources:

Many patient organizations operate with **volunteers** or minimal staff. They lack dedicated grant writers, project managers, or financial officers to handle funding applications and project reporting.

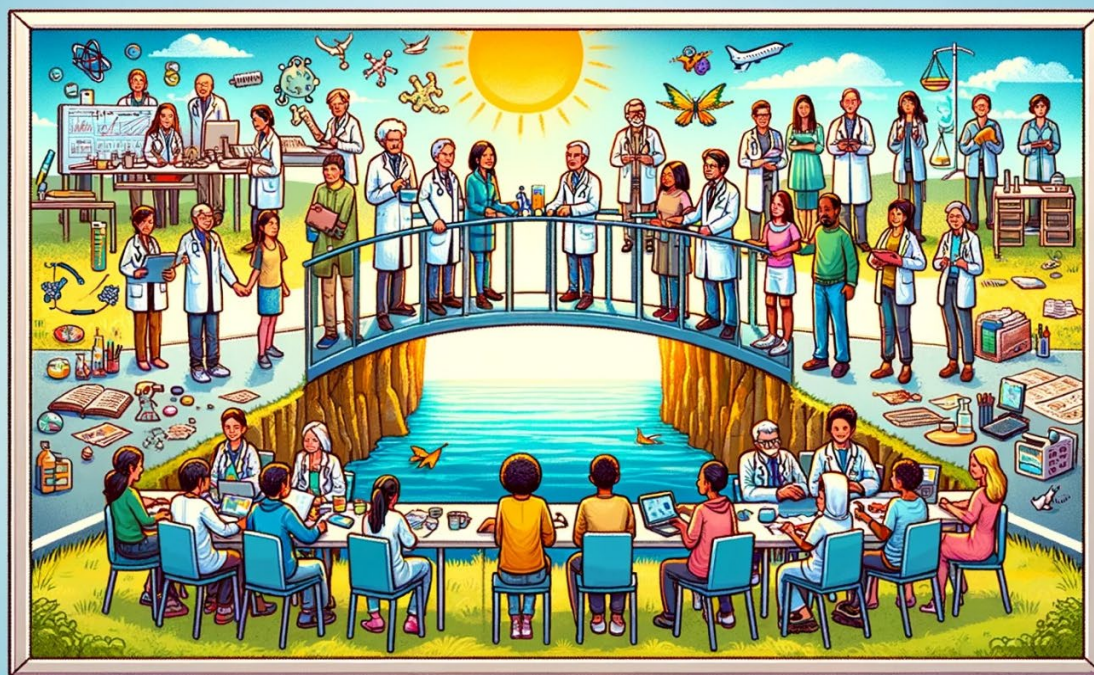
01

02

03



Overcoming challenges together: Humanized Solutions, your bridge to funding opportunities



Humanized as the bridge between associations, researchers, pharma, and funding bodies.

Our mission: We turn your potential into actionable partnerships and successful participation in funding opportunities from the conception of the projects.

How Humanized helps you overcome these challenges

6. We simplify complex funding processes

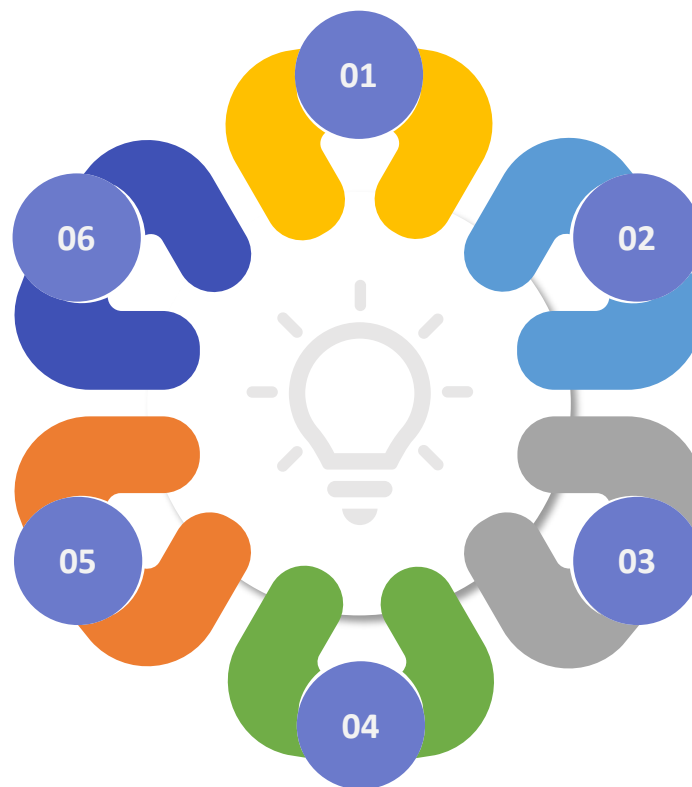
guiding you through every step — from identifying the right calls to participating in strong, competitive proposals. E.g. Easy to understand checklists.

5. We connect you with trusted partners

e.g., researchers, companies, and institutions looking for meaningful collaboration with patient groups.

4. We translate between worlds

bridging the gap between scientific, corporate, and patient perspectives to ensure clear, effective communication.



1. We structure your involvement

ensuring your role in projects is impactful, recognized, and never tokenistic.

2. We provide tools and expertise

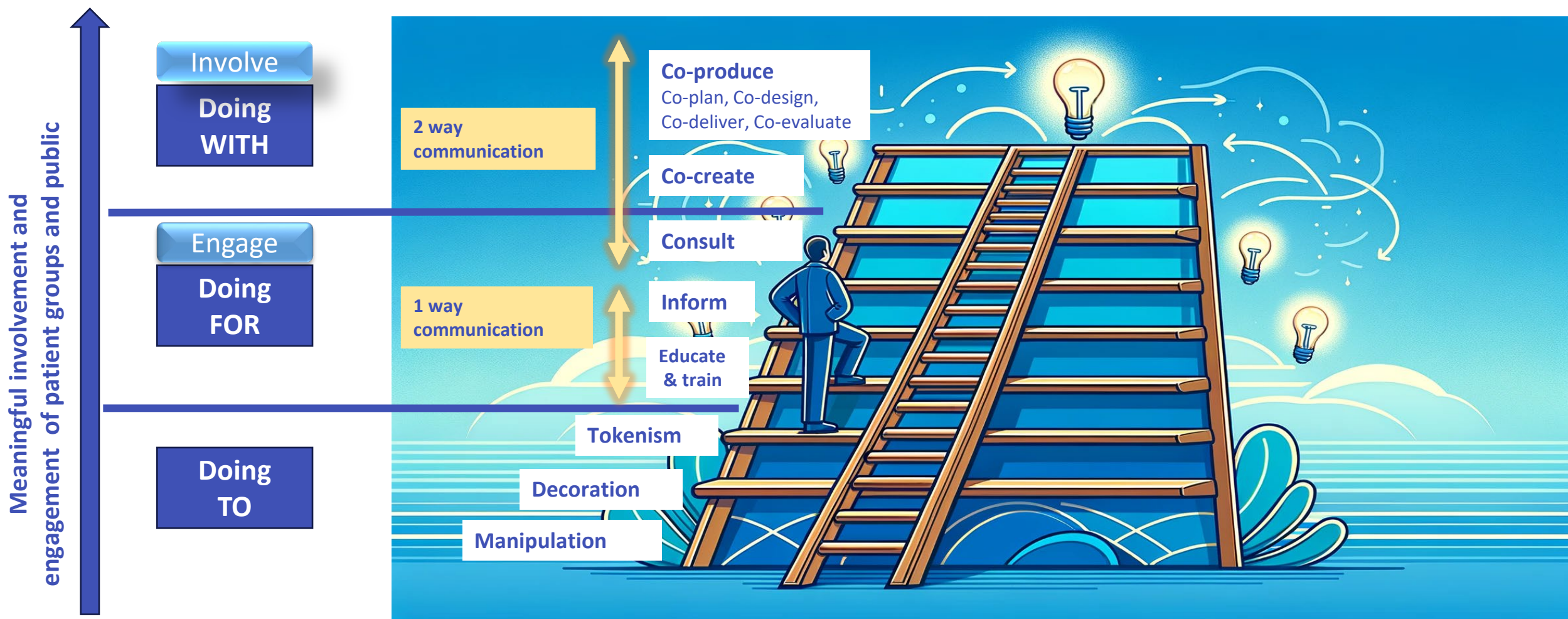
to professionalize your organization, making you a strong candidate for future collaborations and funding.

3. We advocate for your sustainability,

helping you think beyond a single project and build long-term strategies.

At Humanized, we believe that collaboration shouldn't be complicated — and that your passion deserves the right platform to grow.

We ensure robust partnerships that meet specific people's needs and preferences.

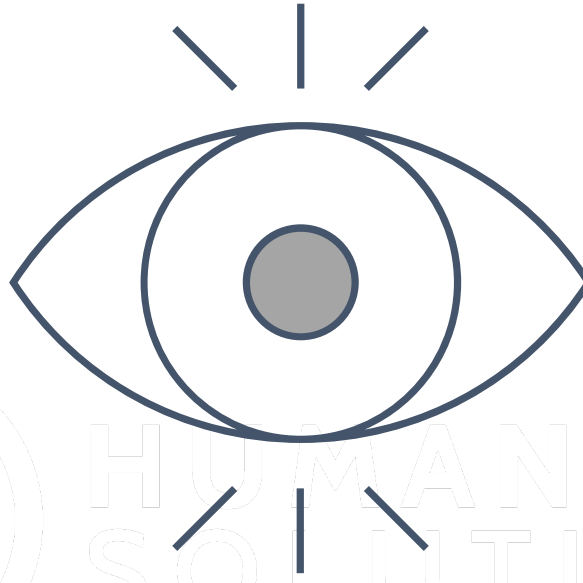




MISSION

Help stakeholders when they work *with* and *for* patients and citizens by actively involving them in every stage of the life cycle of medicines.

We are committed to promoting inclusive, patient-centered research, development, and access to safe and effective medications. Through collaboration and engagement, we strive to enhance the overall well-being and healthcare outcomes of individuals.



VISION

Our vision is a future where patients and citizens have a meaningful voice and are integral partners in shaping the development and use of medicines.

We envision a healthcare system that embraces diversity, values patient perspectives, and ensures equitable access to innovative and reliable treatments. By fostering a culture of collaboration and transparency, we aim to transform the landscape of medicine to better serve the needs of all.



VALUES

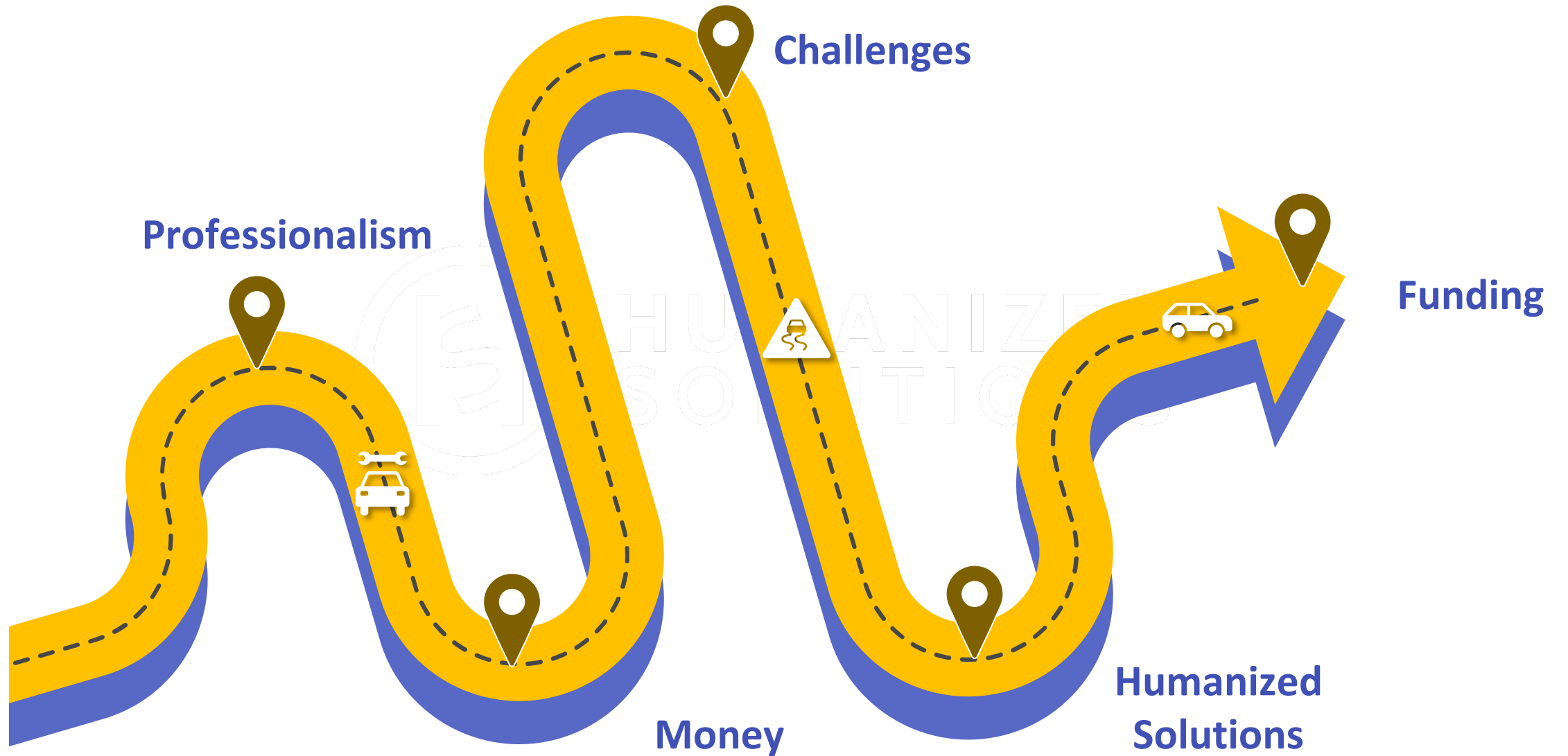
- Patient-Centered Approach
- Inclusivity and Diversity
- Collaboration and Engagement
- Ethical and Transparent Practices
- Advocacy and Empowerment
- Evidence-Based Decision Making

By adhering to these mission, vision, and values, Humanized is dedicated to fostering a patient-centered healthcare system that respects the rights and preferences of individuals, promotes collaboration, and ultimately improves the lives of patients and citizens.

Our mission is closely aligned with 7 several Sustainable Development Goals (SDGs)

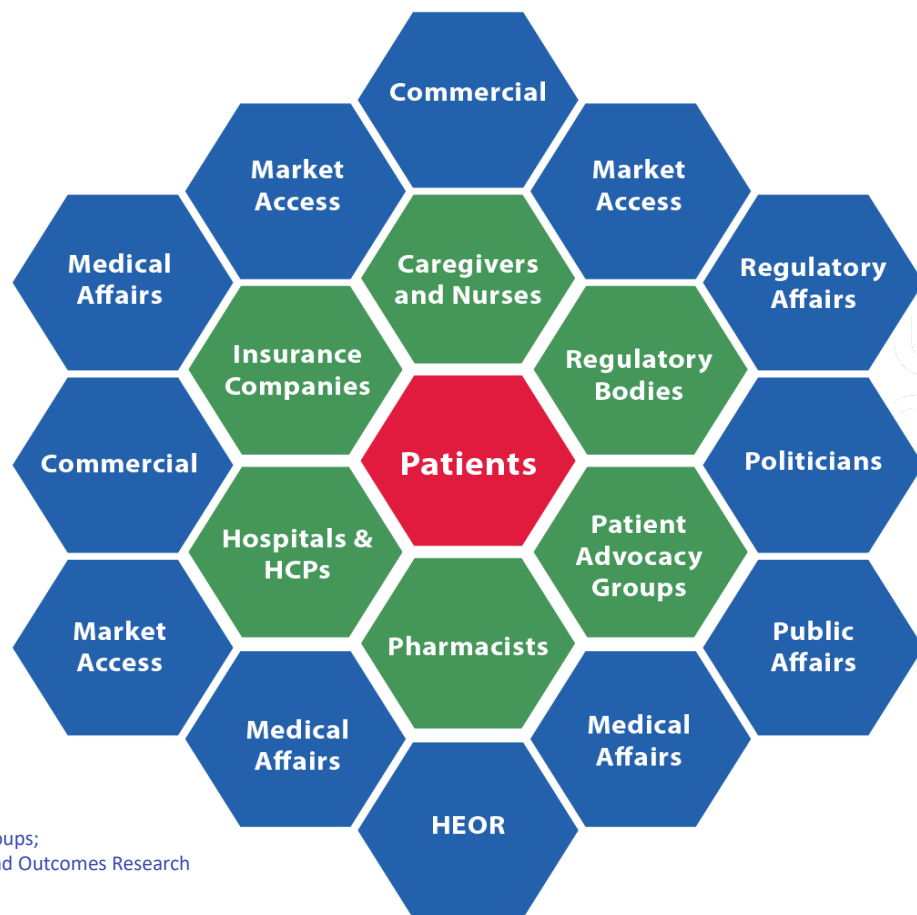


By ensuring that our solutions are inclusive and accessible, we support the ethos of leaving no one behind, which is at the heart of the SDGs. Additionally, by adopting environmentally sustainable practices, we can contribute to climate action and responsible consumption and production.





Patients at the heart of business strategy



PAGs: Patient Advocacy Groups;
HEOR: Health Economics and Outcomes Research

Overview

Patient centricity has become one of the strategic pharma companies' priorities for a decade or so

- To craft business strategy based on the needs and wants of the end customer (patients)
- Make sure patients get best medical outcomes and quality of life, considering their disease and the treatment they have been prescribed

As an ageing population, combined with a lack of money for social care from governments, will mean that the skills to self-manage chronic conditions at home will become essential.

Nowadays, pharmaceutical companies want to express their mission to put patient care first.

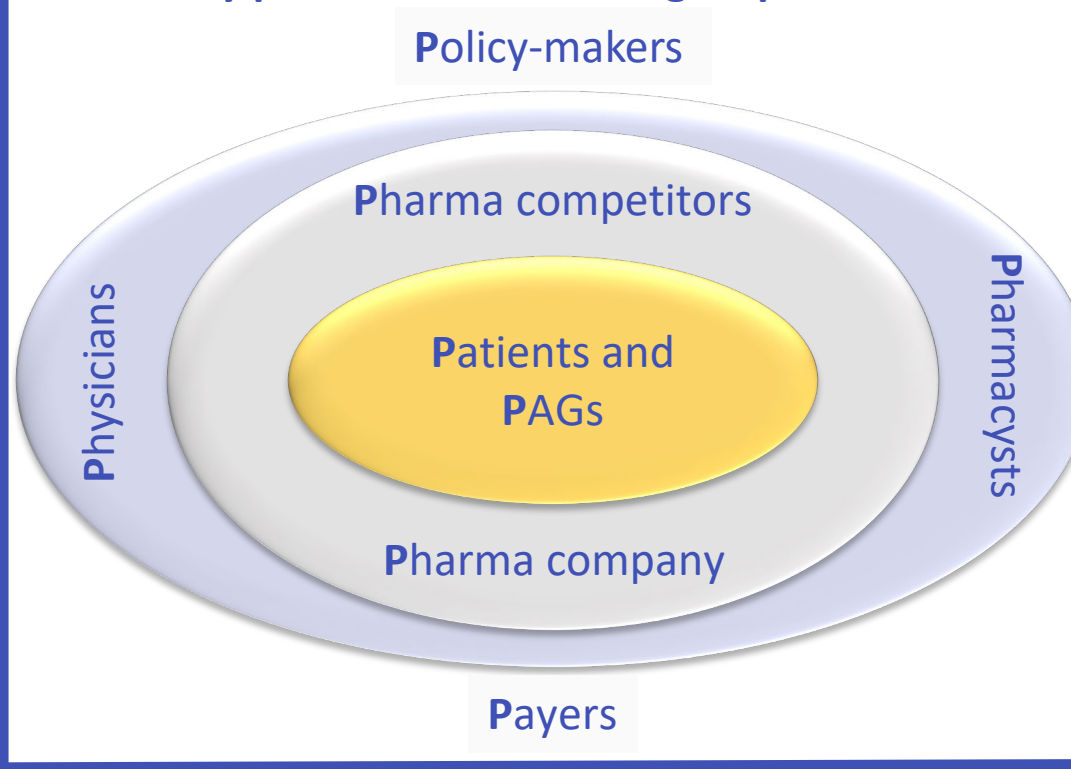
Nowadays, all stakeholders want to speak with the patient: “from buzzword to activation”

Importance of Patients and Patient Advocacy Groups (PAGs) in pharma business model

Patients

- ✓ Patients are becoming more aware and knowledgeable
 - Medical information is easily accessible
- ✓ Their power is increasing with digital technologies
 - More than half of mobile phone users download health apps, and 65% of those users access their health apps daily¹.
 - Likewise in Europe, one in five patients were more likely to go online to investigate their health decisions in 2016 than in 2014².
- ✓ Patients are more demanding:
 - For example, four out of five patients expect to be more active in managing their health than in the past³
 - Want the most effective and best tolerated medicines
 - Easy to use
 - And available at affordable price

Key pharma stakeholder groups: The 7Ps



PAGs

- ✓ More and more influential
 - May be part of the policy maker/payer decision-making processes
- ✓ PAGs can support pharma companies with whom they partner and share common ground
- ✓ On the contrary, they can damage the corporate reputation of companies with which they do not have good relationships and with which they do not share the same strategic vision

The patient voice gained power and has an increasing role on corporate reputation and impacts the products all along their life cycle



"Myth or Fact?" (Quick Quiz)

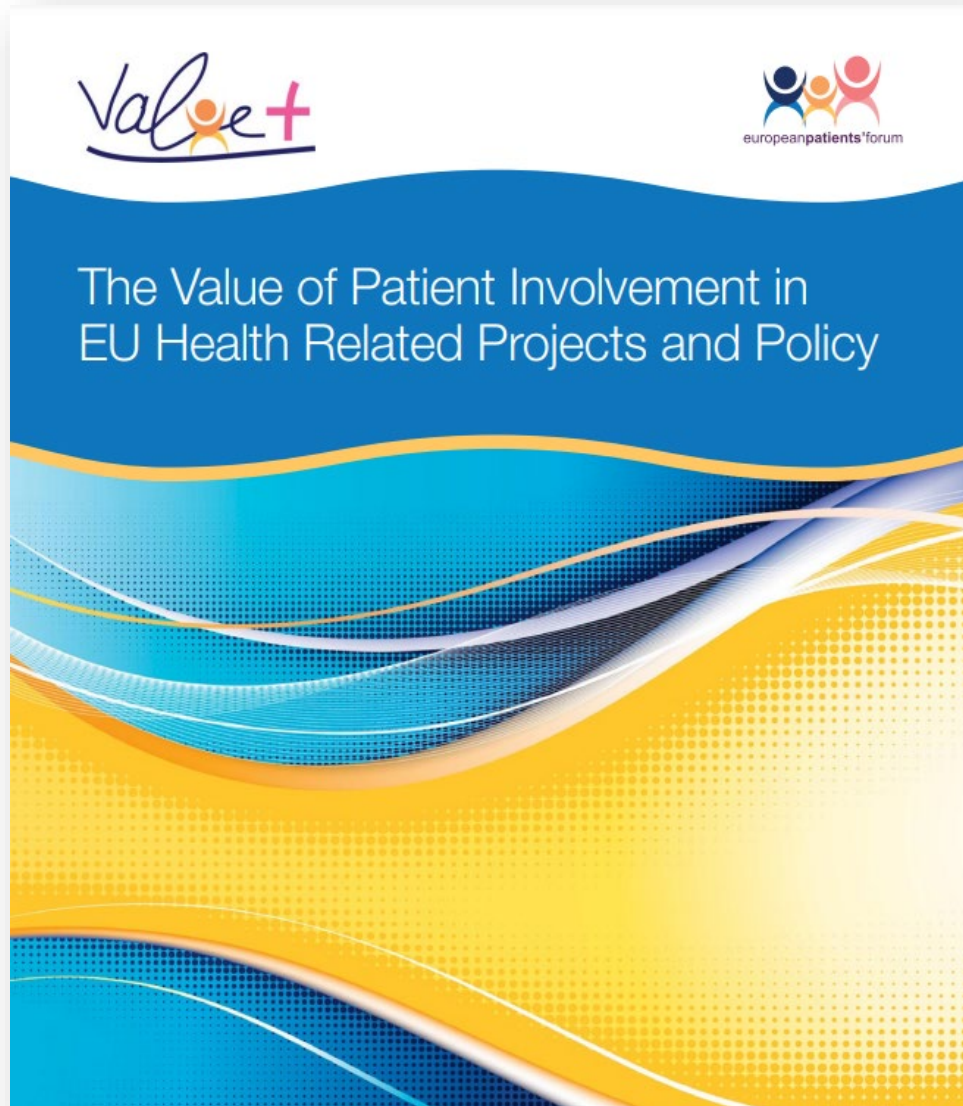
- "You need to be a large organization to apply for EU funding."
- "Patient groups can't be official partners in research projects."
- "All funding applications require co-funding."
- "European projects only fund scientific research."
- "You must already have partners before looking for funding opportunities."
- "Administrative tasks in funded projects are handled by the coordinator, so patient groups don't need to worry about them."
- "Patient associations can't influence policy through funded projects."

Importance of Patient and Public Involvement and Engagement (PPIE): Requirements of Funding and Regulatory Bodies



- **Patient and Public Involvement and Engagement is now a requirement of many funding bodies**, leading to an increased focus on patient involvement in research, drug, medical device and digital initiatives.
- Similarly, **regulatory bodies are recognizing the value of Patient and Public Involvement and Engagement in ensuring the safety and efficacy of healthcare products and services.**
- Incorporating PPIE approach into healthcare initiatives **not only enhances their relevance and effectiveness, but also ensures alignment with the requirements of funding and regulatory bodies.**
- This further emphasizes the importance of listening and integrate the patient and citizen voice in driving people-centric innovation and improving healthcare outcomes.

The Value of Patient Involvement in EU Health Related Projects and Policy by European Patients' Forum (EPF)



Citizens, Equality, Rights and Values programme

This programme aims to protect and promote rights and values as enshrined in the EU Treaties and the Charter of Fundamental Rights in particular by supporting civil society organisations active at local, regional, national and transnational level.



In this short video, representatives of organisations working to protect and promote EU rights and values talk about the CERV programme.

They explain its four main pillars and what the programme is working to achieve.

They also explain how an organisation interested in taking part in the programme can apply for funding.

The CERV programme in a nutshell

The Citizens, Equality, Rights and Values (CERV) programme was launched in 2021 and will run for seven years until 2027. It was created along with the 2021-2027 Justice programme under the Justice, Rights and Values Fund.

The CERV programme seeks to support and develop open, rights-based, democratic, equal and inclusive societies based on the rule of law. That includes a vibrant and empowered civil society, encouraging people's democratic, civic and social participation and cultivating the rich diversity of European society, based on our common values, history and memory.

The CERV programme has four pillars:

1. Equality, Rights and Gender Equality - promoting rights, non-discrimination, equality (including gender equality), and advancing gender and non-discrimination mainstreaming
2. Citizens' engagement and participation - promoting citizens engagement and participation in the democratic life of the Union, exchanges between citizens of different Member States, and raising awareness of the common European history
3. Daphne - fight violence, including gender-based violence and violence against children
4. Union values - protect and promote Union values

Civil society organisations active at local, regional, national and transnational level, as well as other stakeholders, can apply to receive CERV funding for initiatives aimed at citizens' engagement, equality for all and the protection and promotion of rights and EU values.

Access to health and care services for people in vulnerable situations

HORIZON-HLTH-2024-CARE-04-04-two-stage

Topic: Call for proposal

Internal navigation

GENERAL INFORMATION
TOPIC UPDATES
TOPIC DESCRIPTION
DESTINATION
CONDITIONS AND DOCUMENTS
START SUBMISSION
TOPIC Q&AS

General information		
Programme Horizon Europe Framework Programme (HORIZON)		
Call Ensuring access to innovative, sustainable and high-quality health care (Two stage - 2024) (HORIZON-HLTH-2024-CARE-04-two-stage)		
Budget overview		
Type of action HORIZON-RIA HORIZON Research and Innovation Actions	Type of MGA HORIZON Lump Sum Grant [HORIZON-AG-LS]	Closed
Deadline model two-stage	Opening date 30 March 2023	Deadline dates 19 September 2023 17:00:00 Brussels time 11 April 2024 17:00:00 Brussels time

Topic updates

Feb 13, 2024 12:10:30 PM

In order to best ensure equal treatment, successful stage 1 applicants do not receive the evaluation summary reports (ESRs) for their proposals, but this generalised feedback with information and tips for preparing the full proposal.

Information & tips

- The proposals should address all the individual sub-criteria in each appropriate section of the proposal (Excellence, Impact, Implementation). E.g., the state of the art should be clearly referenced, the methodology and - where relevant – the technical robustness of AI should be clearly described, the pathways to the expected outcomes and impacts, the scale and significance of project's contributions to the expected outcomes, and all other aspects need to be addressed.
- Please be reminded, as per the topic text, that proposals are expected to involve the people/groups studied in the design and implementation of the research and innovation activities and where relevant service providers and other stakeholders.
- Multidisciplinary and social sciences and humanities (SSH) aspects should be duly considered and integrated in the methodology.
- If your proposal contains clinical studies, please read carefully the definition and guidance on the template 'Information on clinical studies' published on the call page in the Participant Portal ([Information on clinical studies \(HE\)](#)) and remember to upload the template filled in when submitting your proposal.
- In stage 2 the eligible costs will take the form of a lump sum contribution as defined in the Decision of 7 July 2021 authorising the use of lump sum contributions under the Horizon Europe Programme. To get started, please read [lump sum funding](#) and the [guide Lump sum funding - what do I need to know](#), with details on how to complete the Excel workbook. Recommended: Excel 2013 (Windows) / Excel 2016 (Mac OS) or more recent.

Importance of PPIE: Requirements of Funding and Regulatory Bodies

Horizon Europe

Citizen engagement and the engagement of industry, social partners and civil society actors are critical to reinforce trust in science, and to facilitate and secure the innovation process and its uptake. Check [HERE](#)

European Partnership On Transforming Health And Care Systems (THCS)

(...) implementation of personalised prevention strategies in health and care services, also to make them **person-centred and better adjusted to people's needs** (...). Check [HERE](#)

Innovative health initiative Joint Undertaking (IHI JU)

(...) aims to translate health research and innovation into real benefits **for patients and society**, and ensure that Europe remains at the cutting edge of interdisciplinary, sustainable, patient-centric health research. Check [HERE](#)

Citizens, Equality, Rights And Values (CERV)

(...) promoting **citizens engagement and participation** in the democratic life of the Union, exchanges between citizens of different Member States (...). Check [HERE](#)

Importance of PPIE: Requirements of Funding and Regulatory Bodies

Marie SkłodowskaCurie Actions (MSCA)

(...) building new and sustainable international and inter-sectoral partnerships and networks; better transfer of knowledge between sectors and disciplines (...). Check [HERE](#)

Rising Tide Foundation for Clinical Cancer Research (RTFCCR)

(...) supports truly innovative and unique **patient-centered clinical trials** with the potential to timely impact the lives of cancer patients. Check [HERE](#)

Horizon Europe: Widening participation and strengthening the European Research Area

(...) strengthen their potential for successful participation in transnational research and innovation processes, promote networking and access to excellence. Check [HERE](#)

Erasmus +

(...) strengthens cooperation ties (...) through learning mobility, education exchanges and capacity building, nurturing social resilience, (...) active participation and ensuring regular channels for people-to-people contacts and connectivity worldwide. Check [HERE](#)

Importance of PPIE: Requirements of Funding and Regulatory Bodies

Horizon Europe: Health

(...) including through **patient/citizen engagement, community involvement or other forms of social innovation approaches**, such that research and innovation activities are adjusted to the users' particular expectations, needs, constraints and potential. Check [HERE](#)

Horizon Europe: Culture, Creativity and Inclusive Society

They will aim to expand political participation, social dialogue and social inclusion, **civic engagement** and gender equality. Check [HERE](#)

Horizon Europe: European Innovation Council

(...) promoting the replication of best practices in the innovation field; **enhanced citizens' involvement** in the decision-making process (...). Check [HERE](#)

Horizon Europe: European Innovation Ecosystems


(...) strengths of national, regional and local ecosystems and encouraging the involvement of all actors and territories to reinforce network connectivity for sustainably business growth (...). Check [HERE](#)

Innovative Health Initiative (IHI)

The total budget for Innovative Health Initiative (IHI) for the period 2021-2027 is €2.4 billion.

- €1.2 billion comes from Horizon Europe, the EU's framework programme for research and innovation.
- €1 billion will come from the IHI industry partners
- €200 million will come from other life science industries or associations that decide to contribute to IHI as contributing partners.

From IMI to IHI - We have a new name. Find out why, and what else has changed...
Why we're changing >
X

 innovative health initiative
Apply for funding
Shape our future research
Projects and results
Resources for projects
News & events
About IHI

Home > Projects and results > Health spotlights > Impact on: patients in research

Impact on: patients in research

Patients can and should be much more involved in all aspects of research.




What's the problem?

For many years, patient involvement in research was restricted to participating in clinical studies and trials as research subjects. Today, it is widely recognised that patients can and should be much more involved in all aspects of research, including agenda setting, study design, communication, and ethics. At the same time, many researchers are now well aware that patients bring unique knowledge and skills to projects which can help to improve the quality of research. However, there are still too many projects and initiatives where patients are either not involved at all, or where their involvement comes too late to allow them to really influence the project's direction and outcomes.

What is IMI doing about it?

At IMI, we consider patients equal partners that can and should play an active role in the medicines R&D process. Including patients' perspectives in IMI activities and facilitating patient participation in projects is therefore a top priority for us. As of the end of 2020, 60 % of IMI2 projects involved patient organisations as consortium partners, members of advisory boards, ethics boards or members of stakeholder groups. Through our pool of patient experts and our wider network of contacts, we also involve patients in our wider activities, including as experts for reviewing project proposals and as speakers in our events. In addition, a patient representative is a full member of our scientific committee.

More broadly, IMI projects are developing resources and showcasing best practice when it comes to the question of how and when to best involve patients in research.


Patients involvement
0:00 / 1:00
YouTube

Patient involvement in research: welcome and necessary

Watch



Innovative Health Initiative (IHI)

IHI / IMI is...

...creating a pool of patient experts

Building on the success of the IMI patient pool launched in 2019, IHI has launched a new patient pool which is 120 participants strong. Although patients have been involved in IMI activities since our creation, the pool of patient experts was established to further strengthen the role and voice of patients in IHI and IMI activities at both strategic and operational levels. IHI's patient pool is 70% female, from 25 countries and consists of a combination of patients and caregivers.

...encouraging patient organisations to participate in the development of IMI call topics

Patient organisations with their own research funding programme could become Associated Partners of IMI and contributed to the definition and scope of call topics. Leading patient organisations, trusts and charities like Autism Speaks, Autistica, JDRF, the International Diabetes Federation, Children's Tumor Foundation, Parkinson's UK, TB Alliance, and Obesity Action Coalition were Associated Partners and contributed to IMI projects on various disease areas like diabetes, autism, neurodegenerative diseases and cancer.

...encouraging patient organisations to become project partners

More than 30 patient organisations, including the European Patients' Forum, Alzheimer Europe and Eurordis are full project partners within IMI projects. Their contribution to the consortium includes valuable input on many aspects of the project, by helping define the outcomes that will genuinely benefit patients, determining the appropriate benefit-risk balance in new treatments and providing input into the best ways to involve patients in project governance. Examples of projects that have successful integrated patient organisation partners include [HIPPOCRATES](#).

...promoting patient participation in advisory roles

Within IMI, a patient representative sat as a full member on the IMI Scientific Committee, and IMI/IHI advise that patients are invited to sit on advisory and ethics advisory boards to give their unique perspectives and have impact on medical research.

...promoting patient engagement in medical research

For meaningful patient involvement in research, it helps if patients understand the medicines development process and the jargon associated with it. IMI's [EUPATI](#) and [EFOEUPATI](#) projects created a wealth of educational

Innovative Health Initiative (IHI)

...promoting patient education

For meaningful patient involvement in research, it helps if patients understand the medicines development process and the jargon associated with it.

IMI's [EUPATI](#) and [EFOEUPATI](#) projects created a wealth of educational resources designed specifically for patients who want to get involved in research. The course has trained over 200 patient experts and more than 4 million people have accessed the multi-lingual toolbox. The projects' legacy lives on through the [EUPATI Foundation](#).

...sharing best practice on patient involvement in research projects

Many IMI projects have involved patients in their activities in diverse ways, and have shared their experiences and lessons learnt with the wider scientific and patient communities. For example, [U-BIOPRED](#) produced '[A short guide to successful patient involvement in EU-funded research](#)'. [APPROACH](#) published an article in Research Involvement and Engagement on '[Making the patient voice heard in a research consortium: experiences from an EU project \(IMI APPROACH\)](#)'. [EPAD](#) published an article in the same journal on '[Involving research participants in a pan-European research initiative: the EPAD participant panel experience](#)'.

Humanized Solutions: Support EU and National Funding Initiatives

- Humanized Solutions engages in European and national funding initiatives
- Taking on roles such as Work Package (WP) leaders or leading tasks within WPs, subcontractors, advisors or expert evaluators
- Currently, assessing opportunities to become coordinators
- Contributing our expertise to drive innovation and success in funding initiatives
- We secure that Patient Groups are involved since the conception of the projects



Humanized Solutions: Support European and National Funding Initiatives across several countries

Horizon Europe

Pillar I EXCELLENT SCIENCE

- European Research Council
- Marie Skłodowska-Curie

Pillar II GLOBAL CHALLENGES & EUROPEAN INDUSTRIAL COMPETITIVENESS

- Health
- Culture, Creativity & Inclusive Society
- Digital, Industry and Space

Pillar III INNOVATIVE EUROPE

- European Innovation Council
- European Innovation Ecosystems

WIDENING PARTICIPATION AND STRENGTHENING THE EUROPEAN RESEARCH AREA

- Widening participation & spreading excellence
 - European Cooperation in Science and Technology (COST)
- Reforming & Enhancing the European R&I system

European Partnerships

Cluster I Health:

- Innovative Health Initiative Joint Undertaking (IHI JU)
- Transforming Health and Care Systems (THCS)
- ERA for Health Research
- European Joint Programme on Rare Diseases (EJP RD)/European Rare Disease Research Alliance (ERDERA)
- One Health/AMR Antimicrobial Resistance (AMR)
- European Partnership for Personalised Medicine (EP PerMed)
- Global Health (EDCTP 3)
- European Partnership for the Assessment of Risk from Chemicals (PARC)
- **Brain Health (2025)**
- Pandemic Preparedness

Cross-pillars:

- EIT Health (Pillar III & Cluster health)

Pillar III:

- Eurostars- European Partnership on Innovative SMEs

Cancer
mission

Additional Funding Programmes of European Commission

- Erasmus +
- EU4Health
- Citizens, Equality, Rights and Values (CERV)
- Creative Europe
- The Digital Europe Programme (DIGITAL)
- European Regional Development Fund (ERDF)
 - INTERREG

Additional European and National Funding Programmes

- EUREKA
- "la Caixa" Foundation
- NOVA.ID.FCT
- TRANSCAN
- CanSERV
- Share4Rare
- Portugal 2023
- Other related national initiatives across several countries

Collaboration over competition: In Rare Diseases, creativity and collaboration are survival tools

1. The nature of Rare Diseases:

Scarcity demands unity

2. Cross-Disease collaboration

models e.g. EURORDIS, ERNs, Global Genes – Rare Portal

3. Shared challenges = Shared

solutions e.g. Solutions developed for one disease

– awareness campaigns, patient registries, digital health tools - can often be adapted across conditions. Collaboration allows for resource efficiency and faster innovation).



4. The Power of consortia in funding

e.g. European funding (e.g., Horizon Europe) rewards collaboration.

5. Creativity as a necessity e.g. joint awareness campaigns, shared platforms for patient data, co-host events etc

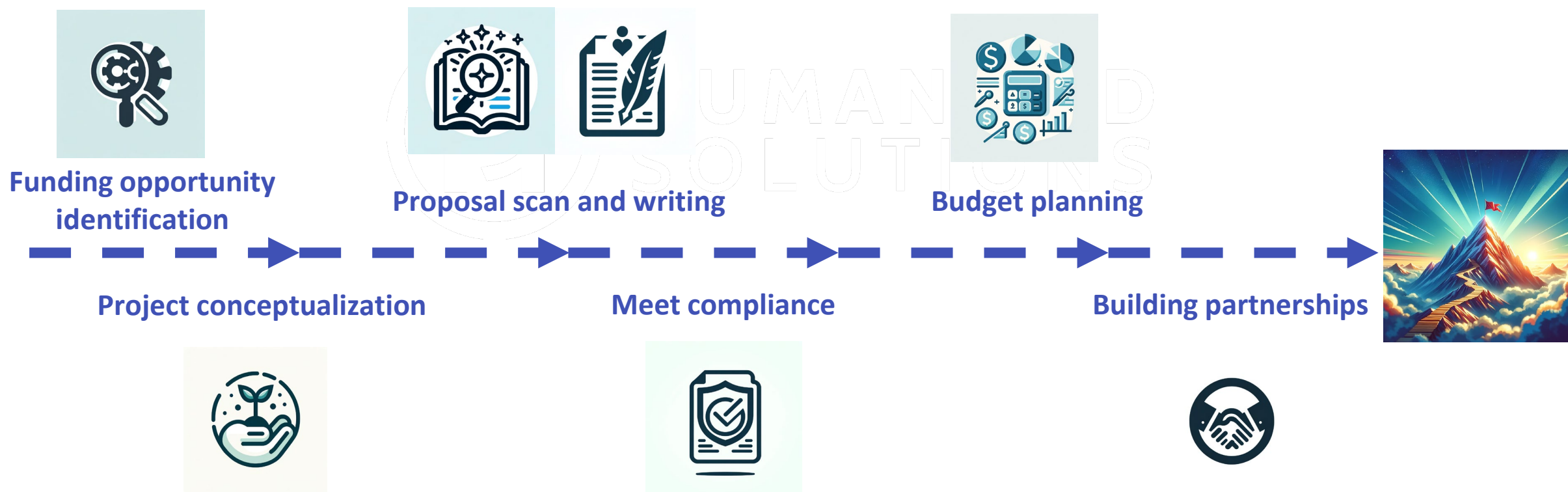
“Necessity is the mother of invention” — in rare diseases, this translates to innovative partnerships.

6. Scientific and industry shifts

e.g. Pharma and biotech are increasingly embracing patient-centered R&D, Collaborative models like Public-Private Partnerships (PPPs) and Open Science

Whether it's joining forces for awareness, research, or advocacy, collaboration turns scarcity into opportunity. Together, we go further—collaboration fuels sustainability.

With our consulting and research services, we ensure that your research and innovation projects are in harmony with patient and public needs and preferences, thus aligning with current requirements of funding bodies



With our consulting and research services, we ensure that your research and innovation projects are in harmony with patient and public needs and preferences, thus with requirements of funding bodies



Project awarded



Build and maintain partnerships

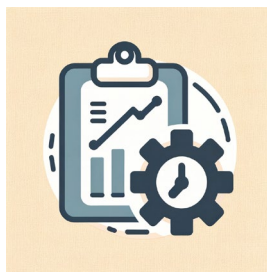


Outreach and communication

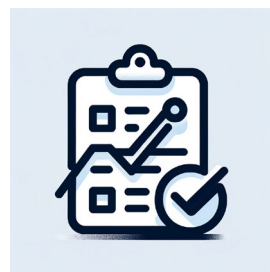


Exploitation and guidance

Project management



Project reporting



Skill enhancement



Performance and impact

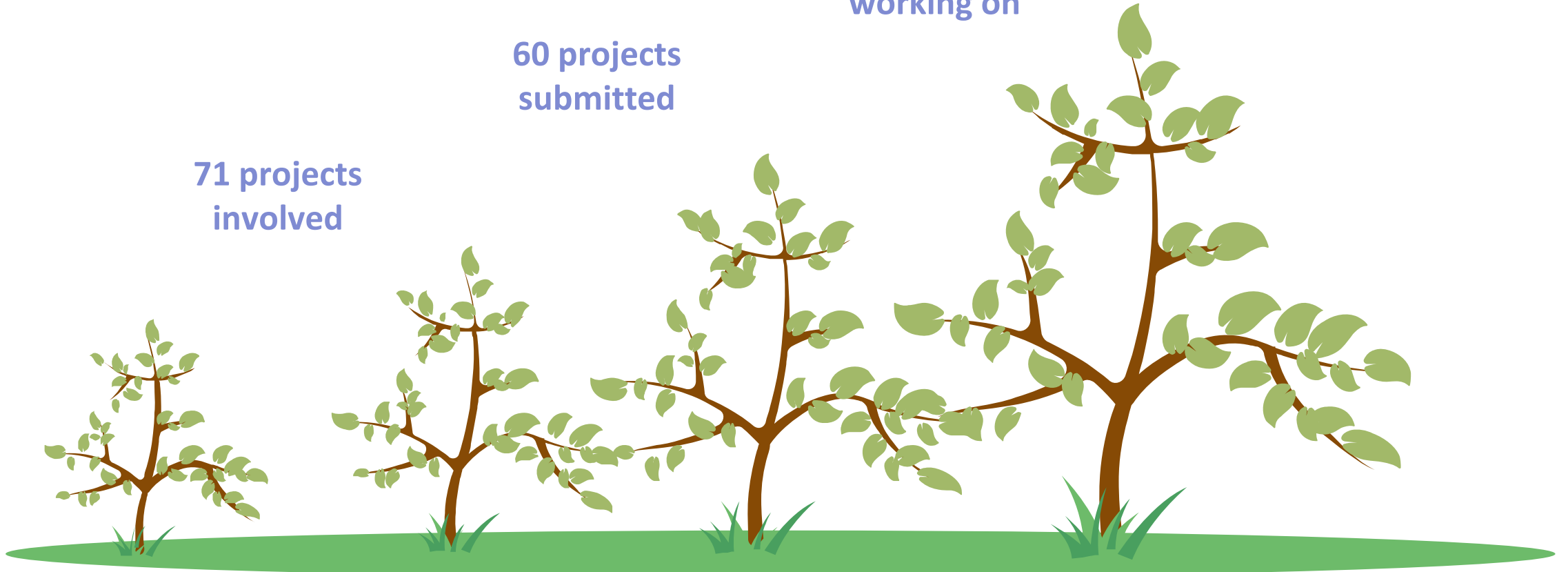


Facts and figures – Numbers from September 2023 to October 2024

71 projects
involved

60 projects
submitted

4 projects
currently
working on



Facts and figures – Programmes involved

Other programmes:
NOVA.ID.FCT (1)
Velux Stiftung (1)
Rising Tide Clinical Cancer Research (1)
AXA (1)

**The Digital
Europe (DIGITAL)**

3

**Citizens, Equality, Rights
and Values (CERV)**

1

Erasmus+

12

Horizon Europe

- Cluster 1: Health (25)
- Cluster 4: Digital, Industry and Space (1)
- European Innovation Council (3)
- Marie Skłodowska-Curie Actions (2)
- European Innovation Ecosystems (1)
- Widening participation and spreading excellence (6)
- ERA4Health (2)
- IHI (3)
- Eurostars (1)

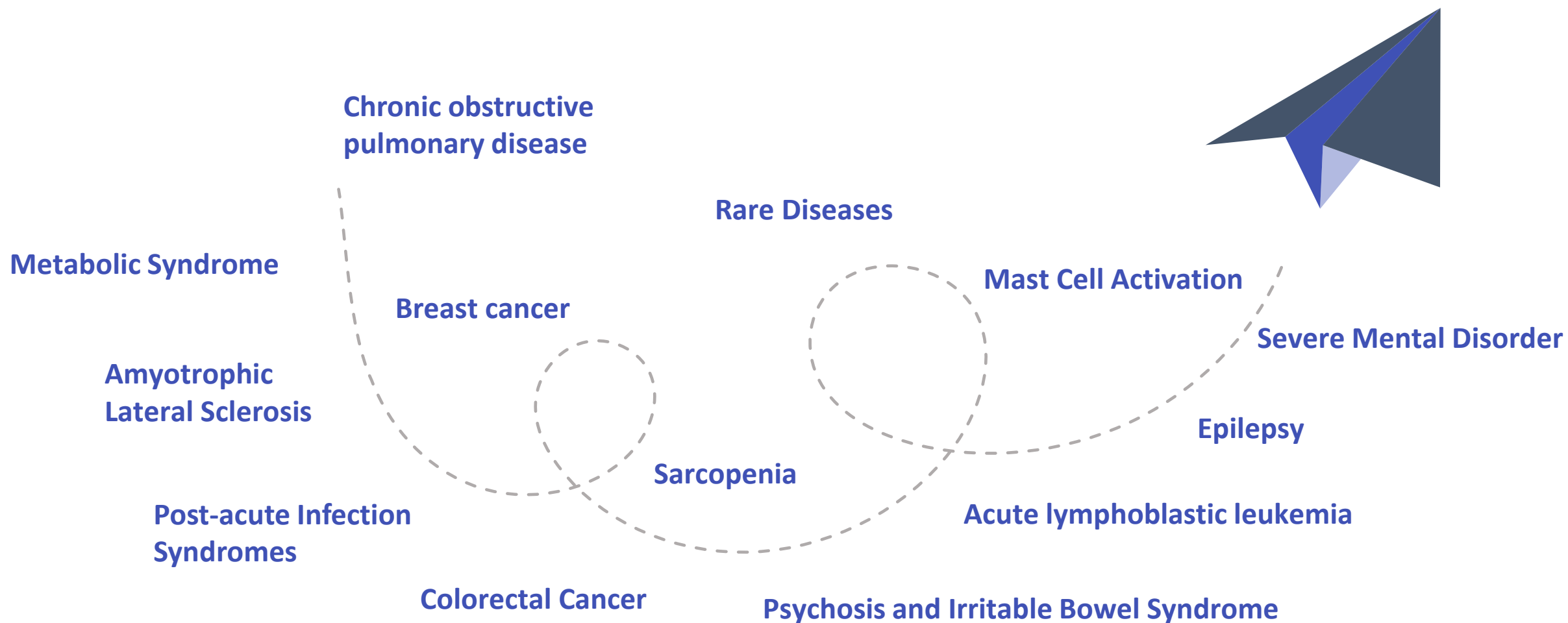
"la Caixa" Foundation

1

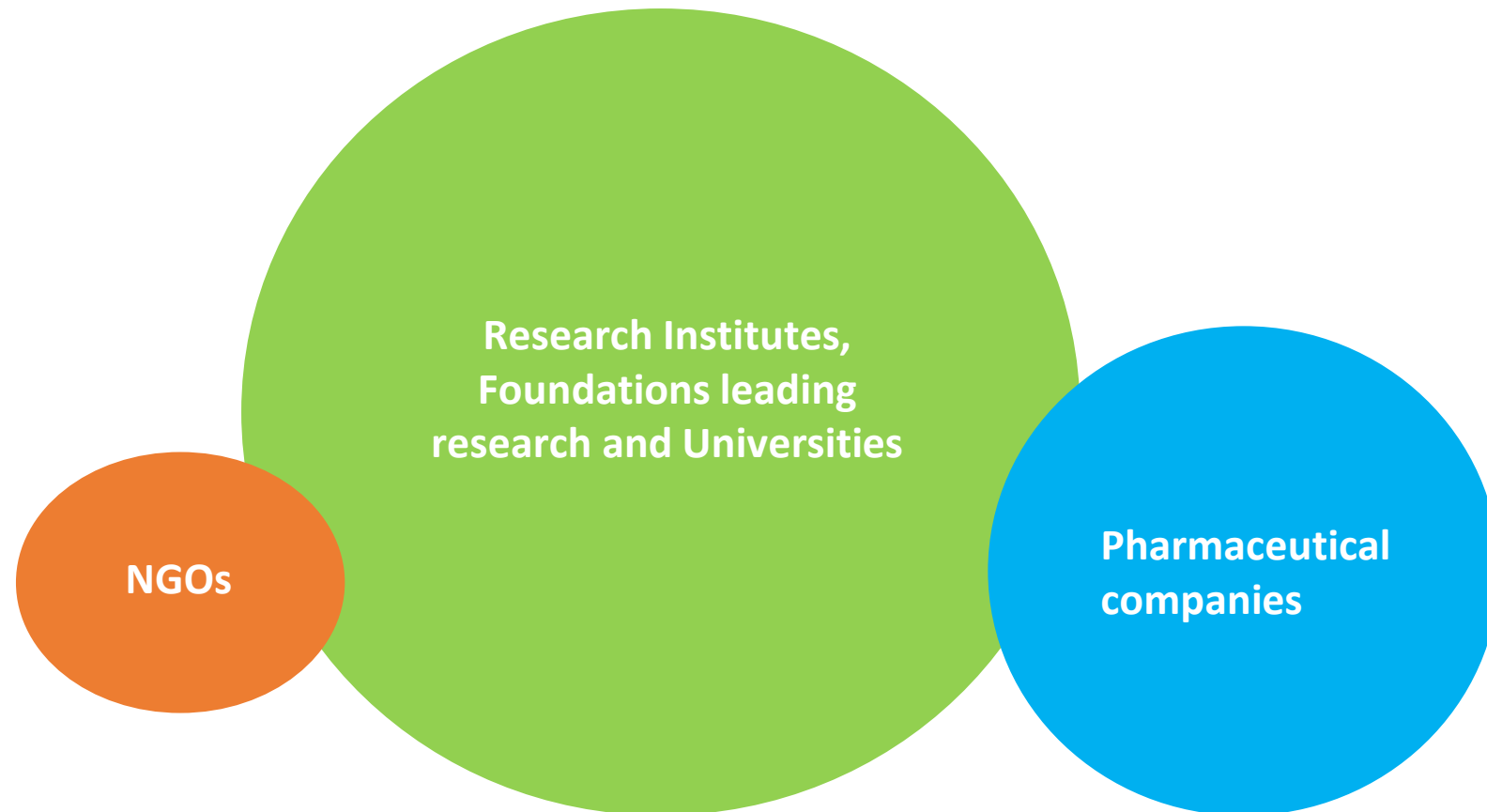
EIT Health

3

Facts and figures – Examples Therapeutic areas



Facts and figures – Main drivers from the projects



Horizon Europe strategic plan 2025-2027



KEY STRATEGIC ORIENTATIONS



Green transition



Digital transition

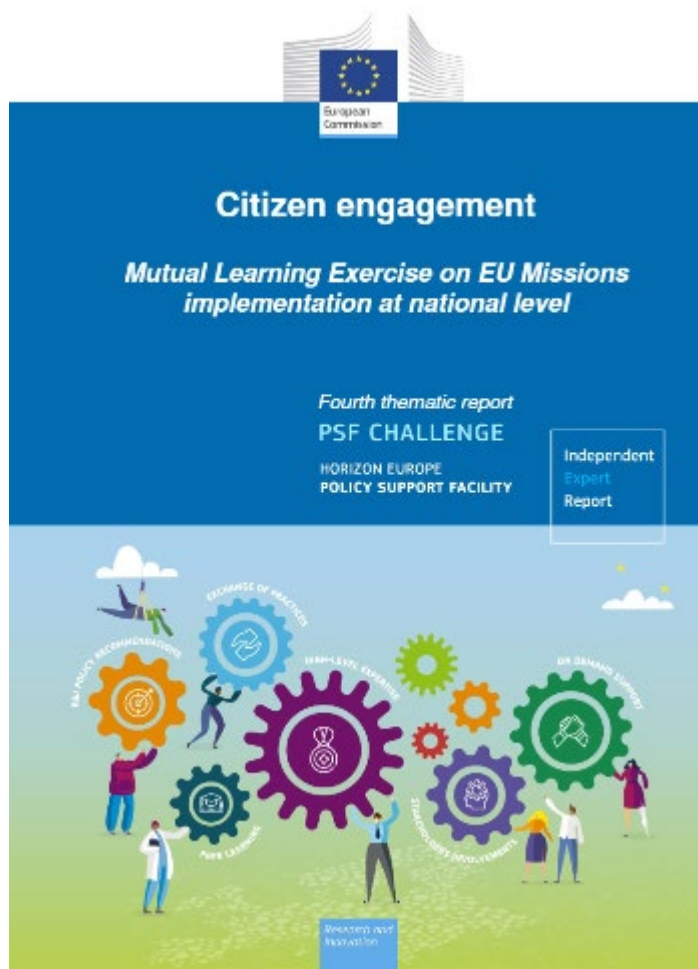

A more resilient,
competitive, inclusive &
democratic Europe

The long-term global challenges faced by the EU require solutions that integrate scientific advances, technological innovation, and social and other forms of innovation. Going beyond the technical paradigm, leveraging social innovation gives rise to solutions that prove more adapted and robust. Moreover, such solutions may result in:

- a greater sense of involvement and greater buy-in by citizens, businesses, social partners and public authorities;
- active, democratic participation in the design of effective and meaningful solutions;
- changes in individual behaviour, work organisation and social practices;

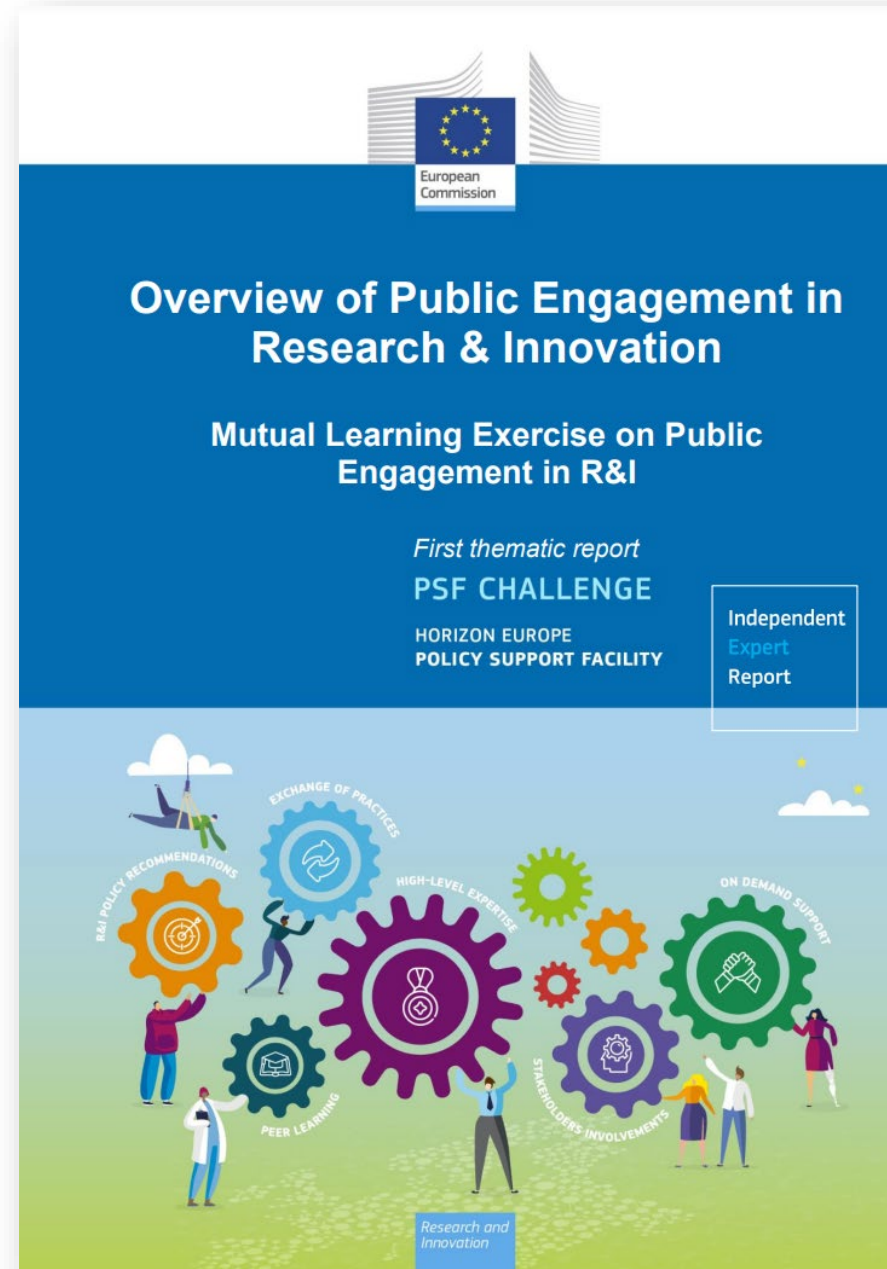
Social innovation is innovation that is social in ends and means. It takes the form of new products, services and business models that simultaneously meet social needs more effectively than alternatives and create new social relationships or collaboration. Social innovation is not only good for society, but also enhances society's capacity to act on common challenges.

Civic engagement on EU Missions implementation at national level



Overview of public engagement in research & innovation

Mutual learning exercise on public engagement: first thematic report



Patient Involvement for Applicants by Patvocates



The contents page features the Rising Tide Foundation and Patvocates logos at the top. The title 'Contents' is centered. The table of contents lists the sections and their corresponding page numbers. At the bottom, the version and date information are provided.

RISING TIDE
Foundation

Patvocates

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Public and Patient Involvement Guidance for Researchers



A short guide to successful patient involvement in EU-funded research Lessons learnt from the U-BIOPRED project by IMI



A short guide to successful patient involvement in EU-funded research

Lessons learnt from the U-BIOPRED project



Short guide on patient partnerships in rare disease research projects





**Our consultancy offers
specialized expertise and
services in facilitating
Patient and Public
Involvement and
Engagement across
diseases and healthcare
sectors.**



Explore our consultancy expertise and services



Explore our consultancy expertise and services



We provide expert training, teaching, coaching, mentoring, and skills development services.

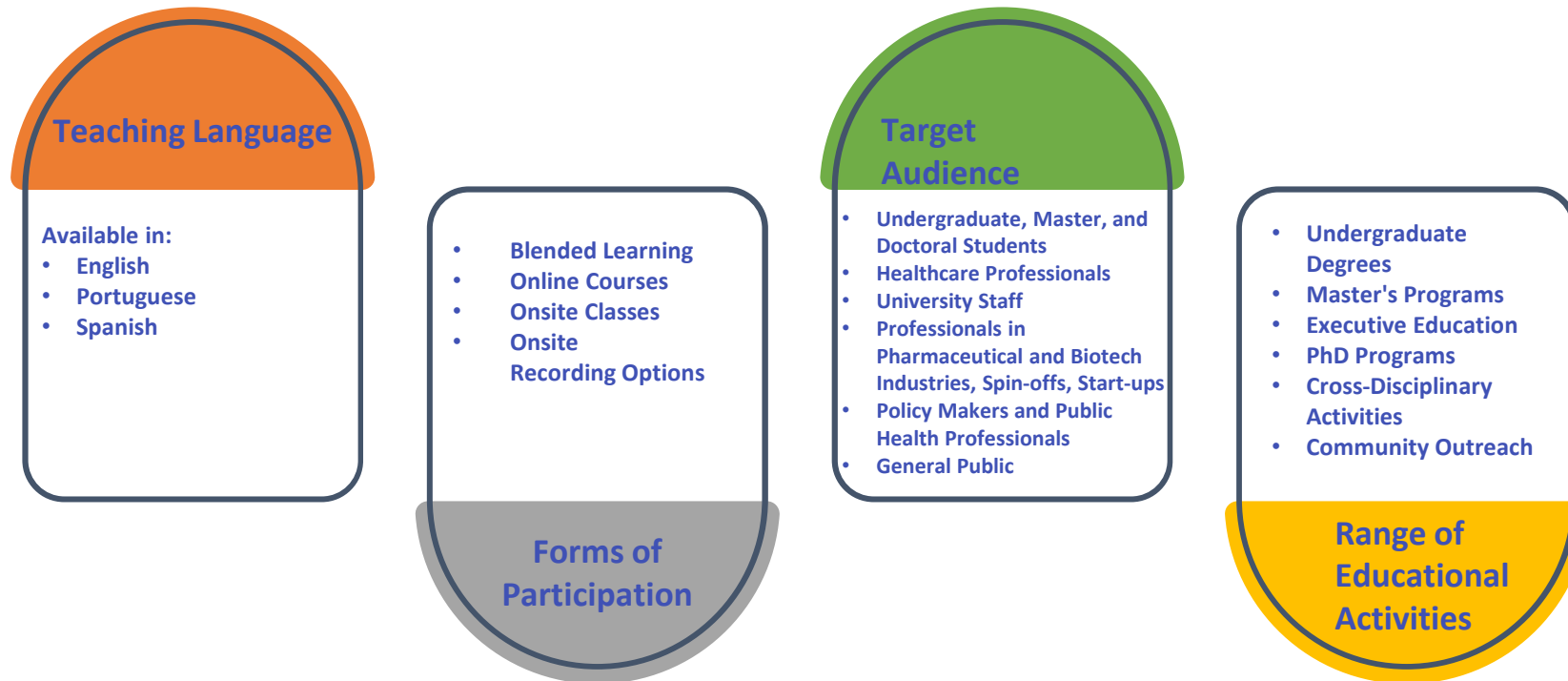


Expert training and development services



- Humanized Solutions provides a range of services to develop skills and knowledge
- We offer expert training in patient-centric healthcare innovations
- Our teaching covers a variety of topics and is tailored to meet individual needs
- Coaching and mentoring are available for individuals or groups
- We focus on developing skills through practical, hands-on experience

Overview



In our training activities, we utilize a project-based learning (PBL) approach to foster practical skills and real-world problem solving. PBL is characterized by its focus on student-centered inquiry and exploration, emphasizing critical thinking, problem-solving, and the integration of various skills across disciplines. Students are encouraged to work collaboratively, think creatively, and apply their knowledge in practical, often interdisciplinary, contexts.

MOOCs (Massive Open Online Courses) & Online Courses: "Learning opportunities in Patient-Centric Healthcare Innovation using digital platforms"

Flexible, expert-led training in patient-centric healthcare, enabling professionals to learn at their own pace, network globally, and stay updated in the field.

Workshops & Trainings offer: "Empowering healthcare through patient-centricity"

Patient-focused healthcare workshops covering digital health to ethics, customizable for any healthcare audience.

Coaching and Mentoring program to elevate Patient and Public Involvement and Engagement (PPIE) in healthcare

Enhances healthcare professionals' skills in patient communication and engagement, through targeted workshops and coaching, aiming to improve outcomes and build trust.

Summer & Winter Schools: "Innovations in Patient-Centric healthcare"

A 2-3 week healthcare program that enhances skills, networking, and learning through PPIE education with cultural insights.

Soft skills development programs when working with patient groups and the general public

Enhances healthcare professionals' soft skills in communication, teamwork, and leadership for improved effectiveness and patient interaction, using workshops and exercises.

Advanced training in patient- centric healthcare innovations

Tailored for evolving patient-centric care and PPIE needs in healthcare, enhancing practical and theoretical understanding.

Other educational opportunities, e.g. speaker

Enhancing healthcare education, providing motivational speaking and facilitation by experts, fostering patient-centered engagement.





Methodology Used by Humanized Solutions

Our scientific methods and techniques

**Community
meetings
and
Focus
Groups**

**Surveys and
questionnaires**

**Patient
Advisory Boards
and similar**

**Storytelling
and narrative
medicine**

**In-depth
interviews and
Photovoice**

**Mixed
methods
research**

**Feedback
mechanisms**

**Co-design
sessions**

**Reflective
journals
or diaries**

**Delphi
process**

Our scientific methods and techniques

**Town Hall
meetings**

**Content
analysis**

**World Café
methodology**

**Community
mapping
and Patient
Journey
Mapping**

**Participatory
design**

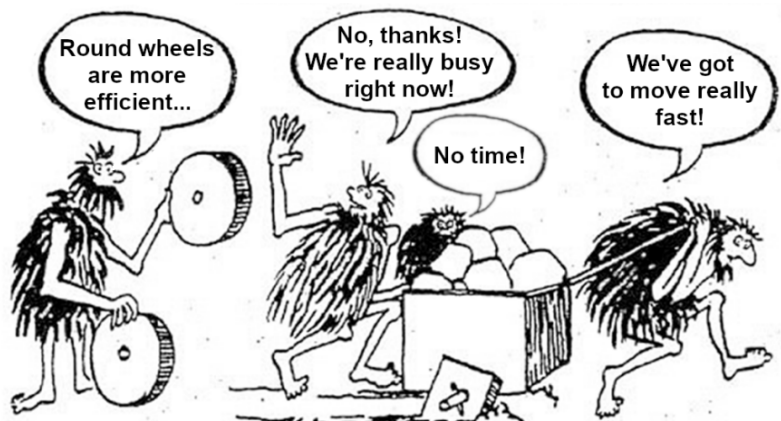
**Stakeholder
workshops
and groups
discussions**

**Consensus
development
conferences**

**Public
consultations**

**Ethnographic
observation**

**Nominal
group
technique**



**At Humanized
we are patient
advocates.
Patients are
waiting, no
time to
reinvent the
wheel.**

Maximizing impact: How our Desk Research methodology fuels our Evidence-Based Approach (EBA) when tailoring services?

Efficiency

Cost-effectiveness

Evidence-based



Avoiding duplication

Comprehensive insight

We start every project with comprehensive desk research to tap into existing knowledge. Our commitment to desk research is central to our evidence-based approach, ensuring each project is innovative, practical, and tailored to specific needs.

Patient engagement planning, conducting, evaluation and monitoring

PARADIGM
Patient Engagement Toolbox

Suggested Working Practices Checklist

COI Guidance tools

EATRIS, EPF, EATG
Patient Engagement Resource Centre

PFMD
Patient Engagement Quality Guidance (PEQG)

Practical Guiding Principles on remuneration

Practical Guiding Principles on Reasonable Agreements
between Patient Advocates and Pharmaceutical Companies

Lay language
summaries (LS)
and in Plain Language
Summaries (PLS)

Envision Pharma
Plain Language Summaries
(PLS) of Publications Toolkit

Clinical Trials Expert Group
Roadmap Initiative to Good Lay
Summary Practice

Patient Engagement
in Clinical Trial
Protocol Design

PFMD
Practical How-to Guides for
Patient Engagement

How-to Guide on
patient engagement in clinical
trial protocol design

TransCelerate BioPharma
Patient Protocol Engagement Toolkit (P-
PET)



We guide you in selecting the tools that best align with your objectives.

Step by Step: How to start engaging with funding and partners

1 Define your mission & focused objectives

Before seeking funding or partners, be clear about:

- Who you are
- What you want to achieve
- Why it matters
- ◆ Focus on specific, actionable goals that align with potential funders' priorities (e.g., research involvement, patient support, awareness campaigns).

2 Map relevant funding opportunities

Research national, European, and private funding programs (e.g., Horizon Europe, EIT Health, foundations).

Subscribe to newsletters, platforms, and alerts:

- EU Funding & Tenders Portal
- Patient advocacy networks (EURORDIS, EPF)

Keep a calendar of upcoming calls.

Step by Step: How to start engaging with funding and partners

3 Identify and connect with potential partners

Look for:

- Identify common goals - Look for organizations with overlapping missions where collaboration creates mutual benefit (e.g., awareness, research involvement, policy influence).
- Researchers in your disease area
- Pharmaceutical companies with related interests (ensure transparency e.g. code of conduct like the EPFIA or national ethical guidelines, define clear boundaries to maintain independence, negotiate fair value to ensure compensation for your time, data or involvement, focus on mutual goals, use written agreements, avoid exclusivity, engage patient meaningfully using EUPATI or PARADIGM frameworks to guide collaboration)
- Other existing patient organizations for joint initiatives

Share best practices & resources: Pool knowledge, tools, and networks

Use platforms like:

- LinkedIn
- ResearchGate
- EU consortia networks
- Events & conferences

◆ Tip: Don't wait for invitations—proactively reach out expressing your interest to collaborate.

Step by Step: How to start engaging with funding and partners

4 Build your professional profile

Prepare a Partner Presentation Pack:

- Short description of your association
- Your strengths (community reach, patient insights, advocacy experience)
- Past collaborations or success stories

Show that you're organized, reliable, and ready to contribute.

5 Learn the basics of funding applications

Understand typical requirements:

- Work Packages (WPs)
- Impact sections
- Budgeting
- Patient Involvement frameworks

Use free training resources (EUPATI, EURORDIS Open Academy, NonprofitReady).

Sign up for Info days

Secure your PIC or OID number

Step by Step: How to start engaging with funding and partners

6 Leverage existing tools & agreements

Use templates for:

- Memorandums of Understanding (MoUs) to formalize partnerships (clarify roles, expectations & shared outcomes)
- Patient engagement agreements

Refer to frameworks like PARADIGM Toolbox or PFMD for best practices.

7 Join a consortium or start small

Look for consortia already forming for calls of interest.

If you're leading, start with smaller grants or local funding to build experience before jumping into large EU projects

Step by Step: How to start engaging with funding and partners

8 Plan for sustainability

Funders want to see how your project will live beyond the funding period.

Include sustainability strategies:

- Future partnerships
- Ongoing community engagement
- Potential for scaling

9 Monitor, evaluate, and showcase your impact

Set simple KPIs (Key Performance Indicators).

After any funded project, document outcomes.

Use success stories to strengthen future applications and attract more partners.

Step by Step: How to start engaging with funding and partners

10 Get support

Work with facilitators like Humanized to:

- Find the right partners
- Navigate funding calls
- Ensure your involvement is impactful and recognized



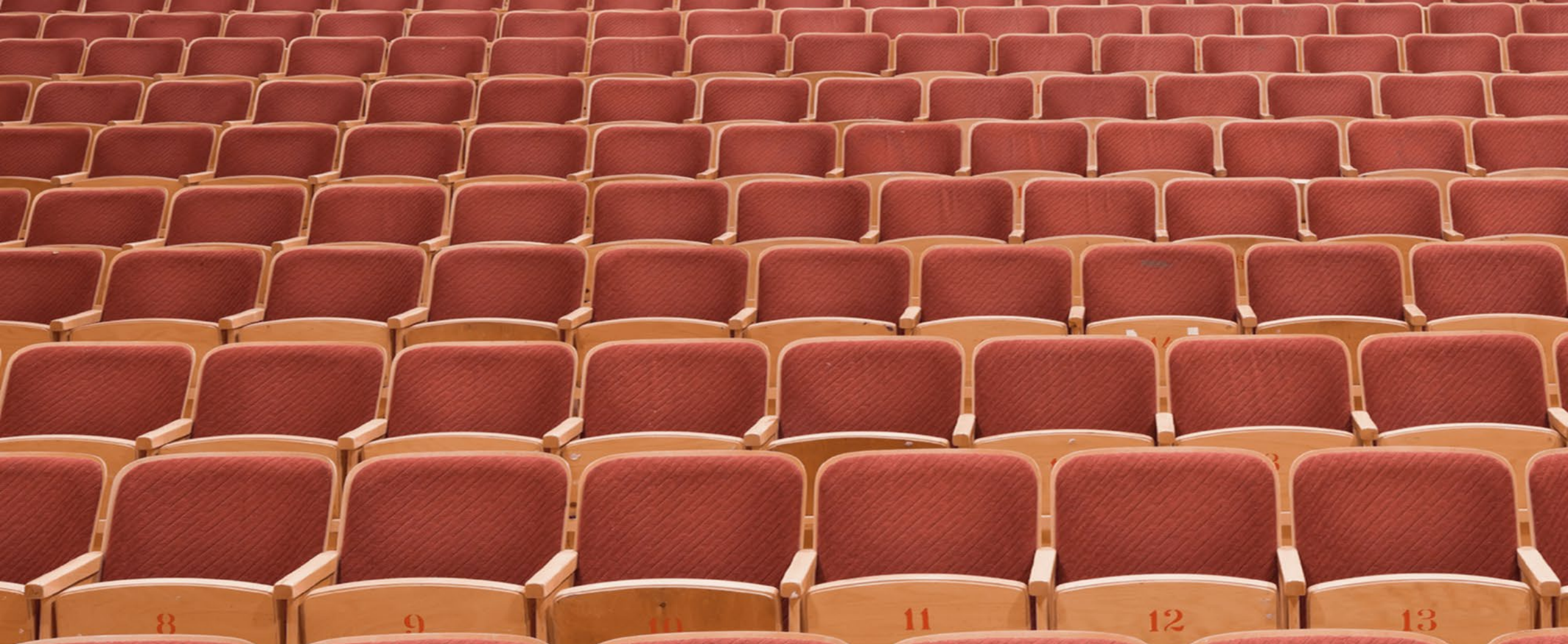
Key takeaway:

Engaging with funding and partners is not just about applying—it's about building relationships, showing value, and being prepared. Start small, stay focused, and grow your network step by step.

**Wishes at
Humanized**







"Nothing About Us, Without Us!"



Vanessa



Alba



José

All team

Medical writers
Graphic designers
Human design facilitator
Project managers
Copywriter & SEO content writer and
storyteller



What we offer:

- **Free, tailored guidance** to help rare disease organizations access funding opportunities and develop strategic partnerships.
- Support in navigating EU and national funding calls, building strong consortia, and preparing professional applications.
- Advice on sustainable growth, collaboration best practices, and effective engagement with industry, researchers, and policymakers.



How It Works:

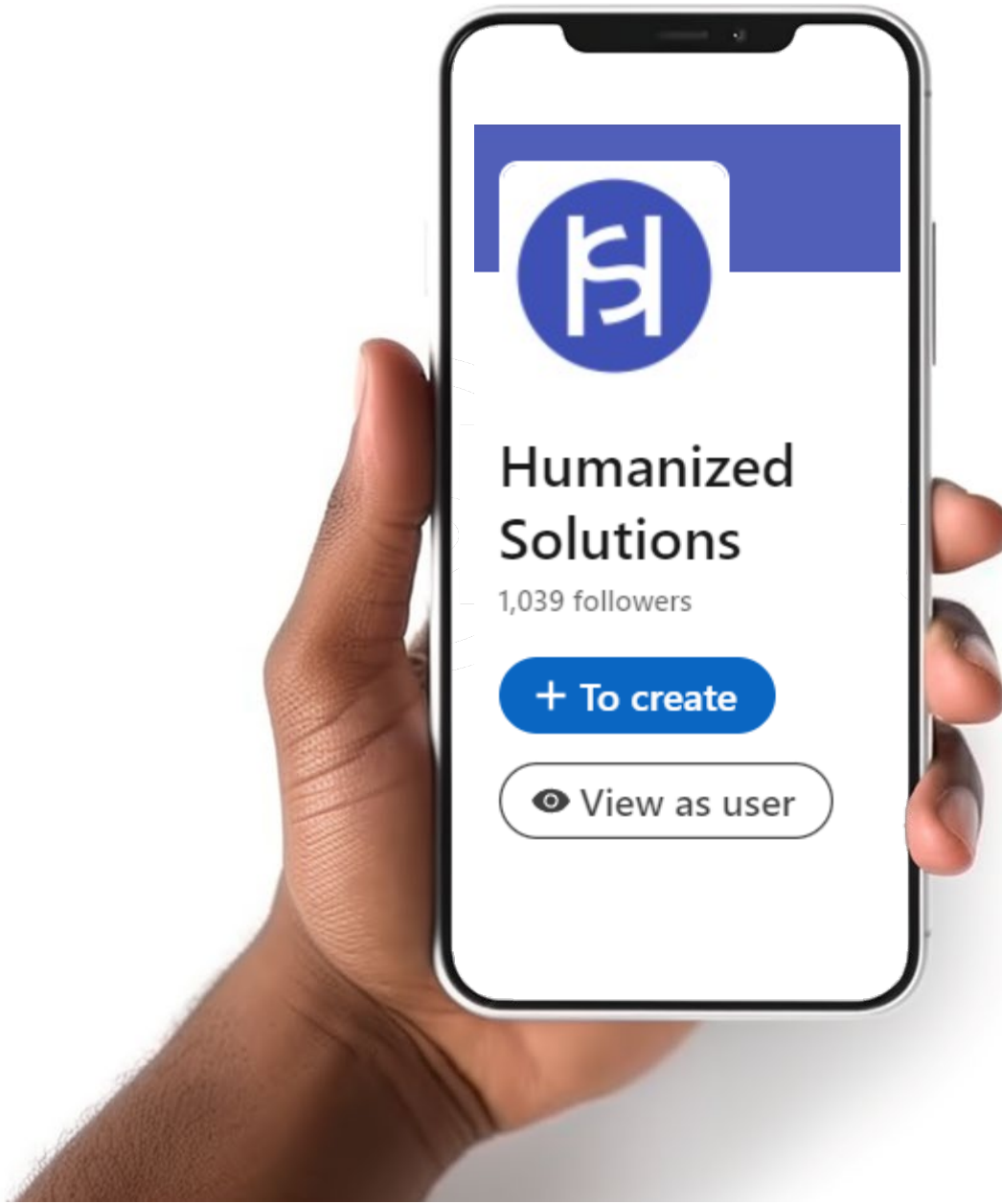
- Each selected organization will receive up to 6 hours of dedicated pro bono consulting over a period of 2 months.
- Sessions are flexible and delivered online (via Zoom/Teams), scheduled based on your availability.
- Support can include:
 - Identifying suitable funding opportunities
 - Reviewing or co-developing parts of a funding application
 - Guidance on partnership building and consortium strategies
 - Providing templates (MoUs, partnership agreements, etc.)
 - Answering specific questions about project management, sustainability, or professionalization



Let's
Talk

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