

Stride velocity 95th centile (SV95C): From EMA qualification in Duchenne to the application in 26 other conditions

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**Muscular
Dystrophy UK**
Fighting muscle wasting conditions
**MDUK Oxford
Neuromuscular Centre**



Disclosure

In the context of digital technology, I have given consultancy to Dyne, Aparito, Sanofi, Wave, Roche and Sysnav

Background

Clinical Gold Standard → New Biomarker Qualification

Major challenges of current state (1)

Patients with rare disease may travel a lot to access the research center

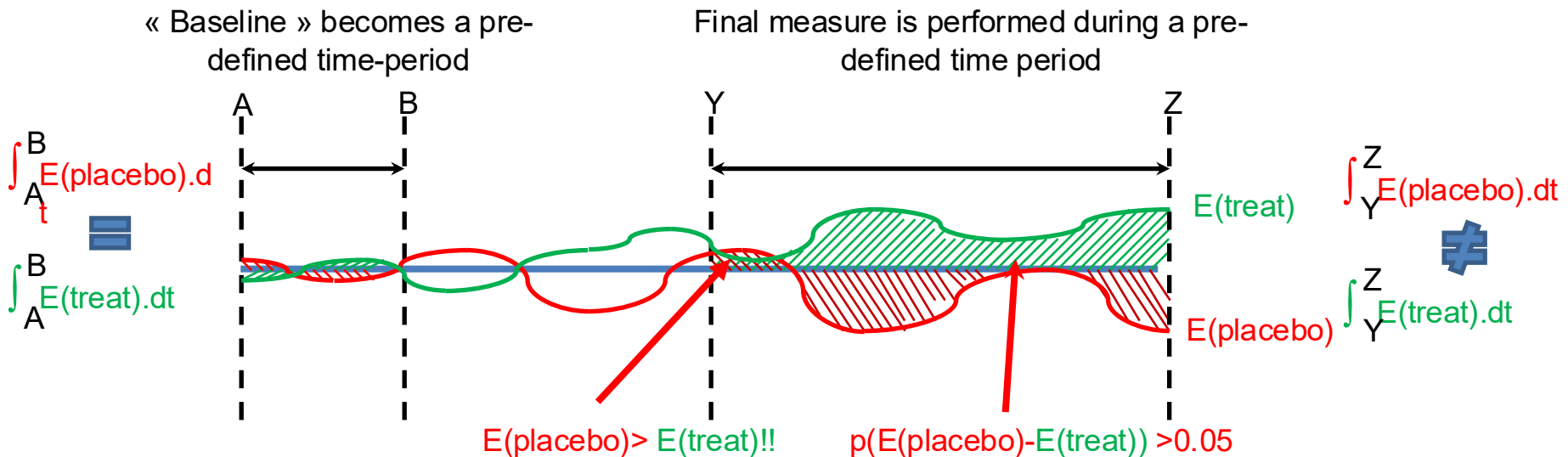


Background

Clinical Gold Standard → New Biomarker Qualification

Major challenges of current state (2)

All measures performed in the hospital, it remains a single point assessment, and highly dependant on patient's form and motivation



Background

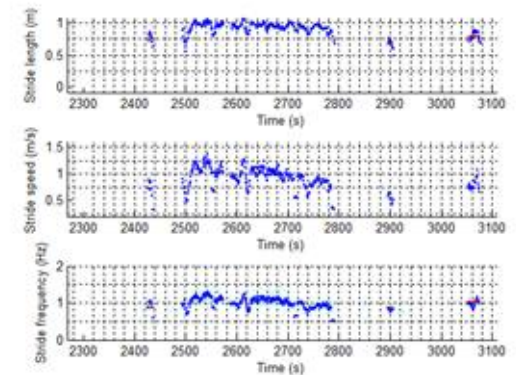
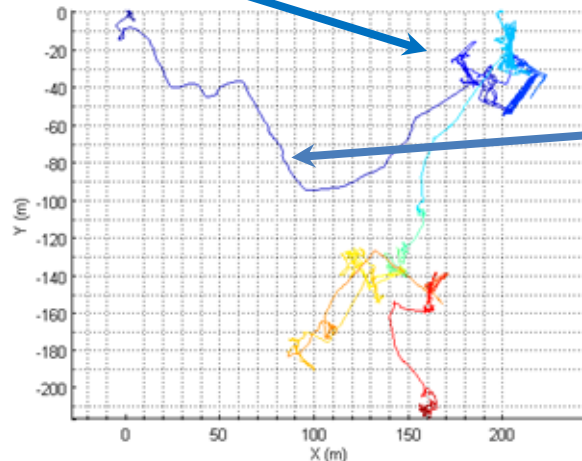
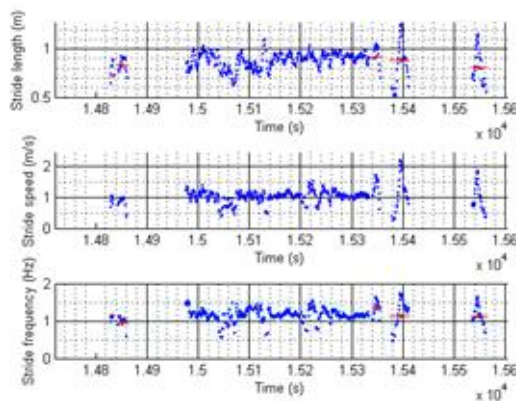
Clinical Gold Standard → New Biomarker Qualification

Major challenges of current state (3)

Short duration tests are deeply influenced by patients reflexes, longer tests by motivation

Patient performs the 6MWT...

... then flies away after





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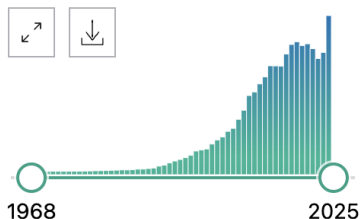
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132,063 results

RESULTS BY YEAR



TransCatheter aortic percutaneous coronary replacement and cor valve stenosis and c international, multic controlled trial.

Kedhi E, Hermanides RS, Amat-Santos IJ, Andreas

1

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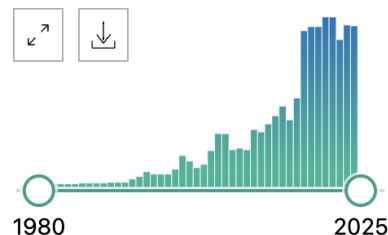
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2,335 results

RESULTS BY YEAR



Patient Preferences in Cochle

Freeman MH, Patro A, Lindquist NR, Moberly AC, Haynes DS, Bennett MI
Otol Neurotol. 2025 Jan 1;46(1):54-
PMID: 39627903

INTERVENTIONS: Survey administer
Sources of information regarding CI
deciding on a manufacturer, and ma

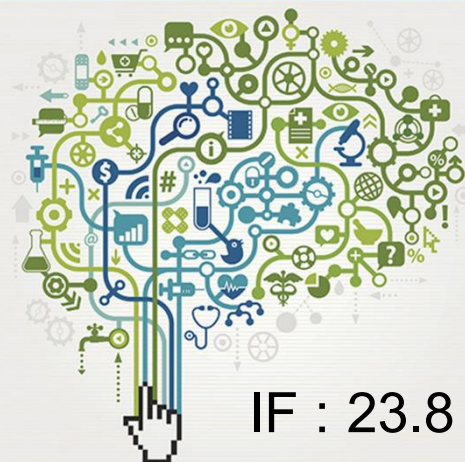
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Volume 4 | Issue 11 | November 2022



IF : 23.8

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IF : 15.35

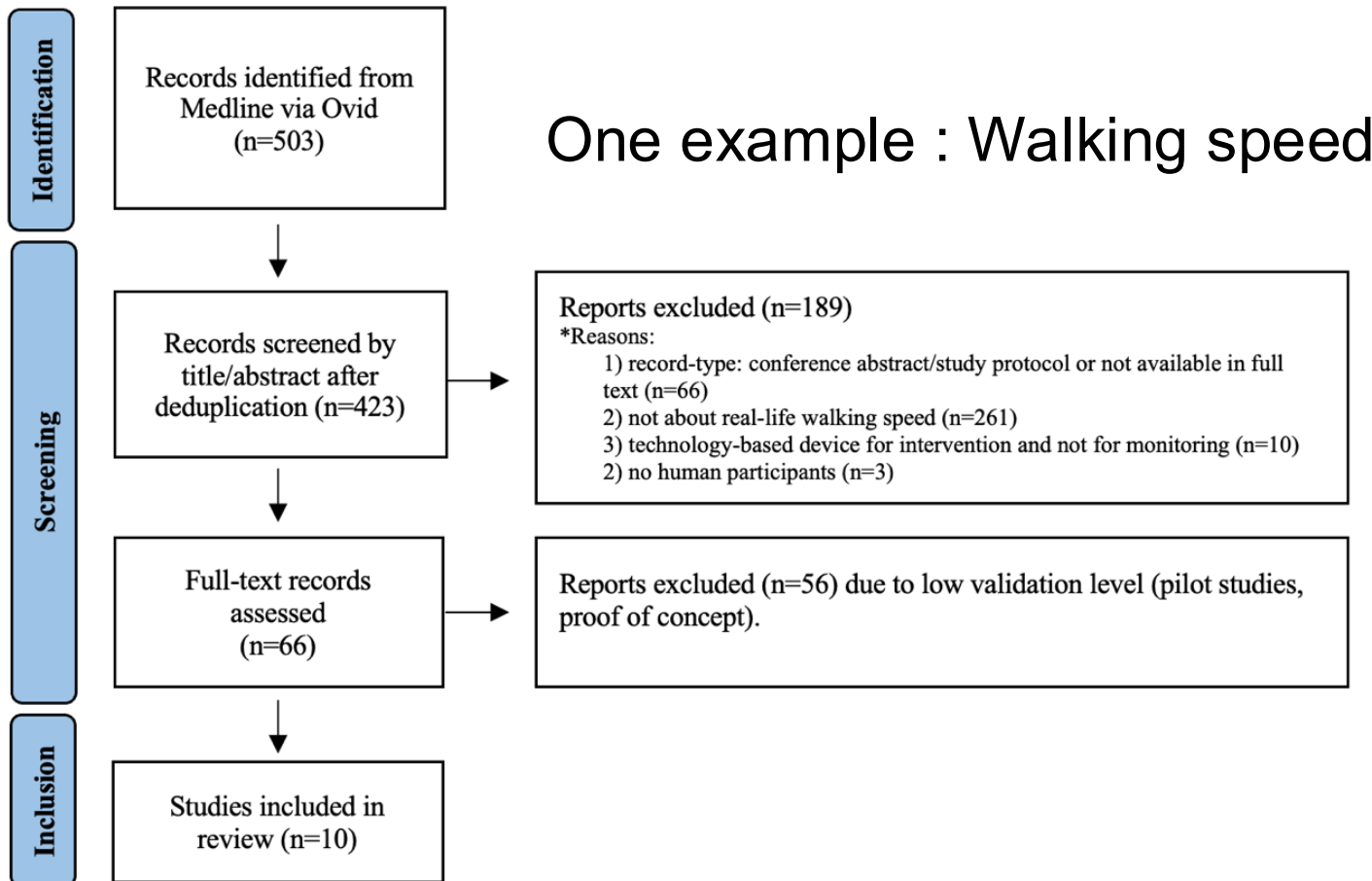
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8 | 1 | 24

Digital Biomarkers





TYPE Systematic Review
PUBLISHED 17 February 2026
DOI 10.3389/fdgth.2026.1726549



OPEN ACCESS

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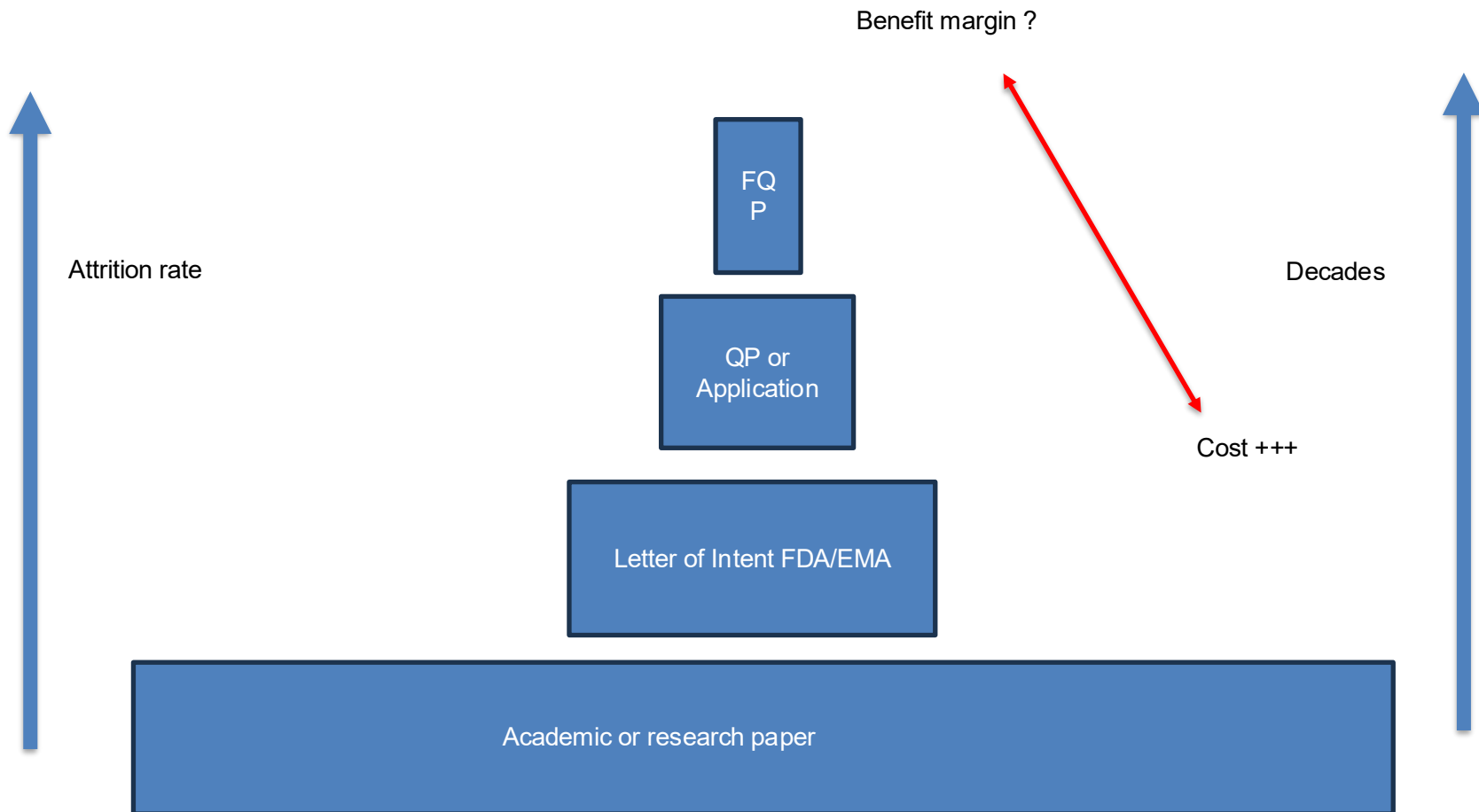
ACCEPTED 21 January 2026

PUBLISHED 17 February 2026

Real-world walking speed as a digital biomarker and outcome measure for clinical trials—a systematic review, regulatory status and future directions

Margaux Poleur^{1*}, Cyril Tychon², Stephen Gilbert^{3,4},
Martin Daumer^{5†} and Laurent Servais^{6†}

¹University Department of Neurology, Citadelle Hospital, Liège, Belgium, ²Department of Pediatrics, University of Liège, Liège, Belgium, ³Else Kröner Fresenius Center for Digital Health, TUD Dresden University of Technology, Dresden, Germany, ⁴Faculty of Business and Economics, TUD Dresden University of Technology, Dresden, Germany, ⁵SLCMR E.V. – The Human Motion Institute, Munich, Germany, ⁶Department of Paediatrics, MDUK Oxford Neuromuscular Centre, University of Oxford, Oxford, United Kingdom



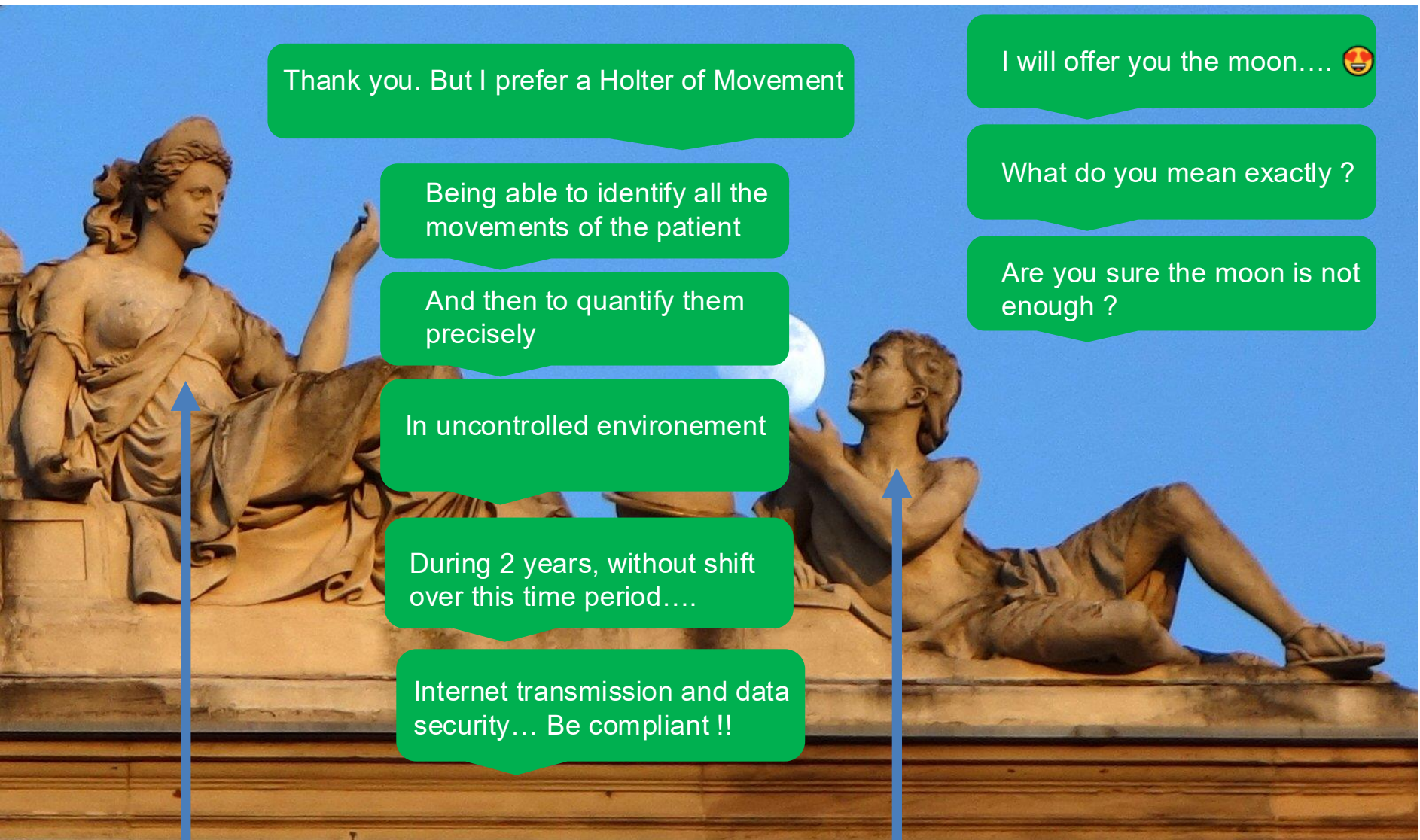
So why are wearable devices not more used as primary outcome ??

What can I do with that ??



Clinical trial





Thank you. But I prefer a Holter of Movement

I will offer you the moon.... 🌕

What do you mean exactly ?

Are you sure the moon is not enough ?

Being able to identify all the movements of the patient

And then to quantify them precisely

In uncontrolled environment

During 2 years, without shift over this time period....

Internet transmission and data security... Be compliant !!



The doctor



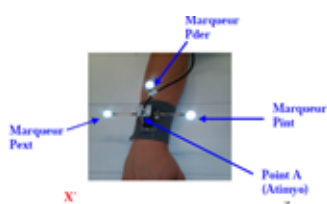
The engineer

The long and winding road of SV95C

Technical development timeline

Controlled environment → unsupervised usage

Medical device



Identification of the variables

Validation during NHS



2017

Clinical trial



2021

What do we need??

2010

Prototype

V2.0

V3.0

2012

2011

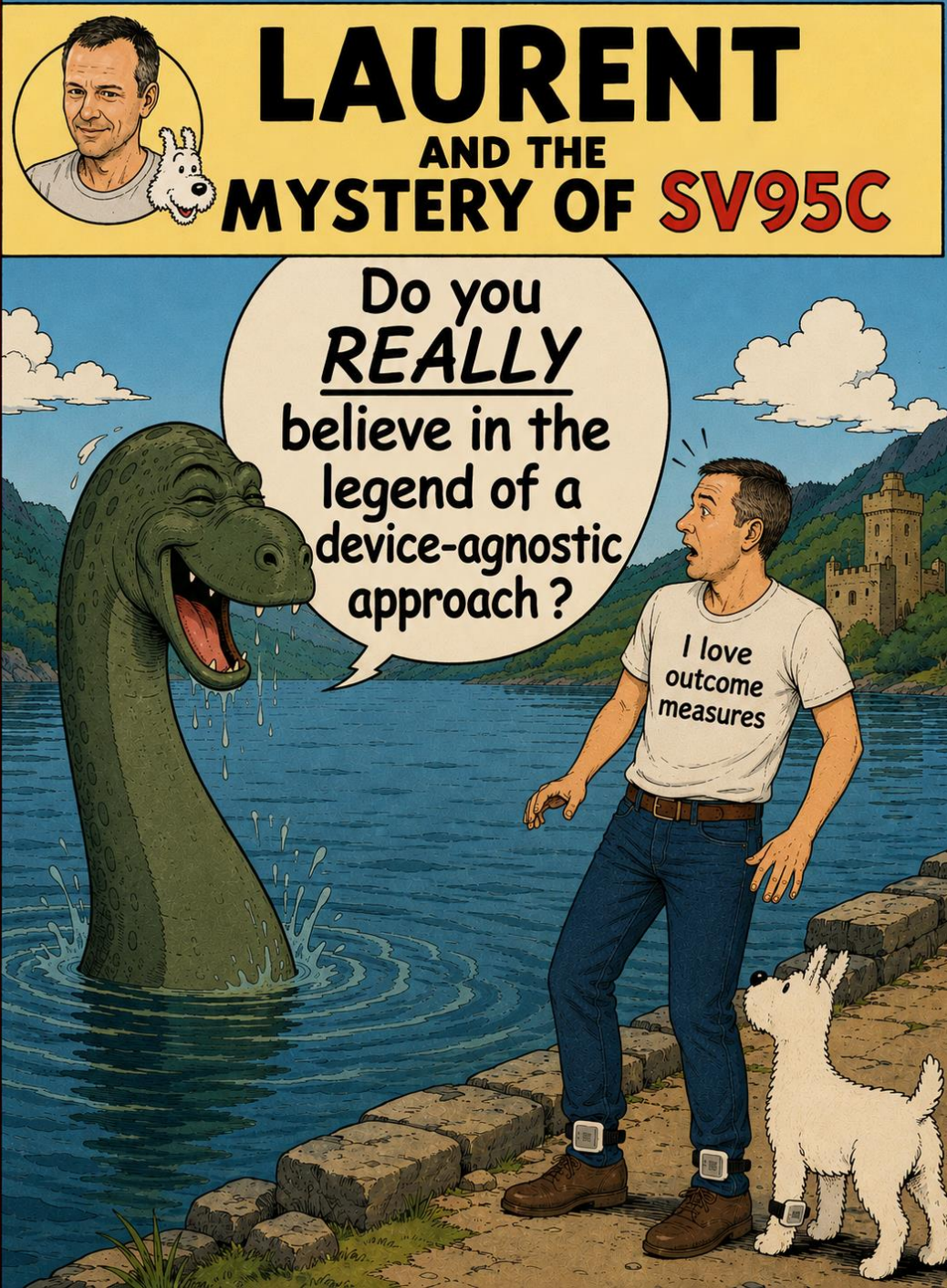


First regulatory qualification of a digital primary endpoint to measure treatment efficacy in DMD

[Laurent Servais](#) , [Damien Eggenspieler](#), [Margaux Poleur](#), [Marc Grelet](#), [Francesco Muntoni](#), [Paul Strijbos](#) & [Mélanie Annoussamy](#)

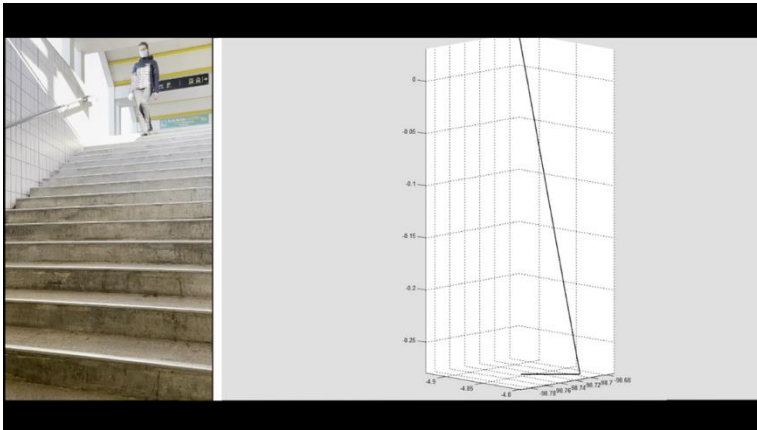
[Nature Medicine](#) 29, 2391–2392 (2023) | [Cite this article](#)

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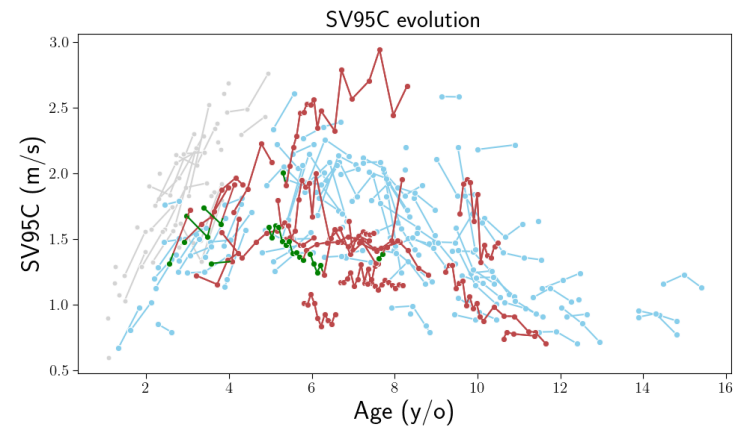


These sensors can collect stride-level data in daily life

1. Strides can be identified and trajectories reconstructed from raw sensor data



2. Several digital variables can be derived from these data, including SV95C, a measure of the top ambulation speed



SV95C=stride velocity 95th centile.



2019



26 April 2019
EMA/CHMP/SAWP/178058/2019
Committee for Medicinal Products for Human Use (CHMP)

Qualification opinion on stride velocity 95th centile as a **secondary endpoint** in Duchenne Muscular Dystrophy measured by a valid and suitable wearable device*

Draft agreed by Scientific Advice Working Party	12 April 2018
Adopted by CHMP for release for consultation	26 April 2018
Start of public consultation	21 September 2018
End of consultation (deadline for comments)	30 November 2018
Adopted by CHMP	26 April 2019

Keywords	Activity monitor, Duchenne Muscular Dystrophy (DMD), Real World Data, Stride Velocity, Ambulatory
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2023



28 July 2023
EMADOC-1700519818-1127132
Committee for Medicinal Products for Human Use (CHMP)

Qualification Opinion for Stride velocity 95th centile as **primary endpoint** in studies in ambulatory Duchenne Muscular Dystrophy studies

Draft agreed by Scientific Advice Working Party (SAWP)	01 September 2022
Adopted by CHMP for release for consultation	15 September 2022 ¹
Start of public consultation	27 February 2023 ²
End of consultation (deadline for comments)	09 April 2023
Adopted by CHMP	20 July 2023

Keywords	Qualification of Novel Methodology, Duchenne Muscular Dystrophy studies, Digital Health Technology, efficacy endpoint, wearable sensor
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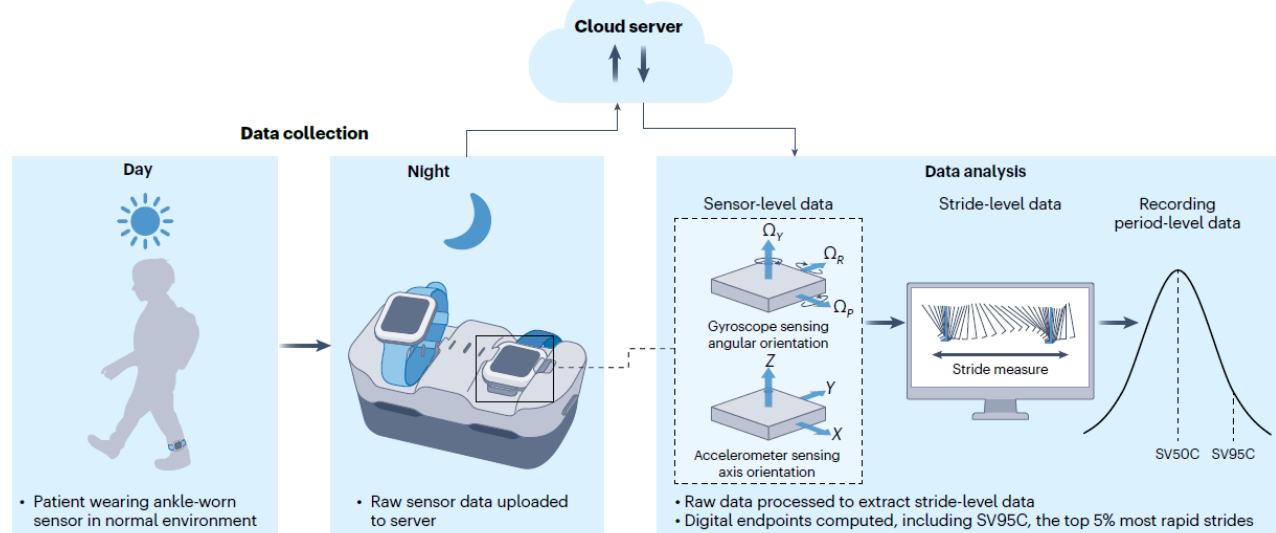
Correspondence | Published: 09 October 2023

First regulatory qualification of a digital primary endpoint to measure treatment efficacy in DMD

Laurent Servais , Damien Eggenspieler, Margaux Poleur, Marc Grelet, Francesco Muntoni, Paul Striibos & Mélanie Annonusamy

Nature Medicine 29, 2391–2392 (2023) | Cite this article

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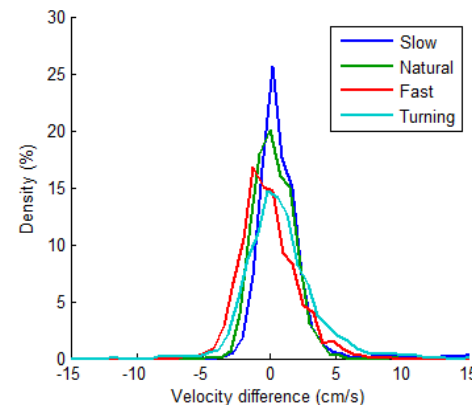
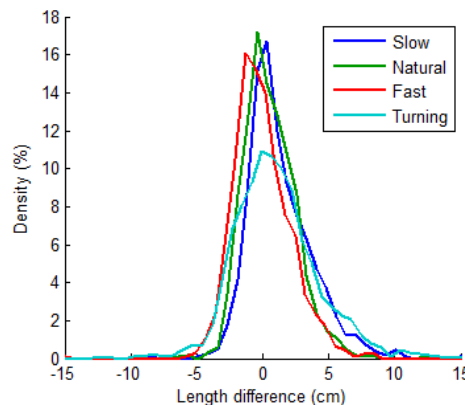
Validation in Optical motion capture room

Gait measurement

- Tests done by 8 healthy controls in an optical motion capture room
 - Walking at various paces

Distribution of measurement errors

- Evaluate the measurements accuracy
 - The error is under 2.5% at 1σ



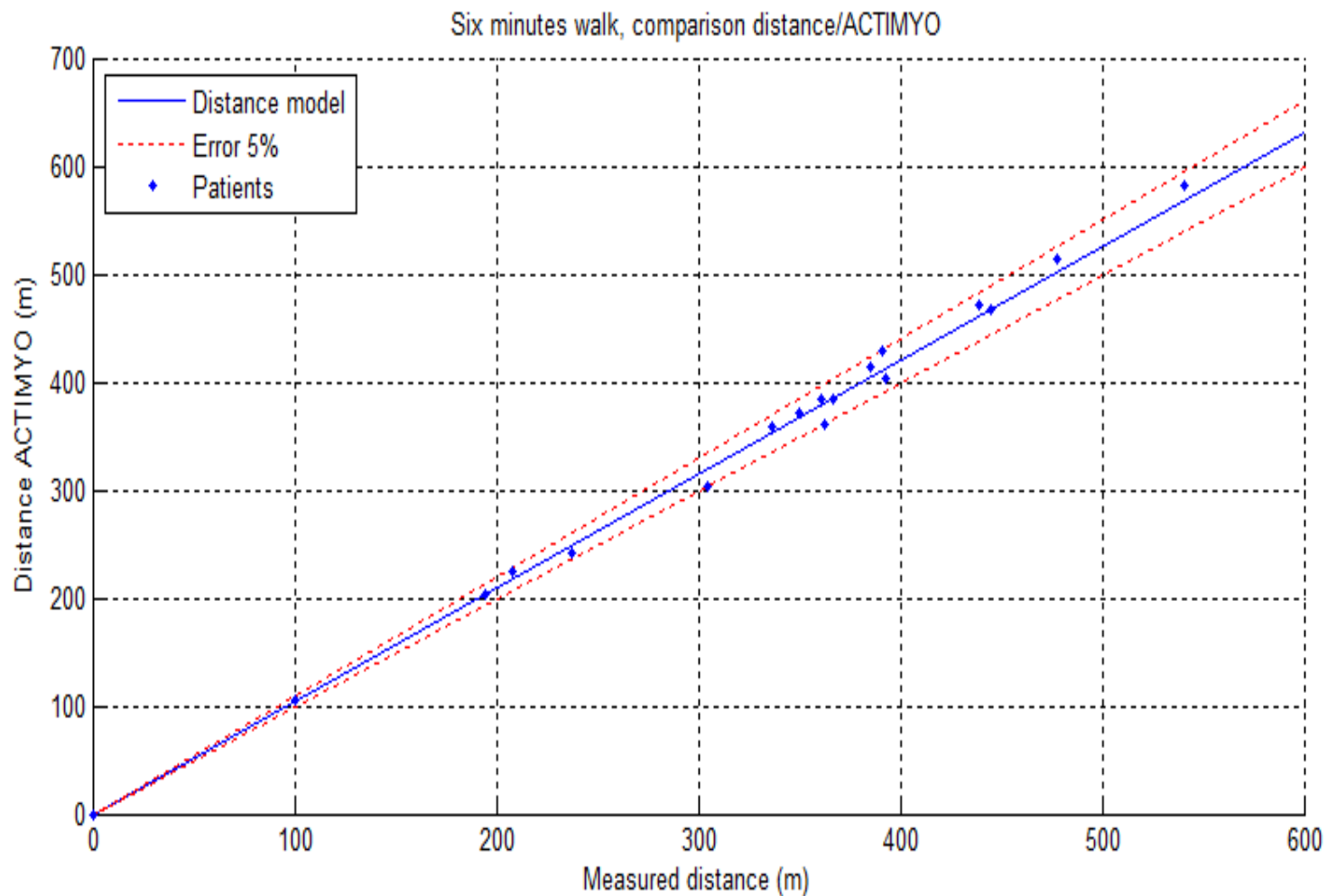
MEASURING WALK WITH ACTIMYO

COMPARAISON ACTIMYO/DISTANCE MESURÉE

- Dista



MEASURING WALK WITH ACTIMYO



Variability of actimetry....



*When it pours, British people walk less.
When it simply rains, they walk more*

Theorem of Servais (Oxford 2021)

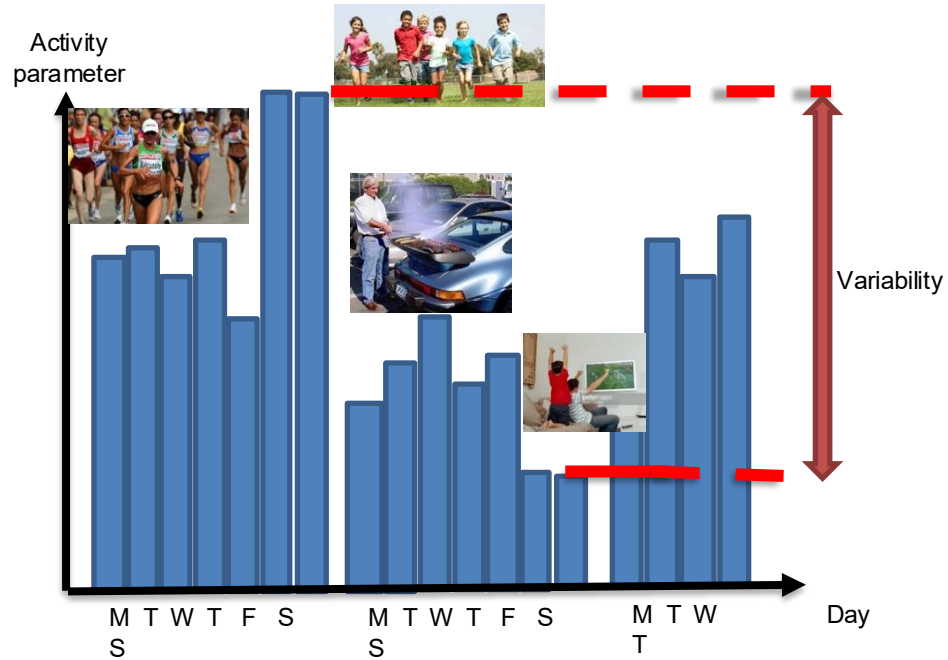
Theorem of Servais (Paris 2014)

... But do they walk a
different way ?

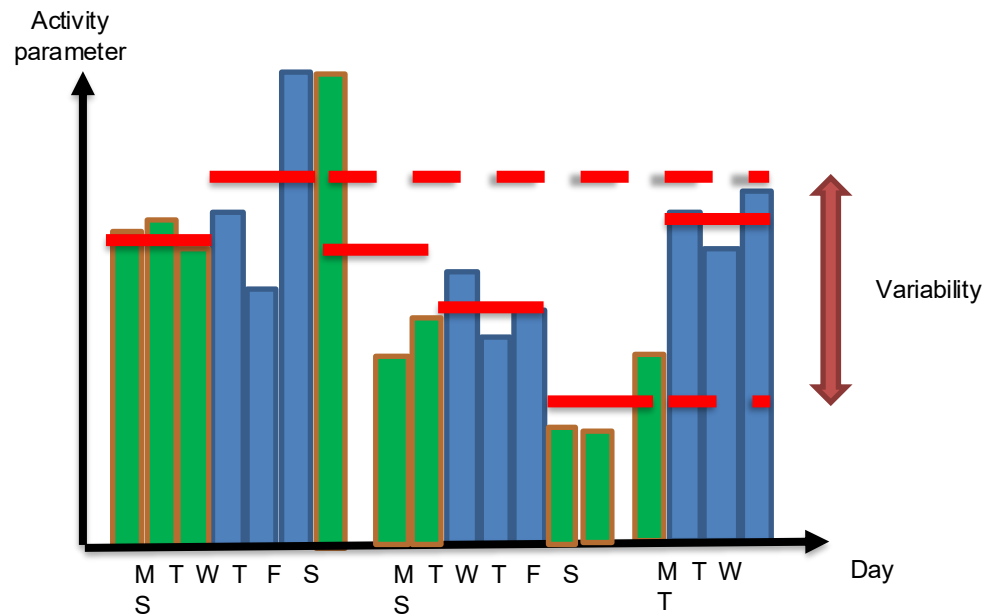


When the French are on strike, they walk more

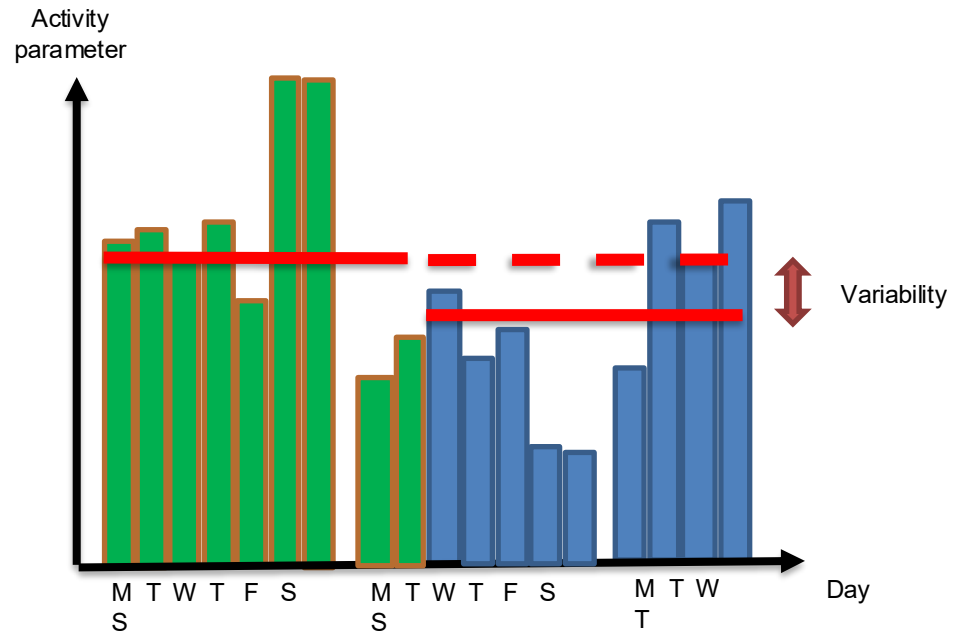
Variability measurements



Variability measurements



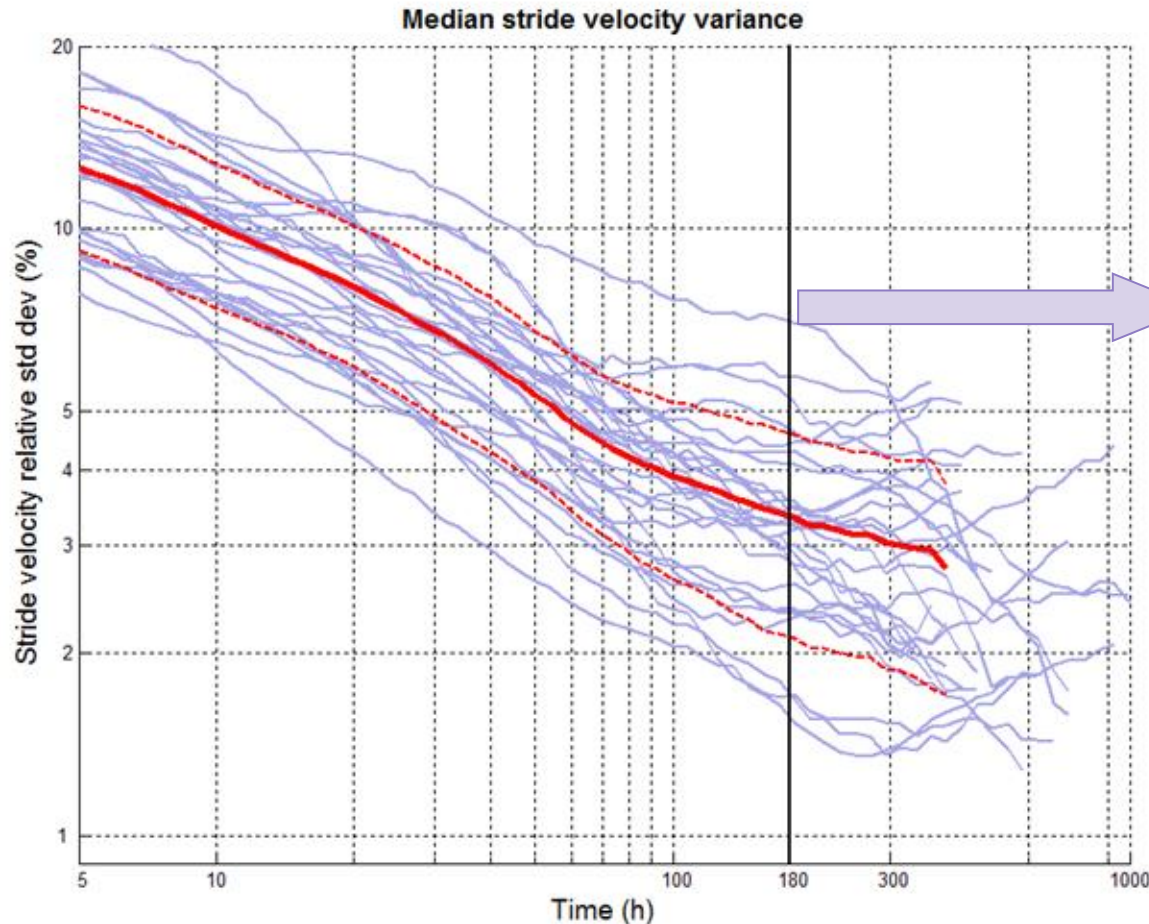
Variability measurements



Variability decreases with increasing length of monitoring

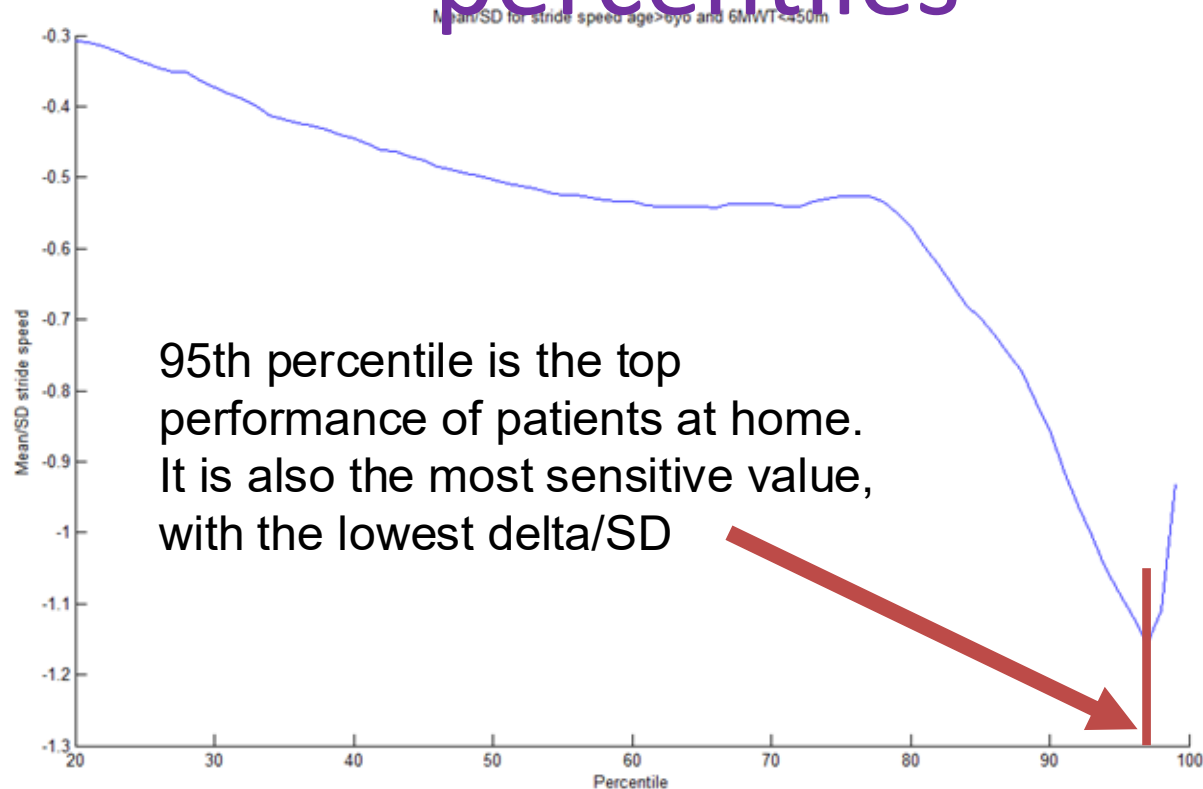
ACTImy5

HOME
MONITORING

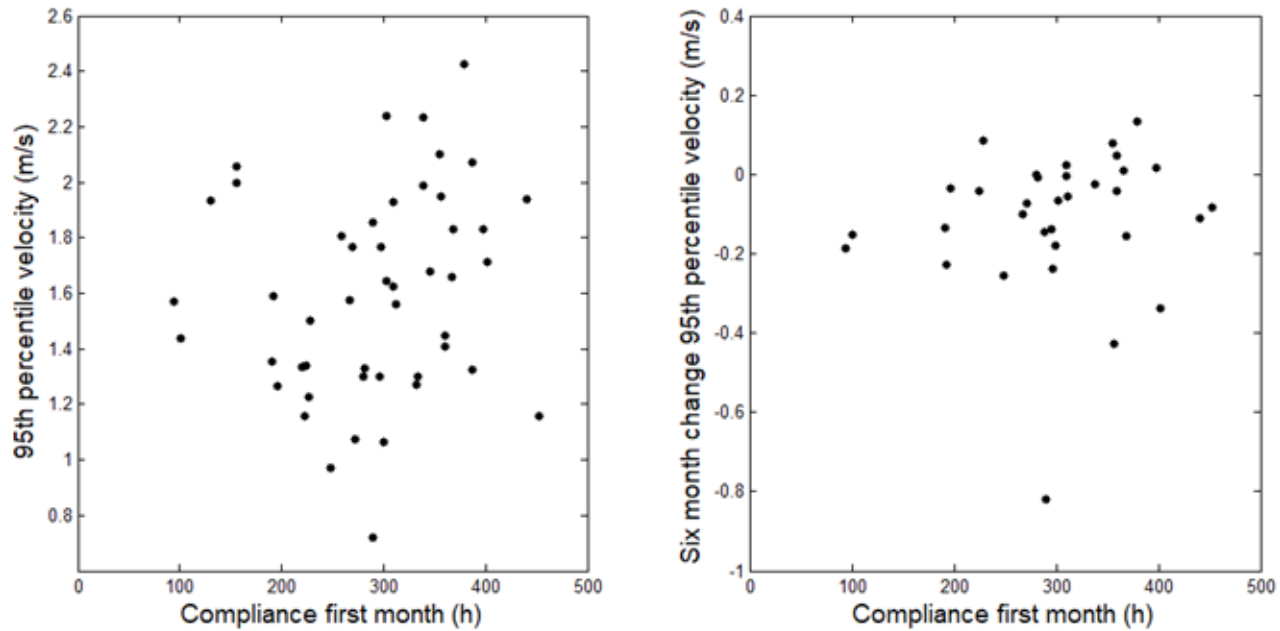


- Averaged variation stabilises at 3.3% after 180 hours (15 days) monitoring
- 15% variability currently “acceptable” for 6MWT

Stride speed as a function of percentiles



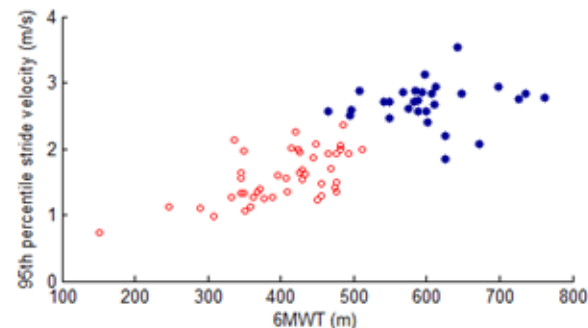
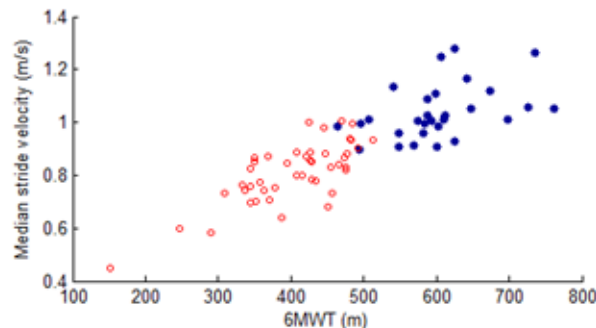
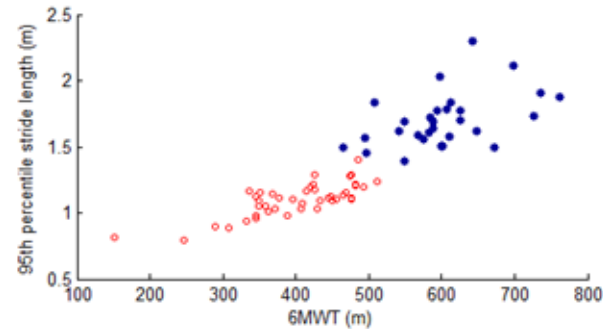
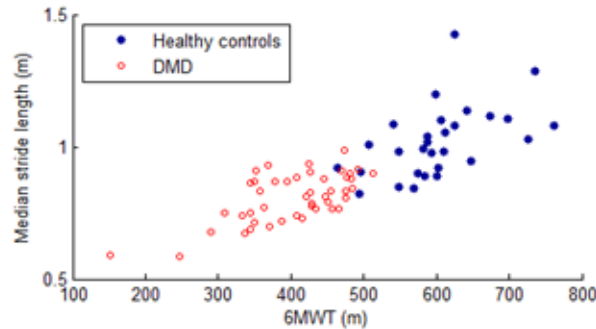
Influence of compliance on SV95C



Absence of correlation between compliance and performance

Normative data in healthy age-matched controls

- DMD and healthy controls correlated with 6MWT



Poleur et al. *Orphanet J Rare Dis* (2021) 16:318
<https://doi.org/10.1186/s13023-021-01956-5>

Orphanet Journal of
Rare Diseases

RESEARCH

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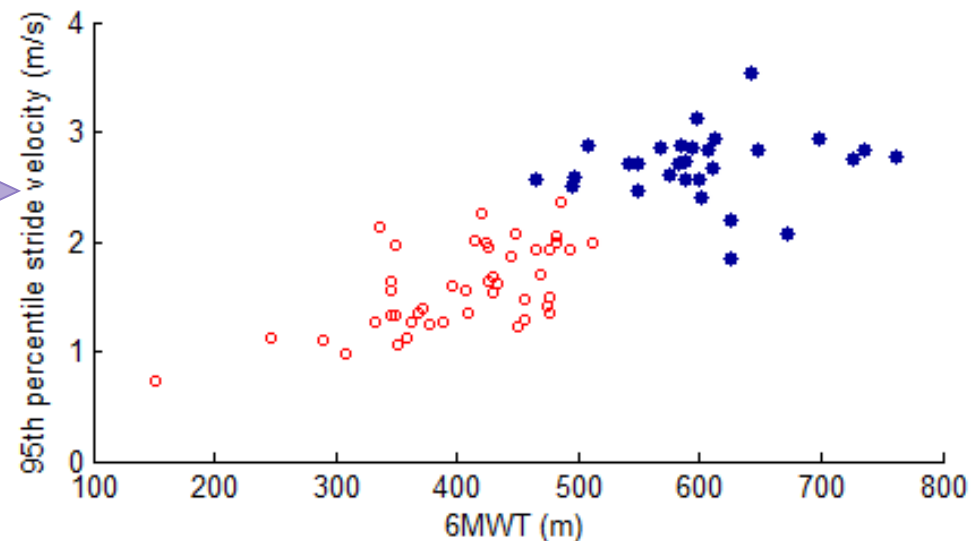


Normative data on spontaneous stride velocity, stride length, and walking activity in a non-controlled environment

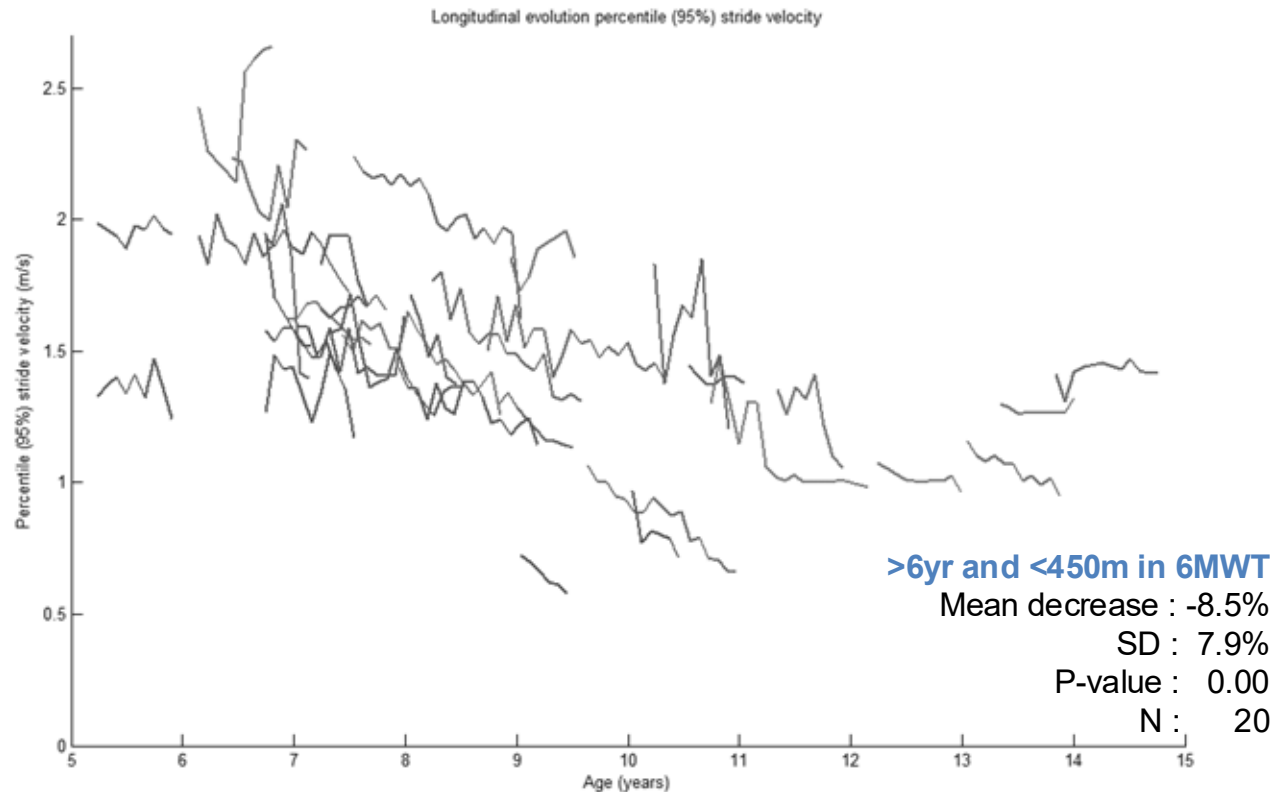
Margaux Poleur¹, Ana Ulinici¹, Aurore Daron¹, Olivier Schneider¹, Fabian Dal Farra¹, Marie Demonceau¹, Mélanie Annoussamy², David Vissière², Damien Eggensteiner² and Laurent Servais^{1,3*}

Correlation with different outcomes

		6MWT		NSAA		4SC	
ActiMyo® Variables	N	ρ	r	ρ	R	ρ	r
50 th Percentile (median) stride length (m)	4 5	0,552**	0,649**	0,554**	0,607**	0,126	0,066
95 th Percentile stride length (m)	4 5	0,679**	0,772**	0,779**	0,816**	-0,301*	-0,251
50 th Percentile (median) stride velocity (m/s)	4 5	0,652**	0,758**	0,712**	0,724**	-0,161	-0,195
95 th Percentile stride velocity (m/s)	4 5	0,542**	0,616**	0,645**	0,689**	-0,547**	-0,484**
Distance walked/hour	4 5	0,371*	0,436**	0,424**	0,435**	-0,304*	-0,313*



Stride velocity 95th percentile

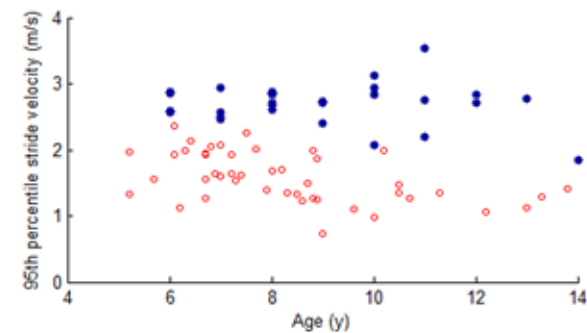
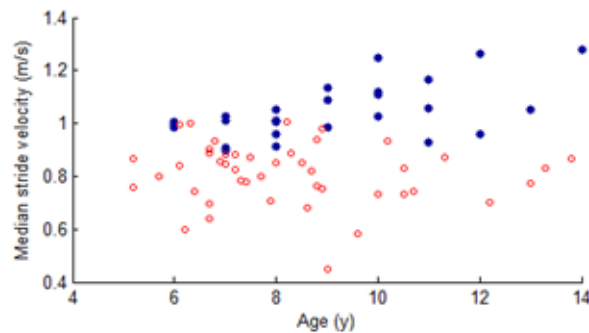
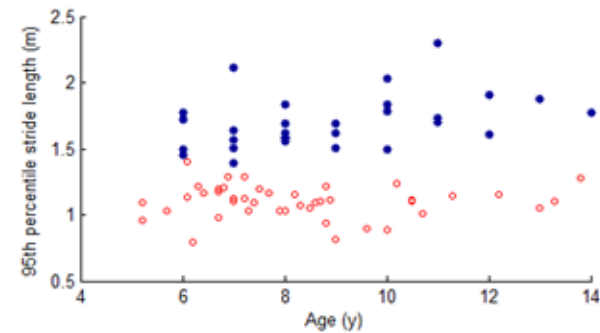
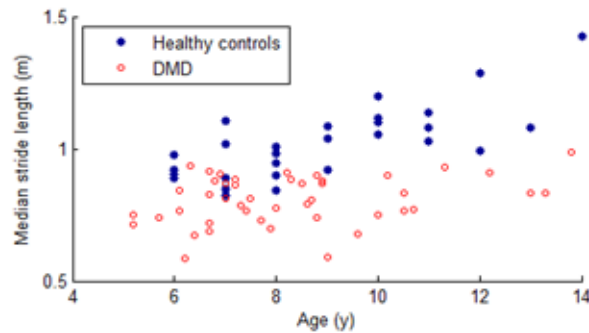


Minimally clinically important difference

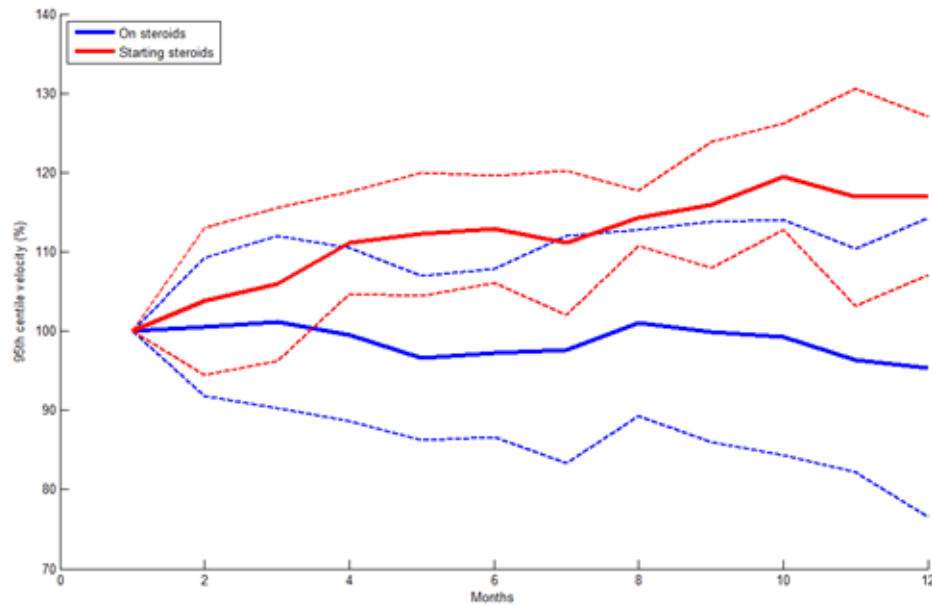
	Mean	SD	Intra-correlation	MCID	Relative MCID
50th Percentile (median) stride length	0.825 m	0.087 m	0.957	0.0179 m	2.17%
95th Percentile stride length	1.101 m	0.129 m	0.951	0.0284 m	2.58%
50th Percentile (median) stride velocity	0.836 m/s	0.116 m/s	0.942	0.0278 m/s	3.33%
95th Percentile stride velocity	1.578 m/s	0.391 m/s	0.937	0.0985 m/s	6.24%
Distance walked/hour	162.6 m/h	87.9 m/h	0.839	35.3 m/h	21.7%

Normative data in healthy age-matched controls

- Clear separation between healthy controls and DMD groups

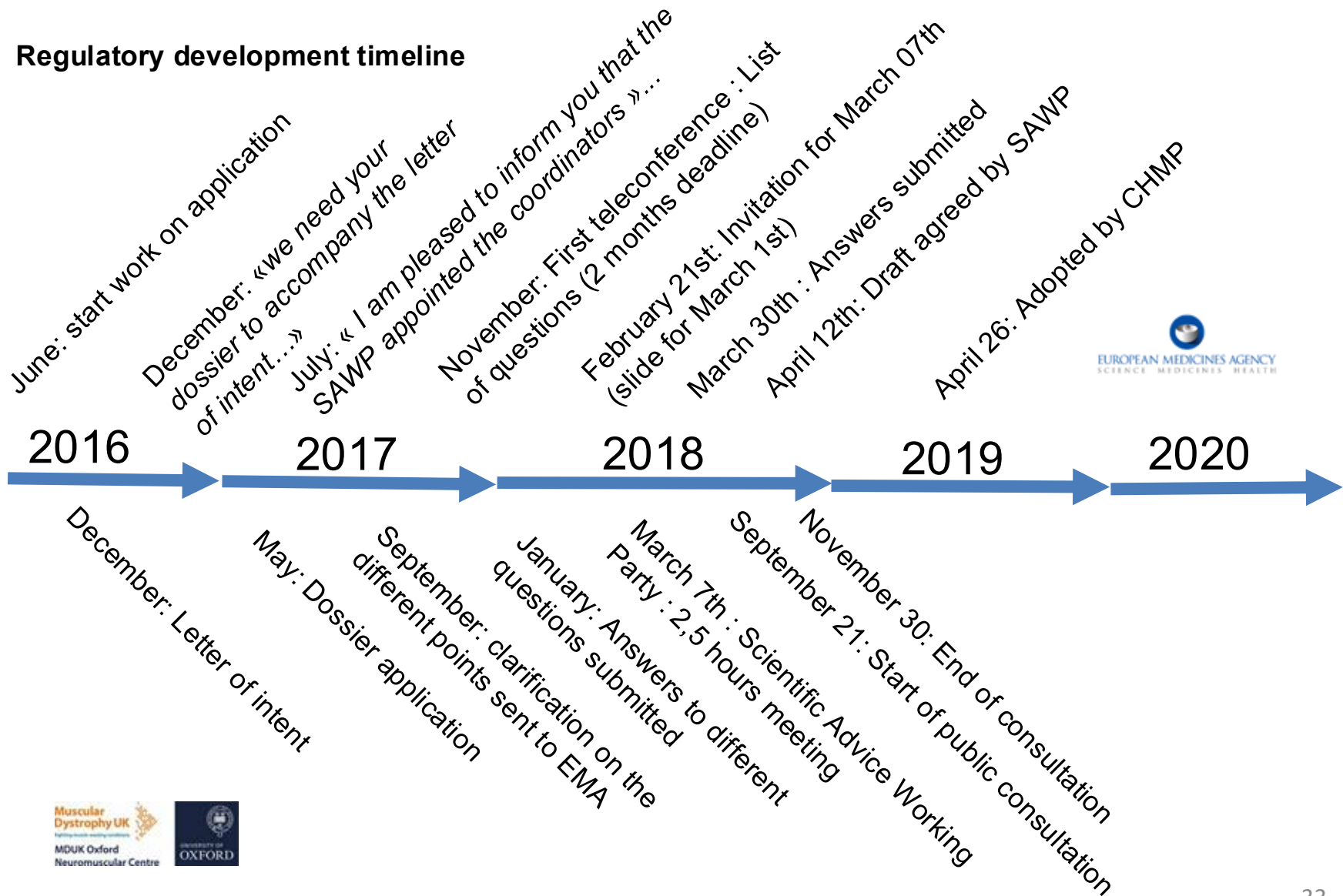


Sensitivity to positive Change : Patient starting steroid treatment

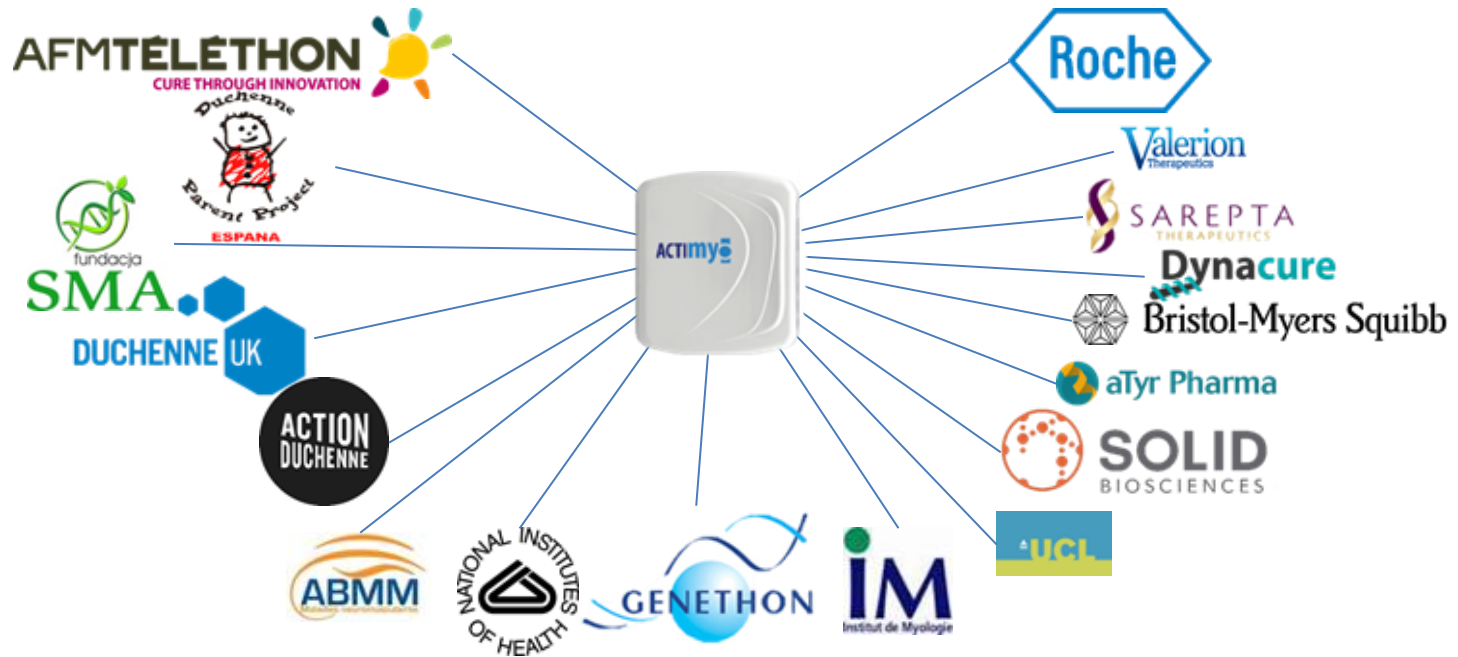


The long and winding road of SV95C

Regulatory development timeline



CHMP qualification has been achieved thanks to the support of a broad community



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH



Key opportunities for clinical development

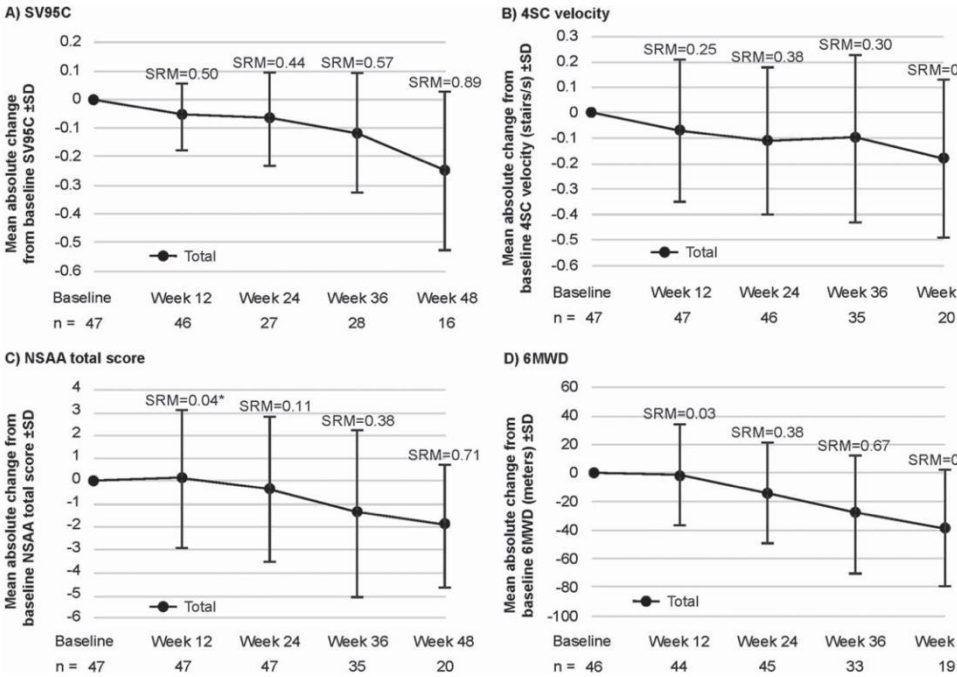
1. Early detection of decline

Journal of Neuromuscular Diseases 11 (2024) 701–714
DOI 10.3233/JND-230188
IOS Press

Research Report

Stride Velocity 95th Centile Detects Decline in Ambulatory Function Over Shorter Intervals than the 6-Minute Walk Test or North Star Ambulatory Assessment in Duchenne Muscular Dystrophy

Michael Rabbia^a, Maitea Guridi Ormazabal^b, Hannah Staunton^c, Klaas Veenstra^b, Damien Eggenpieler^d, Mélanie Anoussamy^d, Laurent Servais^{e,f} and Paul Strijbos^{b,*}

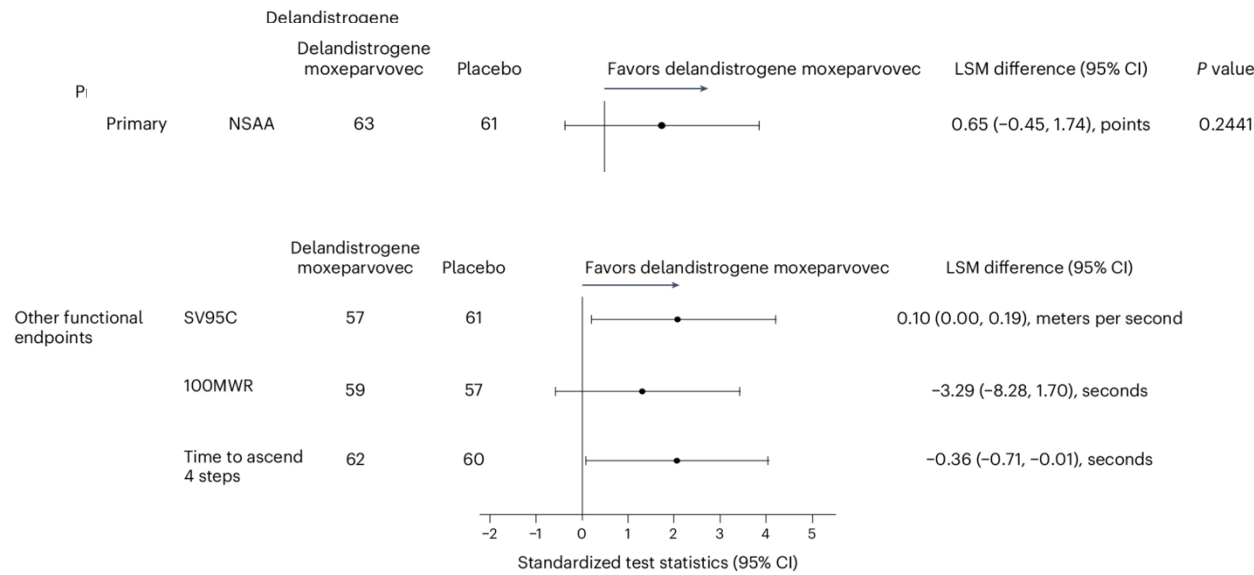


AAV gene therapy for Duchenne muscular dystrophy: the EMBARK phase 3 randomized trial

[Jerry R. Mendell](#) , [Francesco Muntoni](#), [Craig M. McDonald](#), [Eugenio M. Mercuri](#), [Emma Ciafaloni](#), [Hiroyuki Komaki](#), [Carmen Leon-Astudillo](#), [Andrés Nascimento](#), [Crystal Proud](#), [Ulrike Schara-Schmidt](#), [Aravindhan Veerapandian](#), [Craig M. Zaidman](#), [Maitea Guridi](#), [Alexander P. Murphy](#), [Carol Reid](#), [Christoph Wandel](#), [Damon R. Asher](#), [Eddie Darton](#), [Stefanie Mason](#), [Rachael A. Potter](#), [Teji Singh](#), [Wenfei Zhang](#), [Paulo Fontoura](#), [Jacob S. Elkins](#) & [Louise R. Rodino-Klapac](#)

Nature Medicine (2024) | [Cite this article](#)

2. Avoid the risk of false negative



Wearable devices and the future of rare disease clinical trials: Landry's story

Landry Wardlow is a playful 10-year-old from Iowa. He takes swimming lessons, likes outings to the zoo, spends cold winter nights doing art projects and hot summer days killing time at his brothers' baseball tournaments. Typical kid stuff.

But Landry lives with Duchenne muscular dystrophy and his journey is far from ordinary. In addition to navigating life with a rare genetic disease, he is a pioneer in the new era of drug development. That's because Landry recently participated in a groundbreaking clinical trial that incorporated a wearable device.

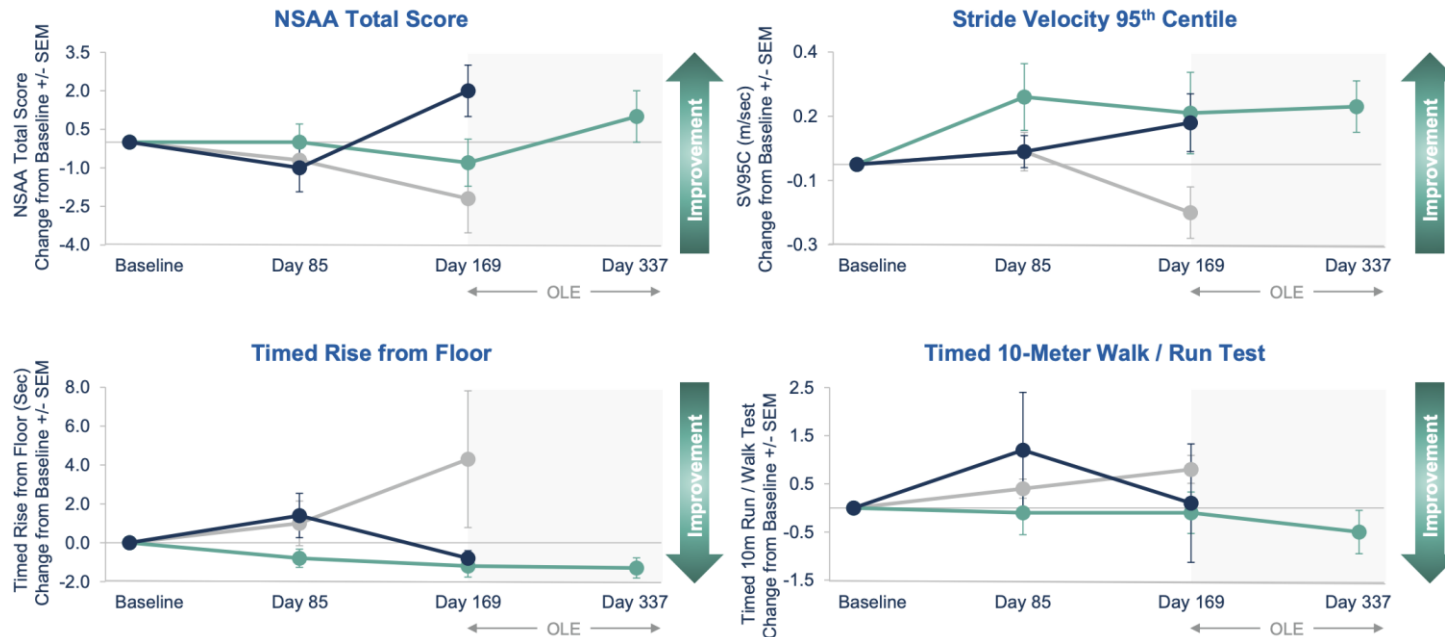
After he was diagnosed with Duchenne at age 4, Landry's mom, Holly, dedicated herself to researching treatment options and finding a clinical trial that might help stop the disease progression. In late 2021, Landry enrolled in a Phase 3 trial for Sarepta's investigational gene therapy for Duchenne. According to topline results from that trial, participants saw meaningful improvements in something called stride velocity 95th centile, or SV95C.¹ SV95C is a measure of how fast someone walks, and it is captured via small wearable devices on each ankle.



3. Early detection of clinical benefit

Improvements Across Multiple Functional Endpoints in Multiple Cohorts

Baseline Values Inform Interpretation of Data; Ongoing Exploration of Longer Timepoints



● Placebo (n=6 for SV95C and n=14 for other endpoints) ● DYNE-251 10 mg/kg Q4W (n = 6 for all endpoints)¹ ● DYNE-251 20 mg/kg Q4W (n = 6 for all endpoints)

1. During the OLE, all participants in 10 mg/kg cohort were dose escalated to 20 mg/kg Q4W regimen.

The Toddler...



Ask him to do something and hope that he does exactly what you want...



It would be best to not ask him anything and let him do what HE wants...

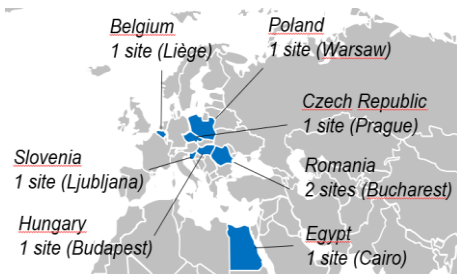
ActiLiège-Next: a multicentric natural history study

Study objectives:

1. Gather 3-year functional data for SV95C to broaden our understanding of this measure
2. Provide longitudinal data to support FDA qualification dossier
3. Investigate feasibility, robustness and sensitivity of SV95C in DMD patients below the age of 4 years old

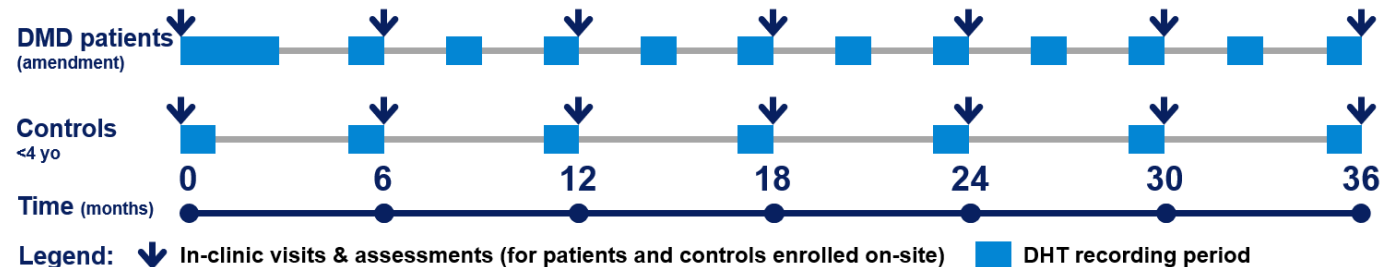
ActiLiège-Next: a multicentric natural history study

8 clinical sites



- Ambulant DMD patients
- Healthy subjects
- 1 to 15 years old

Schedule of assessments for 1-4 y/o



- 3-year follow-up with visits every 6 months for DMD patients and controls enrolled on-site
 - NSAA, 6MWT, 4SC, TRF... when possible
- 3-month baseline DHT wear period, and every 3-6 months afterwards
 - Variables including SV95C

Baseline characteristics of all subjects

<u>Mean (SD)</u> [min; max]	DMD (N=29)*		<u>Controls (N=26)</u>	
Age (<u>months</u>)	34.3 (9.2) [16.1; 47.4]	N=29	31.8 (10.6) [12.8; 47.7]	N=26
NSAA	17.9 (5.7) [6.0; 30.0]	N=22	Not applicable	
6MWT (m)	294 (61) [151; 384]	N=12	404 (104) [300; 508]	N=2†
4SC (s)	6.4 (3.3) [2.8; 14.9]	N=26	4.1 (1.7) [1.4; 6.6]	N=6†
TTR (s)	5.8 (2.4) [0.4; 11.2]	N=28	2.9 (0.7) [1.7; 3.8]	N=6†
SV95C (m/s)	1.3 (0.3) [0.6; 1.7]	N=28	1.8 (0.5) [0.9; 2.7]	N=26

sd=standard deviation; y/o=years old.

Excellent compliance with DHT wear

<u>Visit</u>	<u>Subjects</u>	< 50 h of data	≥ 50 h of data
<u>Baseline</u> <u>(first month)</u>	DMD (N=29)	1 (3%)	28 (97%)
	<u>Controls</u> (N=26)	0 (0%)	26 (100%)
<u>Month 6</u>	DMD (N=28)*	2 (7%)	26 (93%)
	<u>Controls</u> (N=25)†	0 (0%)	25 (100%)
<u>Month 12</u>	DMD (N=25)*	3 (12%)	22 (88%)
	<u>Controls</u> (N=25)†	3 (12%)	22 (88%)
<u>Month 18</u>	DMD (N=21)*	0 (0%)	21 (100%)
	<u>Controls</u> (N=15)†	0 (0%)	15 (100%)

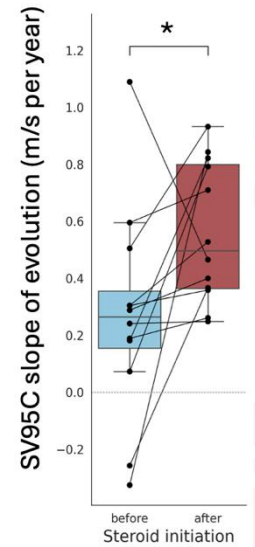
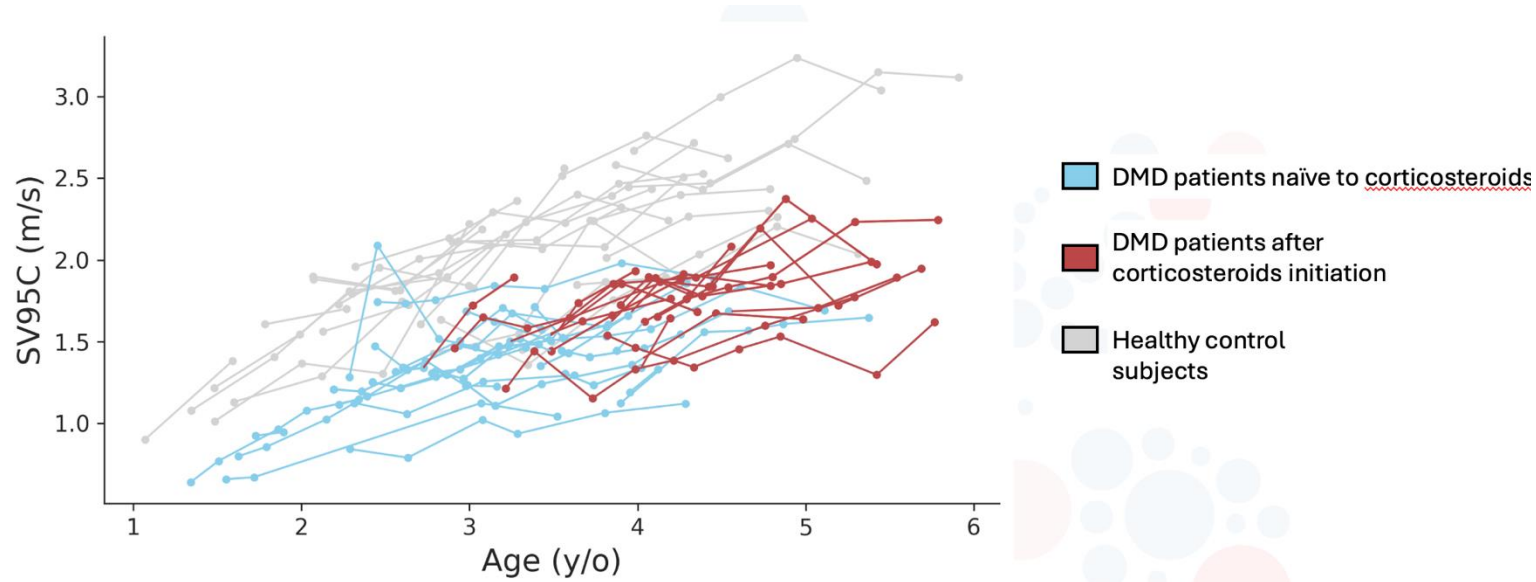
DHT = digital health technology.

Excellent SV95C reliability for young subjects

	ICC2k [†] [95% confidence interval]			
<u>Subjects</u>	<u>Baseline</u>	<u>Month 6</u>	<u>Month 12</u>	<u>Month 18</u>
DMD	0.99 [0.97; 0.99] (N=24)	0.96 [0.91; 0.98] (N=25)	0.96 [0.9; 0.98] (N=20)	0.98 [0.94; 0.99] (N=19)
<u>Controls</u>	0.99 [0.97; 1.0] (N=23)	0.92 [0.8; 0.96] (N=23)	0.98 [0.94; 0.99] (N=21)	0.91 [0.69; 0.98] (N=11)

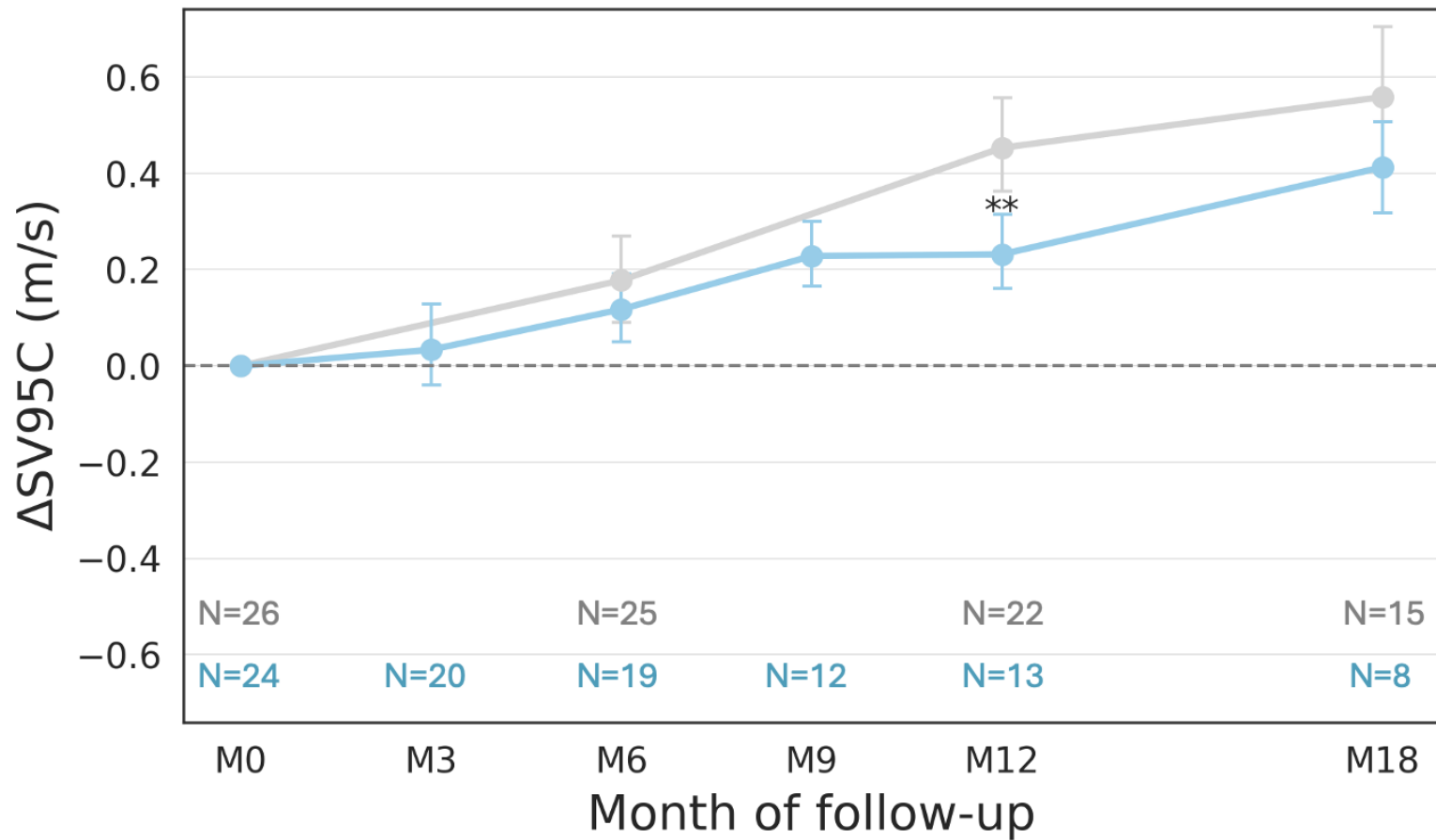
LONGITUDINAL EVOLUTION

SV95C VS AGE, & STEROID HIGHLIGHTS



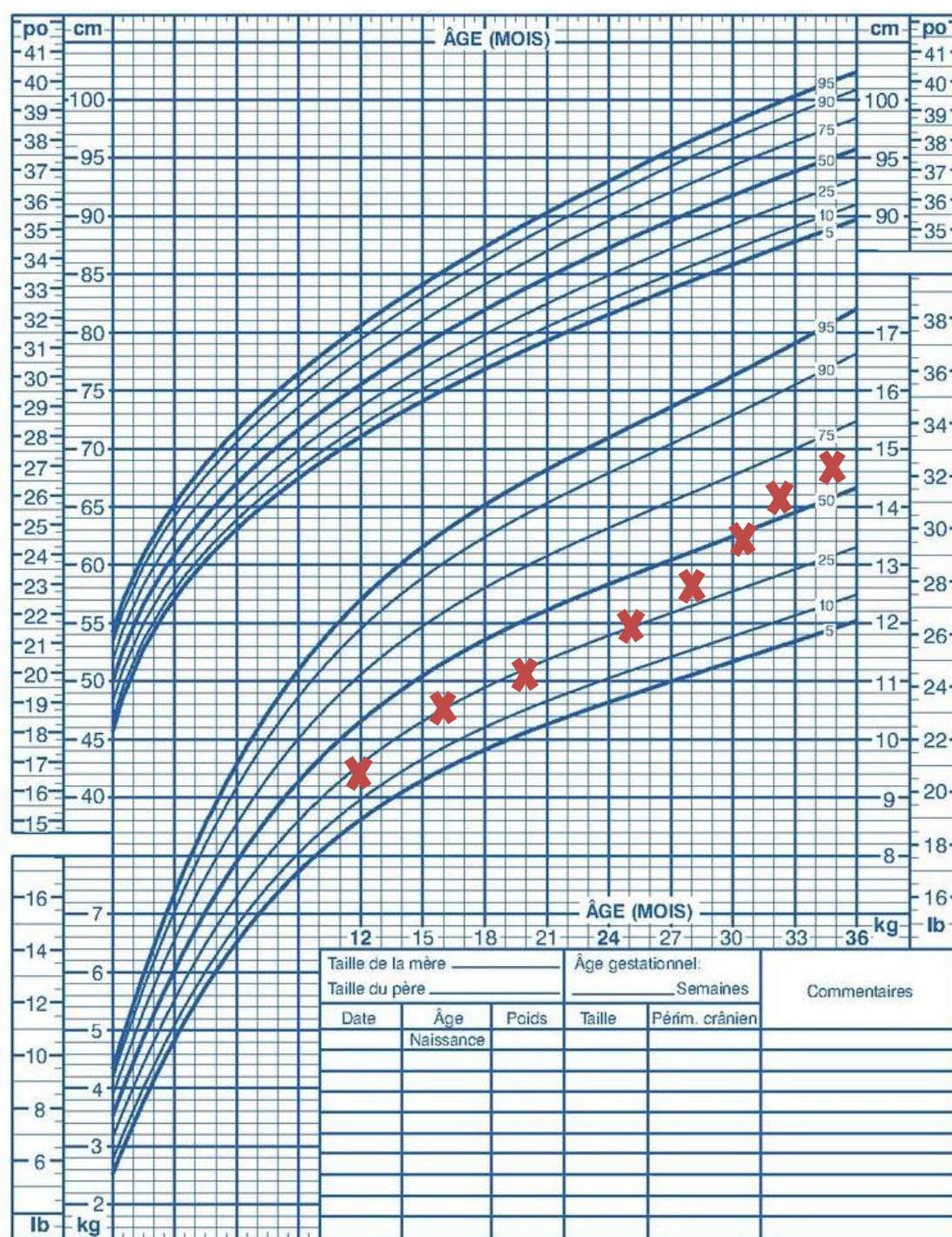
LONGITUDINAL EVOLUTION

ALL AGES (1-15y/o), SV95C & Nb strides/h



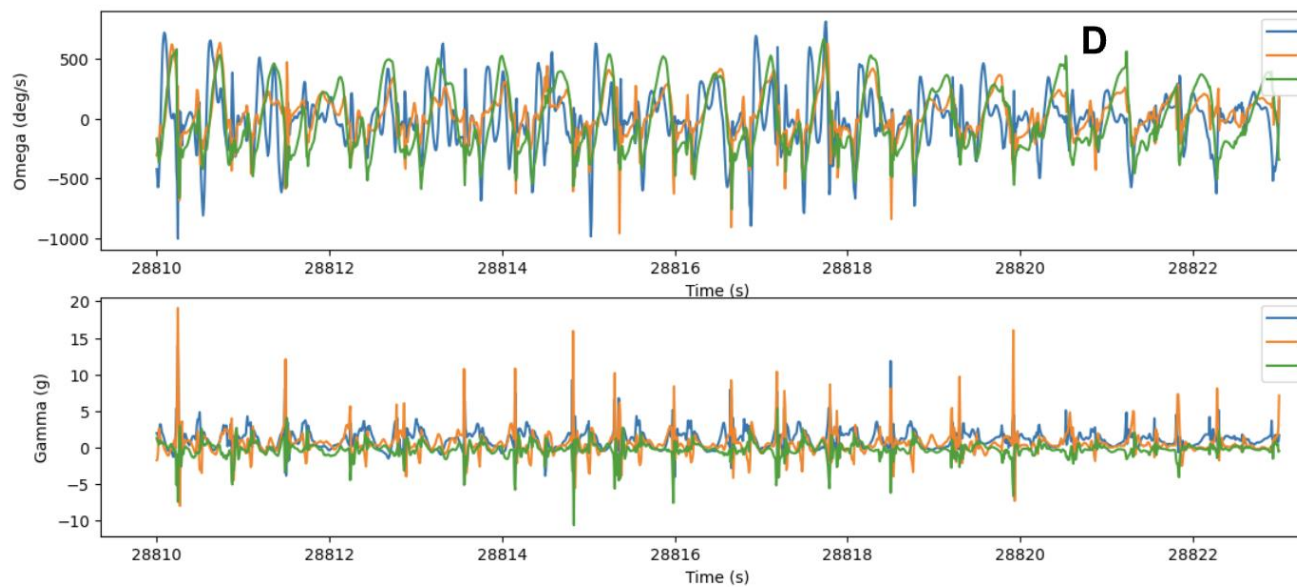
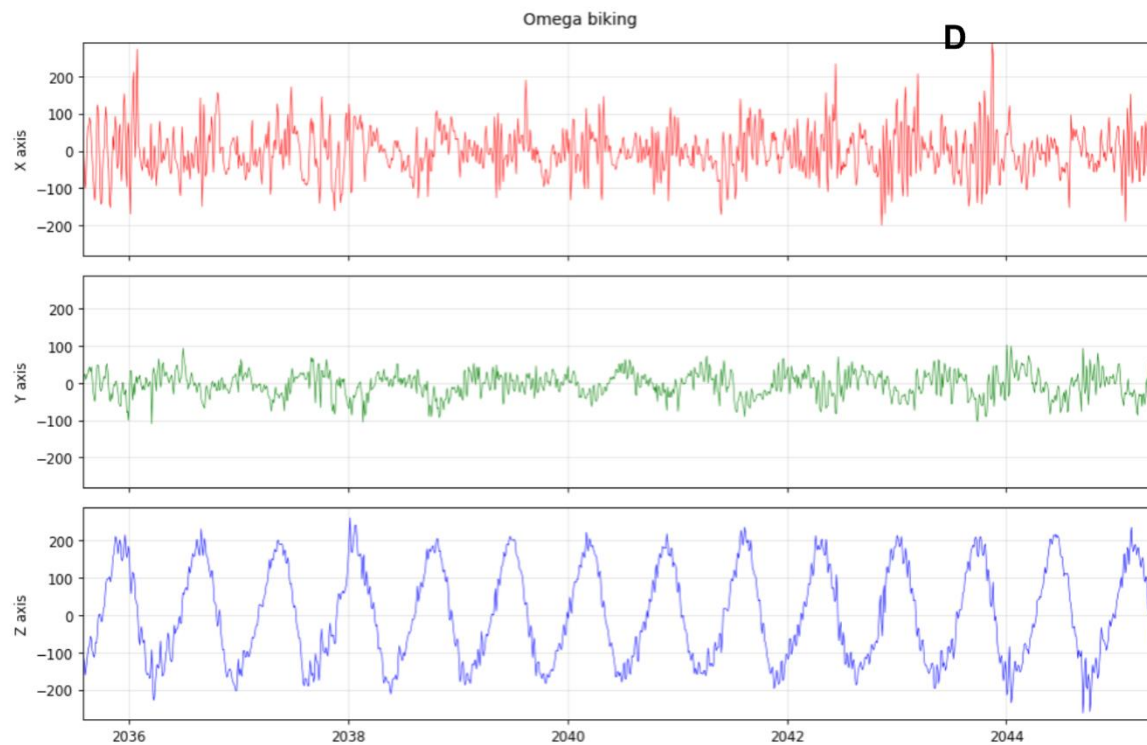
My dream...

Let's prescribe
drug A









SYDE® - A few figures on global footprint

Sub-therapeutic area	Pathologies with active Syde studies	Number of patients currently in active studies
Neuromuscular	DMD	N = 1000+
	SMA BMD LGMD FSHD DM1 & DM2 Nemaline CMT ALS	N = 700+
Neurology	Multiple sclerosis Spinocerebellar Ataxia Friedrich Ataxia Parkinson	N = 500+
Neurodevelopmental	Angelman Syndrome Dup15Q	N = 150+
Short stature	ACH & HCH	N=200+
other rare diseases	CTNNB1 RYR1-RM HSP	N = 30+
Healthy controls	Across all age ranges	N = 300+
Total		N = 3 000+

150+

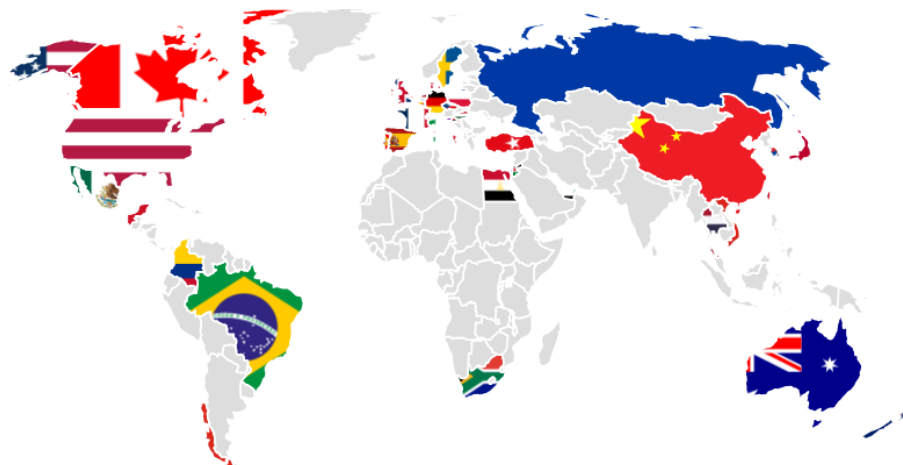
Ongoing clinical trials with Syde®

25+

Indications explored
with Syde®

95+

Languages available
for Syde® patient
materials



Current geographic footprint of Syde® as of 2026

In which conditions has digital outcome demonstrate a better sensitivity to change than traditional scales ?

DMD

Multiple Sclerosis

ALS

FSHD

Reliability, Compliance and analytical validation

SMA

LGMD

BMD

X-MTM

DM1

CMT

Parkinson

Achondroplasia

Knee Osteorthritis

Angelman

Dup 15q

CTNNB1

SMA

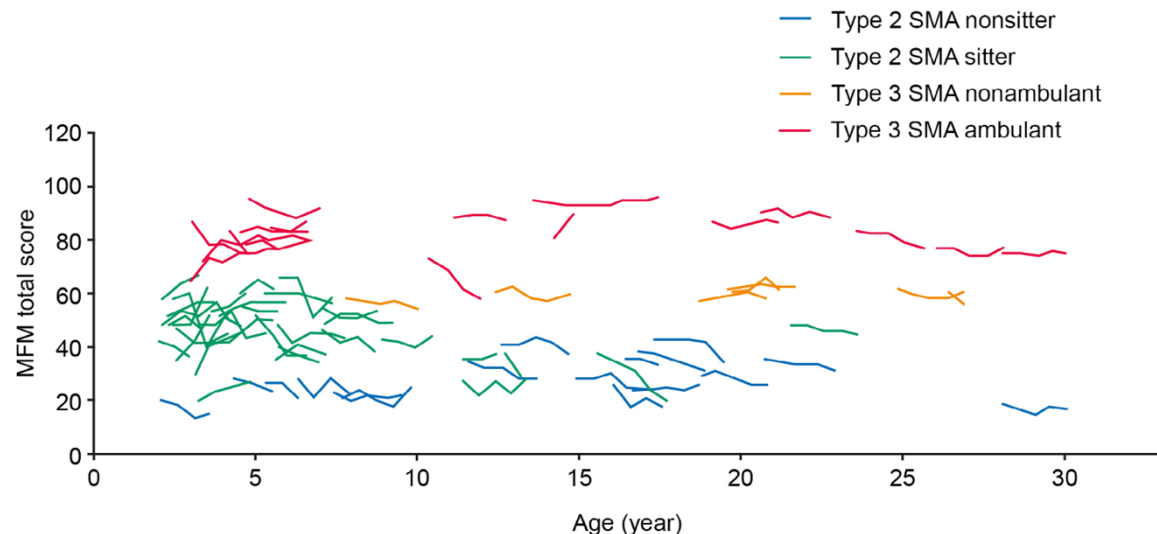
RESEARCH ARTICLE

Natural history of Type 2 and 3 spinal muscular atrophy: 2-year NatHis-SMA study

Mélanie Annuossamy^{1,2}, Andreea M. Seferian¹, Aurore Daron³, Yann Péréon⁴, Claude Cances^{5,6}, Carole Vuillerot^{7,8}, Liesbeth De Waele^{9,10}, Vincent Laugel¹¹, Ulrike Schara¹², Teresa Gidaro¹, Charlotte Lilien^{1,13}, Jean-Yves Hogrel¹ , Pierre Carlier¹, Emmanuel Fournier¹, Linda Lowes¹⁴, Ksenija Gorni¹⁵, Myriam Ly-Le Moal¹⁶, Nicole Hellbach¹⁷, Timothy Seabrook^{17,a}, Christian Czech^{17,18,a}, Ricardo Hermosilla^{17,a}, Laurent Servais^{1,13,19}  & the NatHis-SMA study group^b

Two-Year Data From the NatHis-SMA Study

M. Annuossamy *et al.*



— SMA Type 2 non-sitter — SMA Type 3 non-ambulant
— SMA Type 2 sitter — SMA Type 3 ambulant

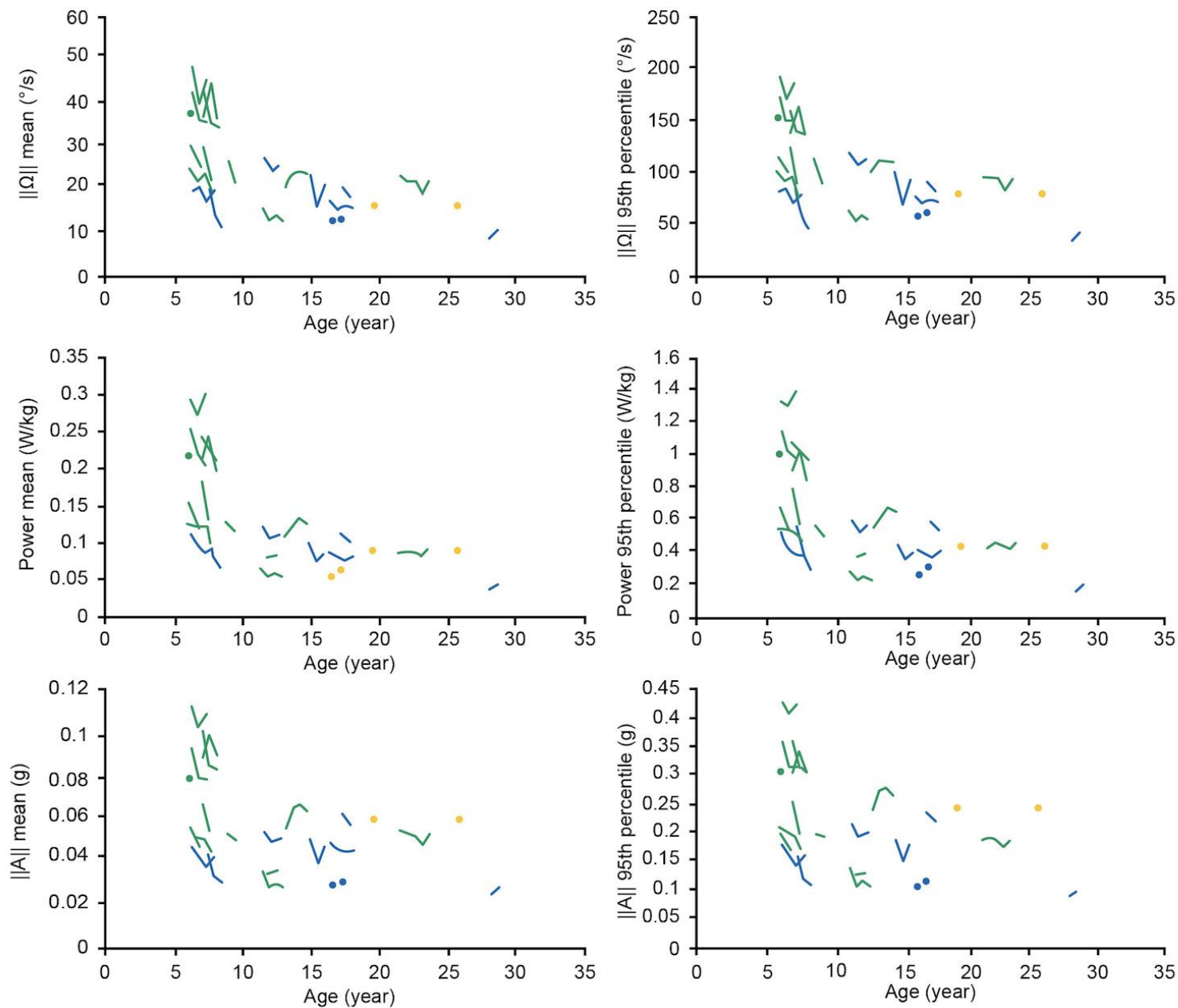
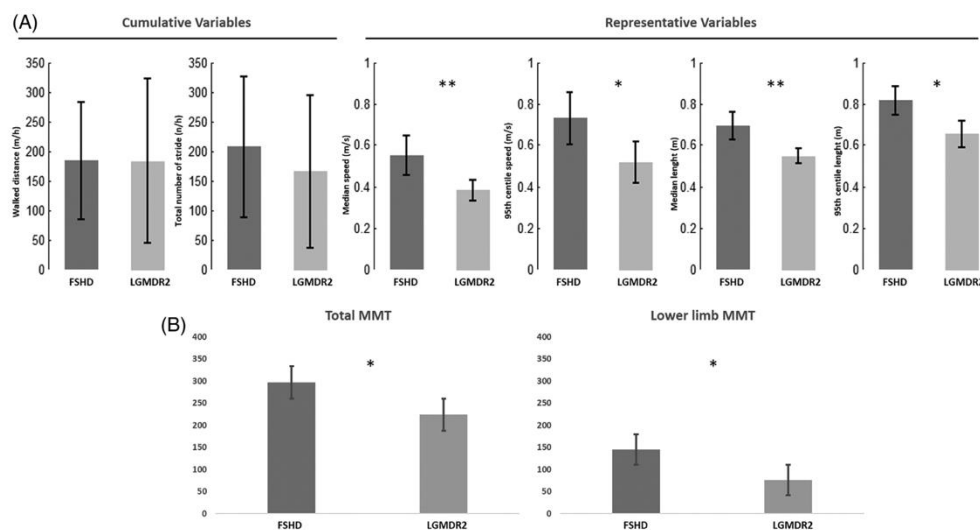
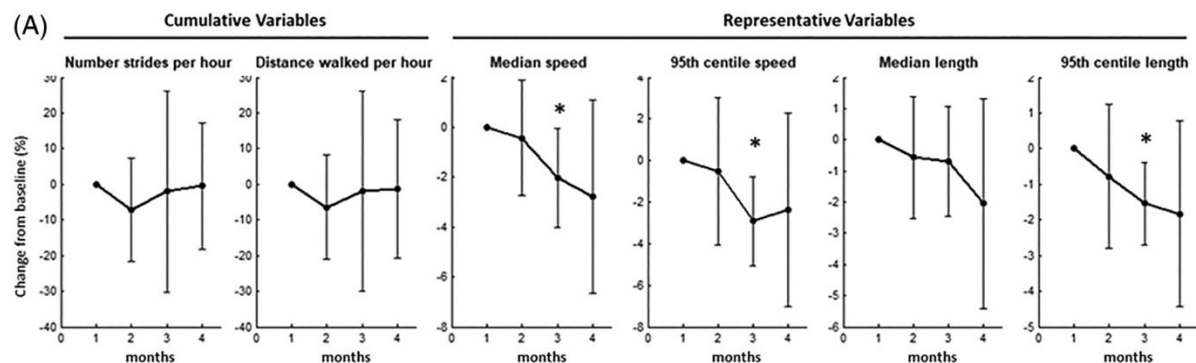


Table 1. Changes in ActiMyo® upper limb activity over 6 and 12 months.

	$\ \Omega\ $ mean (°/s)	$\ \Omega\ $ 95th percentile (°/s)	$\ A\ $ mean (m/s ²)	$\ A\ $ 95th percentile (m/s ²)	vA mean (m/s ²)	vA 95th percentile (m/s ²)	Power mean (W/kg)	Power 95th percentile (W/kg)
Changes from baseline at Month 6								
N	19	19	19	19	19	19	19	19
Mean	−2.66	−9.62	−0.01	−0.02	0.01	0.00	−0.01	−0.05
SD	4.33	15.11	−0.01	0.02	0.02	0.01	0.02	0.08
Median	−2.68	−9.12	−0.01	−0.02	0.01	0.00	−0.01	−0.04
Min	−8.18	−32.49	−0.02	−0.05	−0.03	0.00	−0.05	−0.22
Max	8.04	24.71	0.01	0.04	0.03	0.02	0.03	0.12
P-value*	0.02	0.02	0.01	0.01	0.07	0.04	0.01	0.03
SRM	0.61	0.64	0.71	0.63	0.47	0.60	0.63	0.55
Changes from baseline at Month 12								
N	13	13	13	13	13	13	13	13
Mean	−2.63	−9.12	−0.01	−0.02	0.02	0.00	−0.01	−0.05
SD	3.51	12.40	0.01	0.02	0.03	0.01	0.02	0.10
Median	−1.37	−5.28	0.00	−0.02	0.01	0.00	−0.01	−0.05
Min	−9.53	−38.59	−0.02	−0.05	−0.02	−0.01	−0.06	−0.26
Max	3.55	11.21	0.01	0.04	0.10	0.03	0.02	0.12
P-value*	0.01	0.01	0.02	0.02	0.13	0.35	0.02	0.06
SRM	0.75	0.74	0.71	0.75	0.50	0.40	0.67	0.55

Home-based gait analysis as an exploratory endpoint during a multicenter phase 1 trial in limb girdle muscular dystrophy type R2 and facioscapulohumeral muscular dystrophy

Teresa Gidaro MD, PhD¹ | Erwan Gasnier PhD¹ | Melanie Annoussamy PhD^{1,2} |
 John Vissing MD, PhD³ | Shahram Attarian MD, PhD⁴ | Tahseen Mozaffar MD⁵  |
 Stanley Iyadurai MD, PhD⁶ | Kathryn R. Wagner MD, PhD⁷ | David Vissière PhD² |
 Gennynne Walker PhD⁸ | Sanjay S. Shukla MD, MS⁸ | Laurent Servais MD, PhD^{1,9,10}



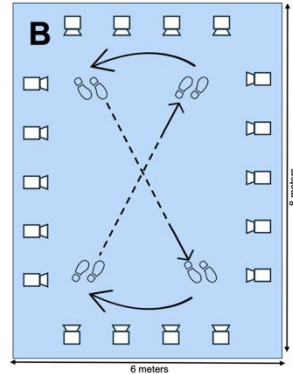
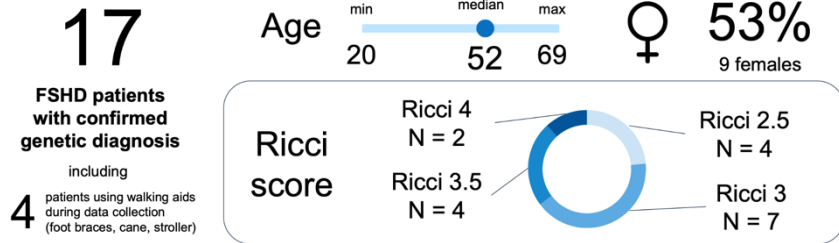


The analytical validation of Syde has been confirmed (97% detection, accuracy 0.5cm/s $\pm$ 3.6cm/s) across disease severity, including patients using assistive devices for walking

UNIVERSITY OF
COPENHAGEN



CHARACTERISTICS OF PATIENTS



Measuring gait with Syde® in patients with Facioscapulohumeral muscular dystrophy (FSHD): Analytical validation in a controlled environment. FSHD IRC, 2025

VALIDATION OF STRIDE DETECTION

Table 1. Results of the stride detection validation (both ankles)

	All patients (N=17)	By disease severity (Ricci)		By ambulatory level	
		Ricci [2.5; 3] (N=11)	Ricci [3.5; 4] (N=6)	Using walking aids (N=4)	Not using walking aids (N=13)
True positive (TP) strides	11128	6730	4398	2794	8334
False positive (FP) strides	75	27	48	5	70
False negative (FN) strides	190	135	55	59	131
Precision [TP/(TP+FP)]	99.3%	99.6%	98.9%	99.8%	99.2%
Recall [TP/(TP+FN)]	98.3%	98.0%	98.7%	97.9%	98.5%

More than 97% of accurate stride detection overall (both ankles), with similar performance at all severity of symptoms and for patients using walking aids.

ACCURACY OF STRIDE VELOCITY MEASUREMENT

Table 3. Accuracy of DHT measurement of stride velocity (SV) (both ankles)

	All patients (N=17)	By disease severity (Ricci)		By ambulatory level	
		Ricci [2.5; 3] (N=11)	Ricci [3.5; 4] (N=6)	Using walking aids (N=4)	Not using walking aids (N=13)
Stride count	10272	6292	3980	2503	7769
Mean MoCap SV (m/s)	0.991	1.084	0.843	0.793	1.054
Mean SV error (Mocap – DHT) (m/s)	0.005	0.011	-0.004	-0.001	0.007
SV error standard deviation (m/s)	0.036	0.040	0.028	0.018	0.040
95th centile of SV error (m/s)	0.054	0.055	0.051	0.034	0.060

Evaluation of Ambulatory Function in Daily Life with an Ankle Wearable Sensor in Ambulant Patients with FSHD

RESULTS

Characteristics of patients

Baseline demographics of FSHD cohort (N=13)

Sex (N female, %) 4 (31%)

Age (years): Mean [min - max] (std) 55 [30 - 70] (13)

Ricci score: Mean [min - max] (std) 3.2 [2.5 - 4.0] (0.5)

Digital outcome identification

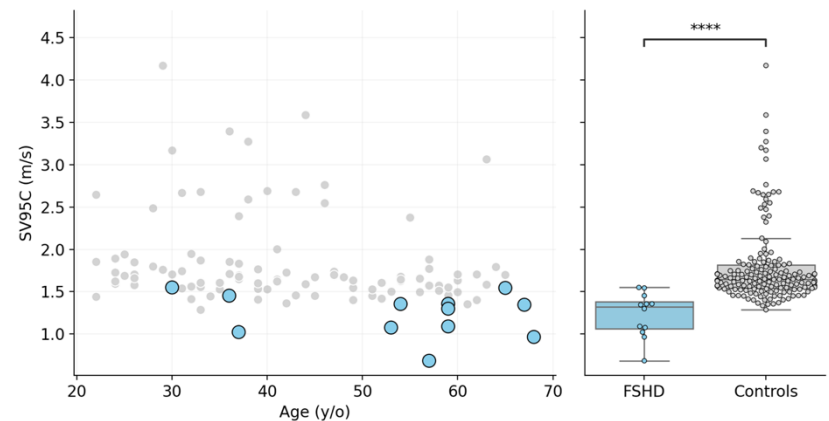
SV95C discriminated patients from controls ($p < 0.0001$) and correlated well with gold standard endpoints (Spearman $p < 0.05$).

Spearman's correlation coefficients (FSHD cohort).

	Ricci score	6MWT	FSHD-COM	FSHD-COM Leg Function
SV95C	-0.60 ($p < 0.05$)	0.85 ($p < 0.001$)	-0.78 ($p < 0.01$)	-0.90 ($p < 0.0001$)

Digital outcome identification

Comparison of SV95C: FSHD vs healthy volunteers.

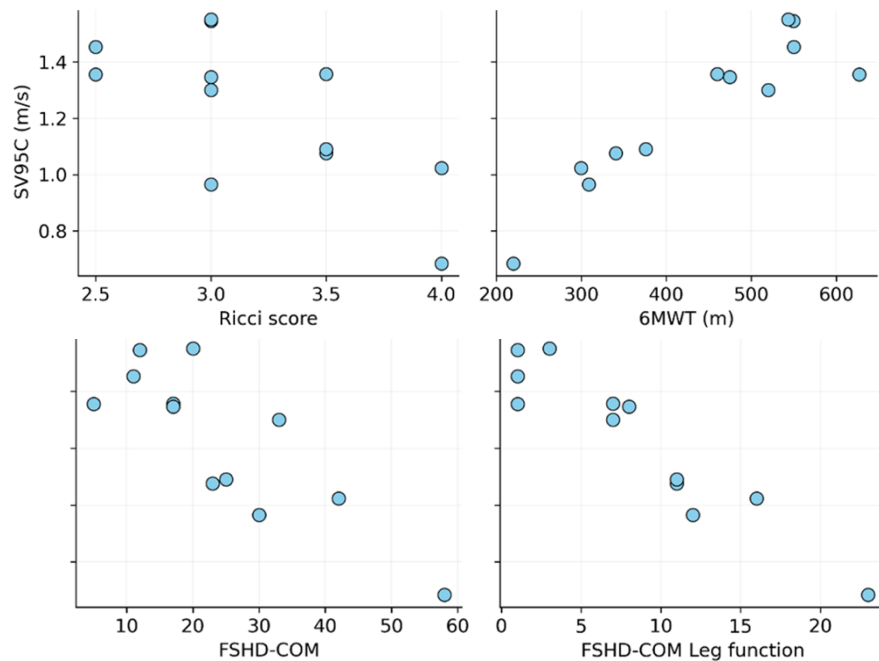


Evaluation of Ambulatory Function in Daily Life with an Ankle Wearable Sensor in Ambulant Patients with FSHD

RESULTS

Digital outcome identification

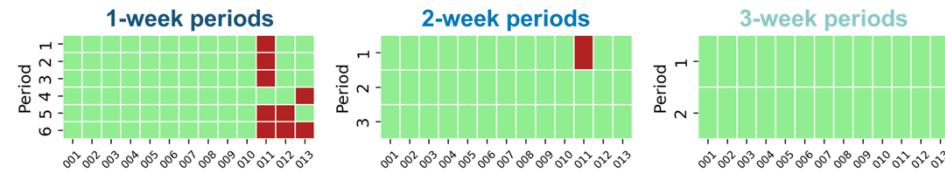
Correlation between SV95C and clinical outcomes.



Impact of recording period duration on data availability and outcome reliability

Individual data availability for different recording period lengths.

Red and green colors figure less and more than 50h of recordings, respectively.

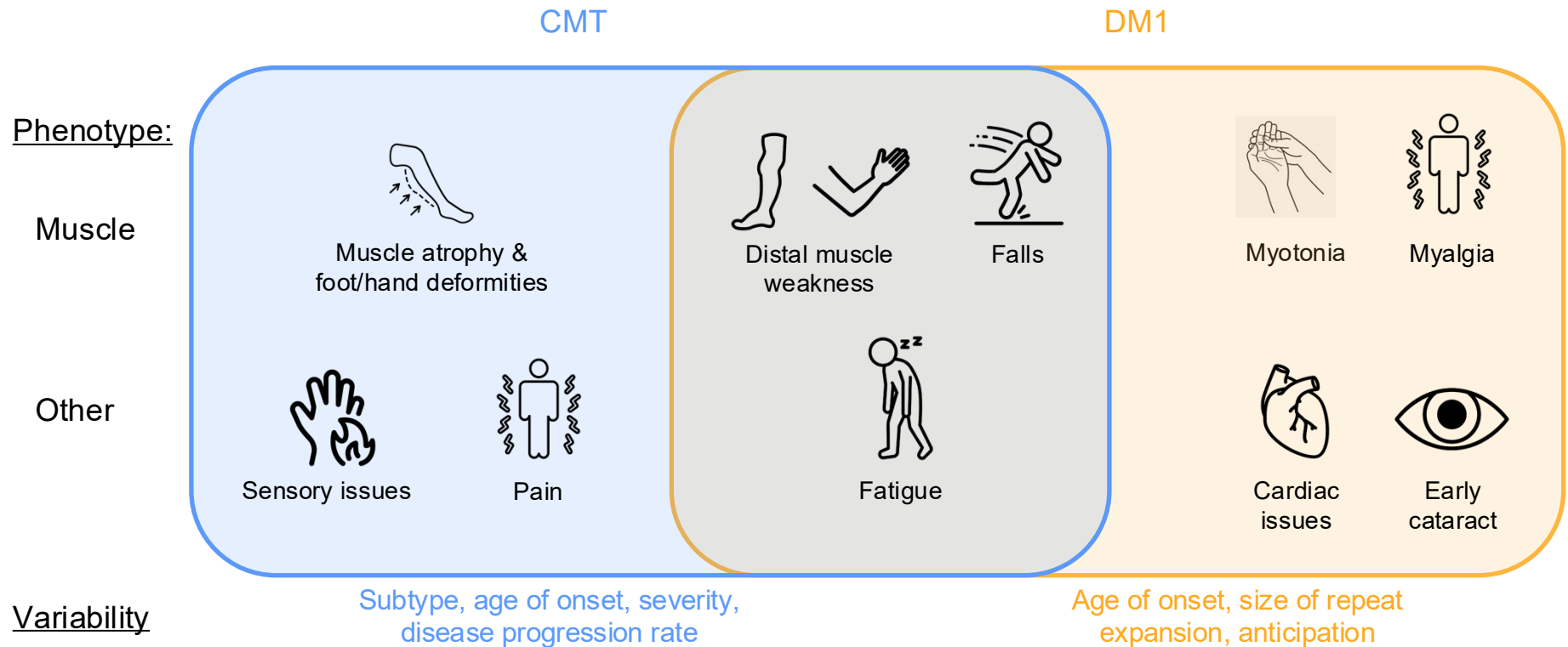


- 88% of patients recorded at least 50h in 1-week periods, 97% in 2-week periods and 100% in 3-week periods .

Intra-class correlation coefficient of peak ambulation speed for different recording period lengths.

	1-week period	2-week period	3-week period
ICC(1,1) [95% CI]	0.971 [0.940 - 0.990]	0.986 [0.967 - 0.995]	0.967 [0.899 - 0.990]
Standard Error Measurement	0.04 m/s	0.03 m/s	0.04 m/s

CMT and DM1 are two diseases with distal weakness

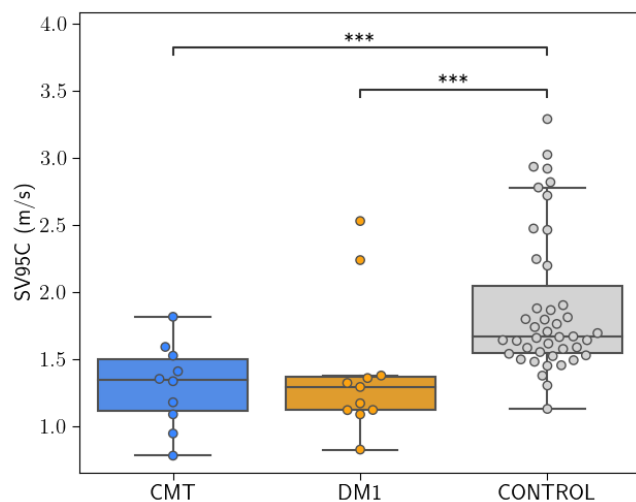


CMT=Charcot-Marie-Tooth disease; DM1=myotonic dystrophy type 1.

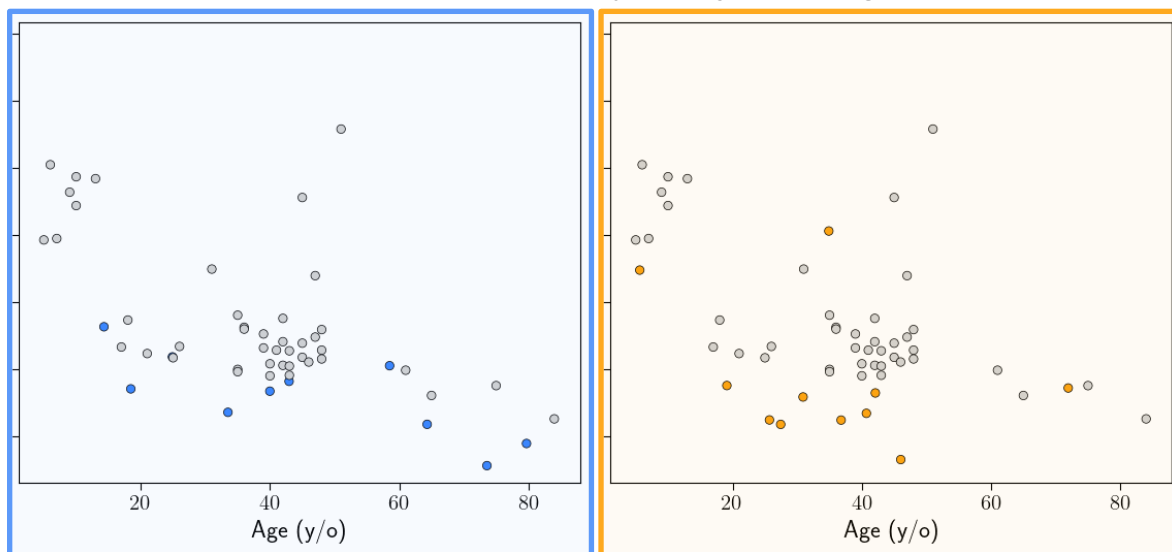


SV95C variable significantly separated patients from controls at all ages

Baseline SV95C by Cohort



Baseline SV95C by Subject's Age



Mann Whitney U test: ns=not significant, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Control

CMT

DM1

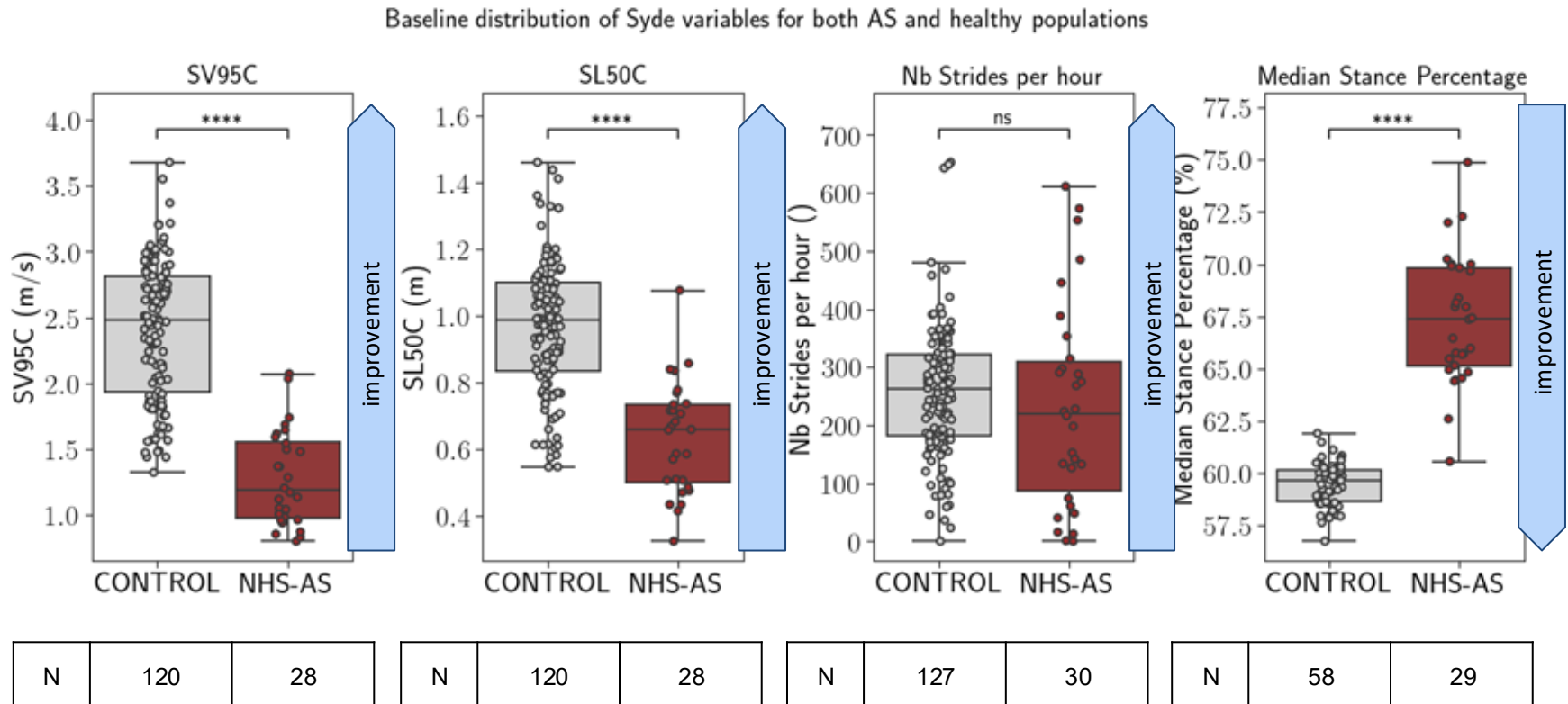
CMT=Charcot-Marie-Tooth disease; DM1=myotonic dystrophy type 1; SV95C=stride velocity 95th centile; y/o=years old.

HOW CAN WE OBJECTIVELY QUANTIFY WALKING IN REAL LIFE FOR ANGELMAN PATIENTS ?





Syde functional variables clearly separate AS population from healthy population, not the activity

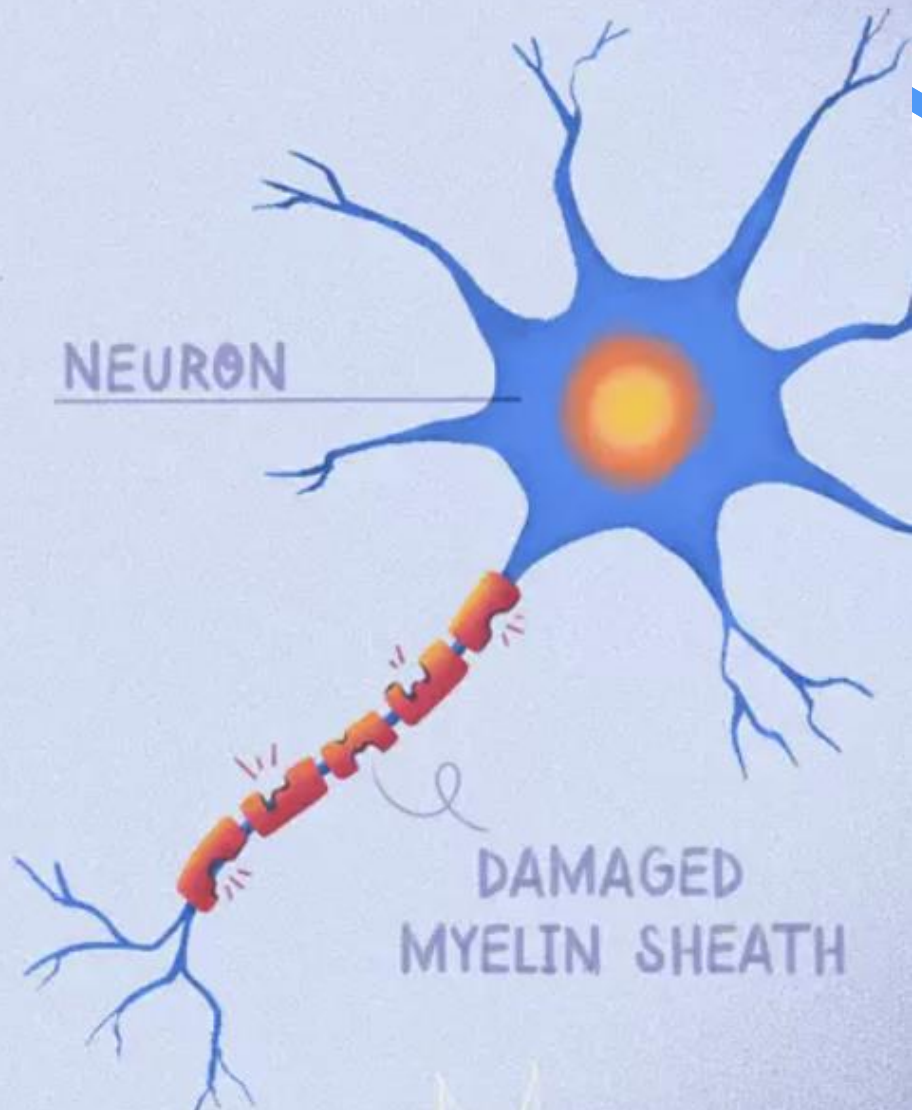


Mann-Whitney U Test p-value: ns: non significant, *:p<0.05, **:p<0.01, ***:p<0.001, ****:p<0.0001

MULTIPLE SCLEROSIS

NEURON

DAMAGED
MYELIN SHEATH





Stride-level measurement of gait as an early sensitive marker of disability progression in ambulatory patients with multiple sclerosis



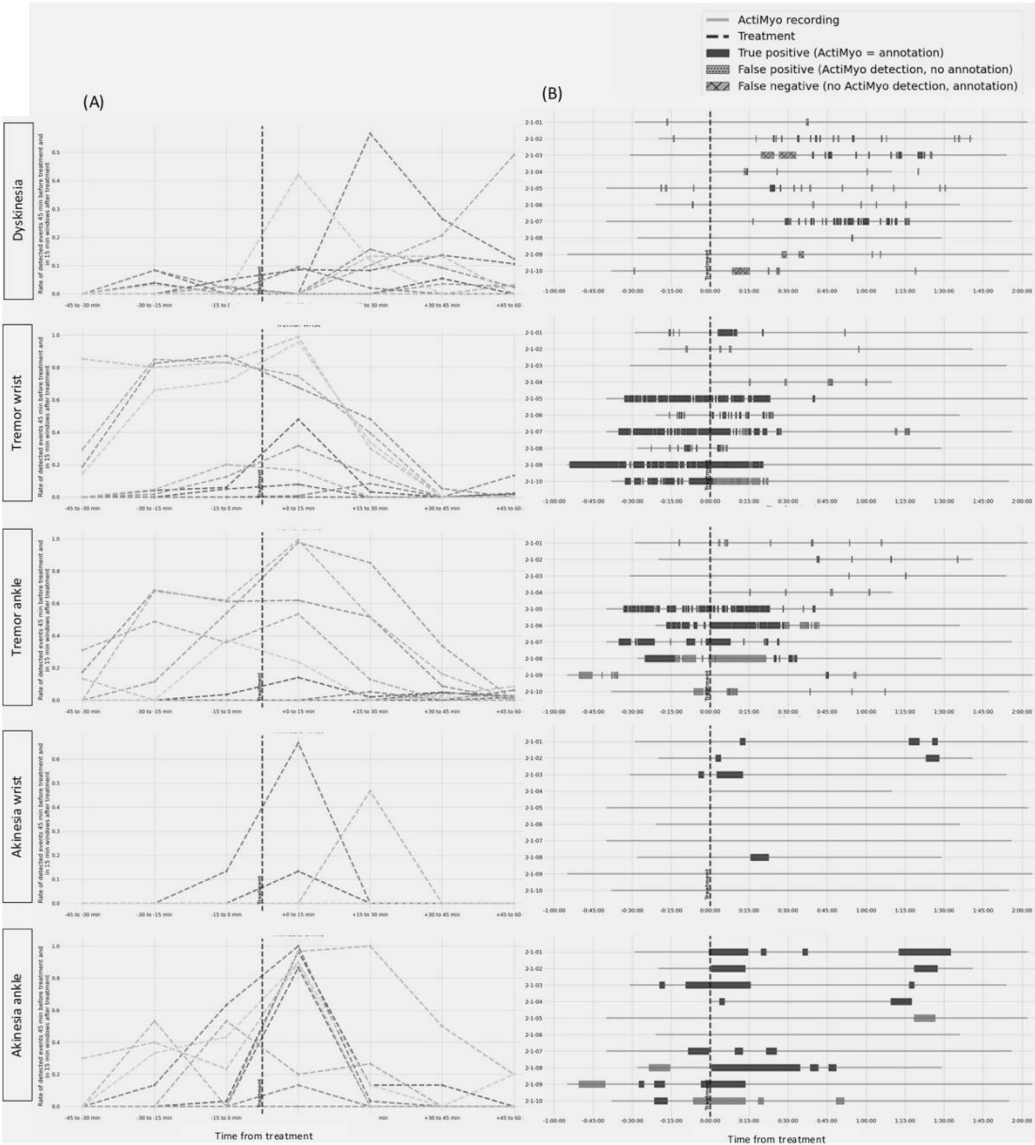
Margaux Poleur,^a Barbara Willekens,^{b,c} Bertrand Degos,^d Damien Ricard,^e Vincent van Pesch,^f Annick Mélin,^g Oihana Piquet,^h Alexis Tricot,^h Laurie Médard,^a Mona Michaud,^h Emilie Lommers,ⁱ Anna-Victoria De Keersmaecker,^{b,c} Irene Coman,^d James Overell,^{j,k} Alexandra Goodyear,^l Paul Delmar,^j Qing Wang,^j Helen Hayward-Koennecke,^j Céline Cluzeau,^h Damien Eggenpieler,^h Paul Strijbos,^j and Laurent Servais^{m,n,*}





OPEN **Wearable inertial device for monitoring Parkinson’s disease symptoms: a pilot study in a controlled environment**

Margaux Poleur^{1,8}, Teresa Gidaro^{2,8}, Stéphanie Delstanche¹, Jean-Marc Gurruchaga³, Alexis Tricot⁴, Léopold Bancel⁴, Stéphane Palfi³, Laurent Servais^{4,5,8} & Bertrand Degos^{6,7,8}



WS95C shows a significant decline at 1 year in both progressive and non progressive patients

Adherence

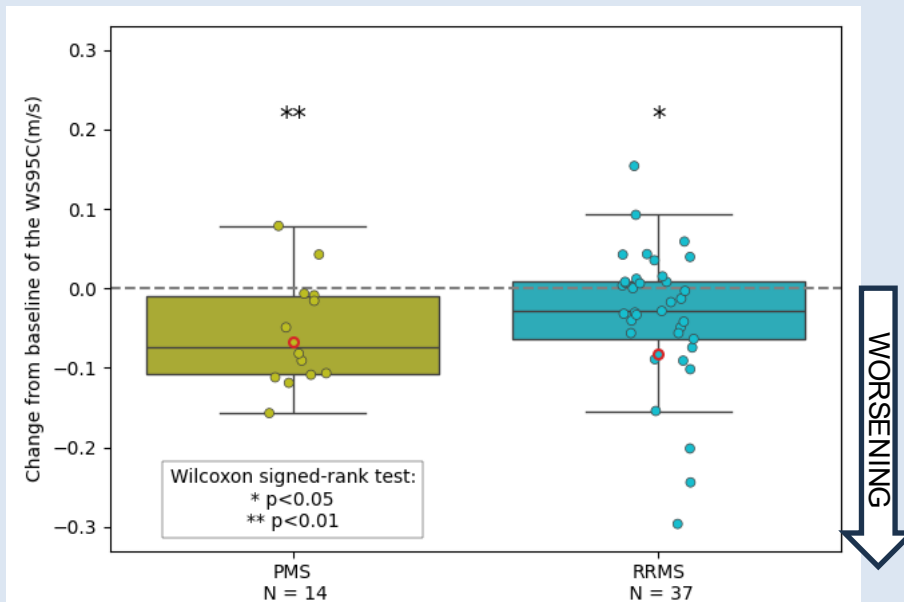
Reliability

Known-group validity

Convergent validity

Ability to detect change

Walking Speed 95th centile



• Participants who experienced relapse(s) between visits

PMS= progressive multiple sclerosis, RRMS= relapsing remitting multiple sclerosis, WS95C= walking speed 95th centile

While EDSS total score detects change only for progressive patients & T25FW does not capture change

Adherence

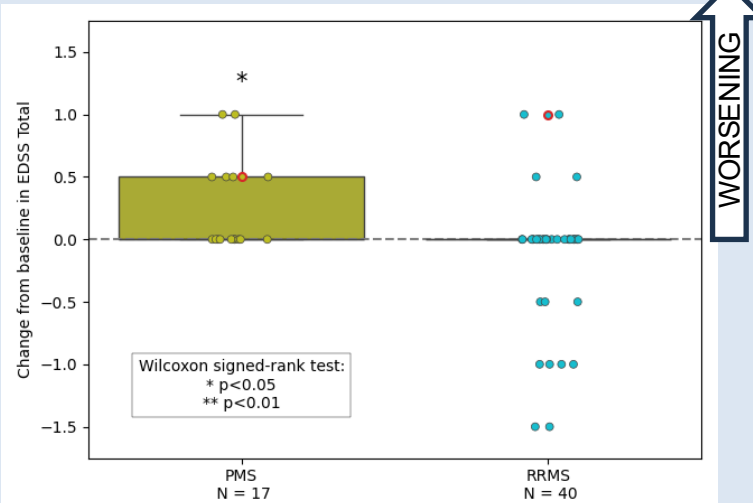
Reliability

Known-group validity

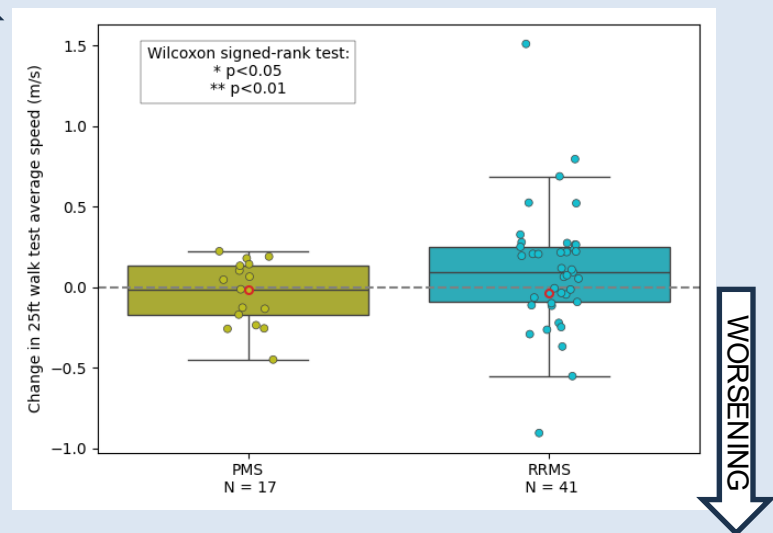
Convergent validity

Ability to detect change

EDSS



T25FW speed



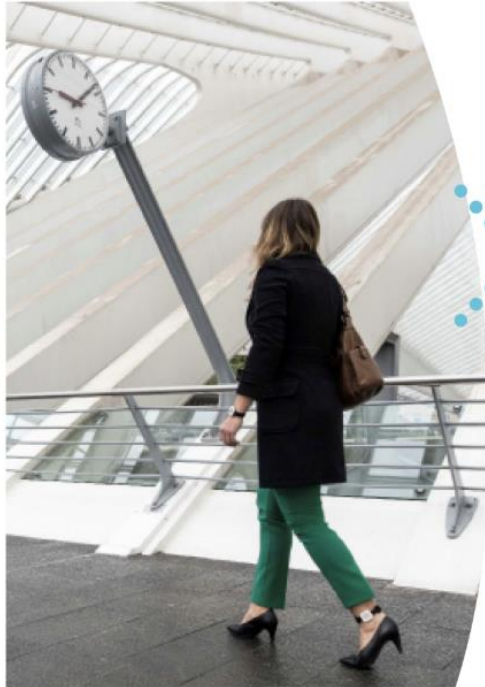
- Participants who experienced relapse(s) between visits

EDSS = Expanded Disability Status Scale, T25FW = Timed 25 Foot Walk (best performance), PMS= progressive multiple sclerosis, RRMS= relapsing remitting multiple sclerosis.

FEASIBILITY, RELIABILITY AND CLINICAL VALIDITY OF STRIDE VELOCITY AS A REAL-LIFE DIGITAL OUTCOME IN KNEE OSTEOARTHRITIS

Camila Gonzalez Barral^{1,2}, Margaux Poleur³, Nicolas Bovy⁴, Georgia Stimpson⁴, Axel Boyer⁵, Frederique Guilbert⁶, Rita Deroisy⁷, Laura Witkam⁶, Damien Eggenspieler², Jean-François Kaux⁷, Laurent Servais^{1,4}

1. Neuromuscular Reference Center, Department of Pediatrics, University and CHU of Liège, Belgium; 2. Sysnav, Vernon, France; 3. University department of neurology, CHR Citadelle, Liège, Belgium; 4. MDUK Oxford Neuromuscular Centre & NIHR Oxford Biomedical Research Centre, University of Oxford, Oxford, UK; 5. Imagerie médicale, CHR Citadelle, Liège, Belgium; 6. Sanofi, Gentilly, France; 7. Department of Physical Medicine & Rehabilitation, University & CHU of Liège, Liège, Belgium



Vous souffrez d'arthrose du genou ?



Vous pouvez aider la recherche à avancer afin de mieux comprendre l'impact de cette maladie sur la mobilité.

Qui ?

Personnes de 40 à 70 ans atteintes d'arthrose du genou.

En quoi consiste l'étude ?

Port de capteurs au poignet et à la cheville pendant 2 mois.
Deux visites à l'hôpital – Aucun traitement, aucun risque.

Intéressé(e) ?

Contactez le Centre de Référence des Maladies Neuromusculaires

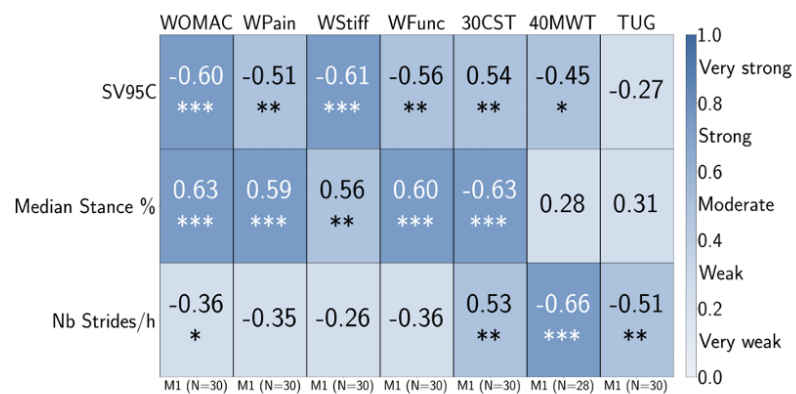
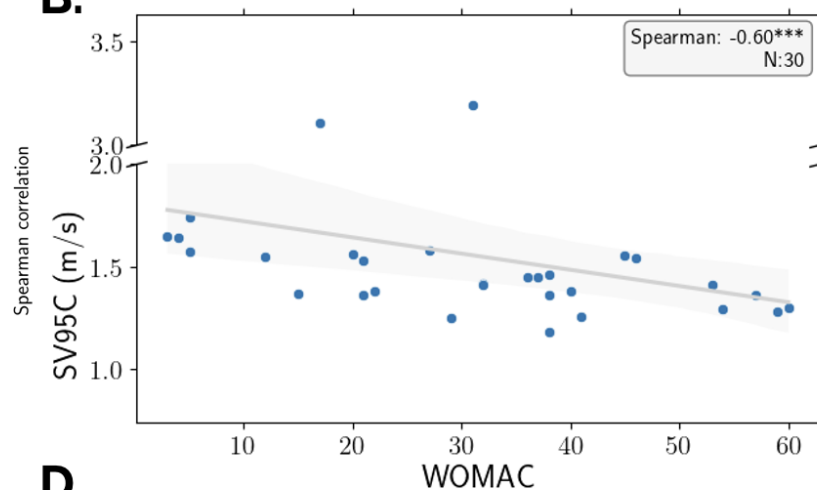
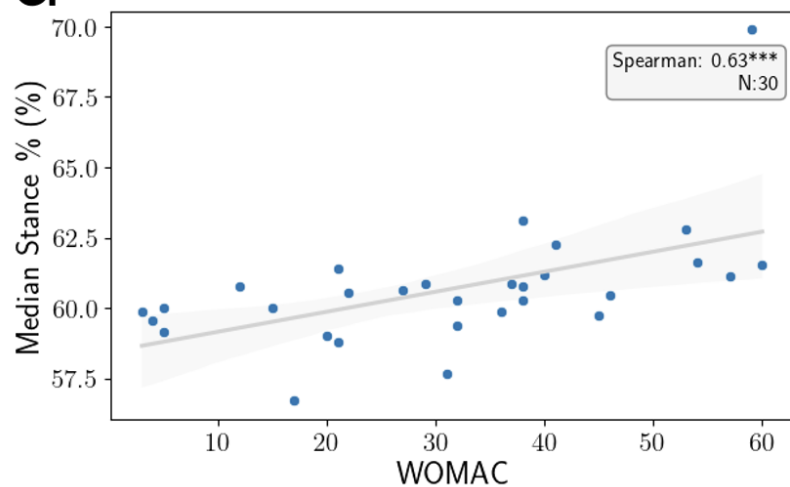
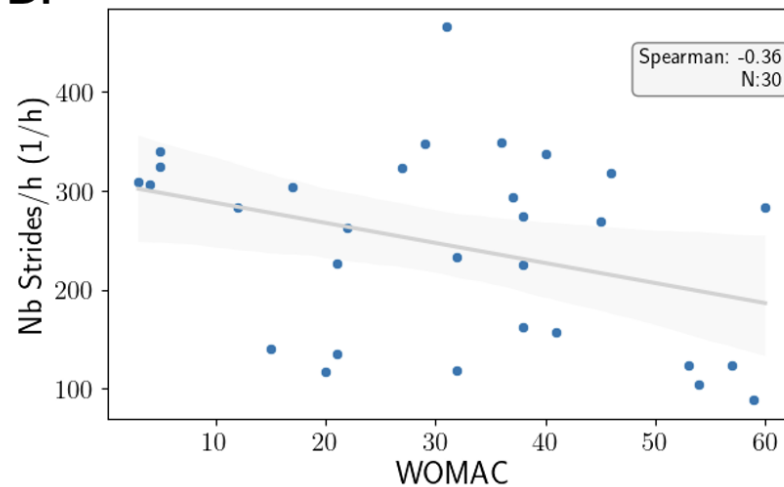
Centre de Référence des Maladies Neuromusculaires:

✉ camila.gonzalezbarral@citadelle.be ☎ +32 (0)4 321 82 22



CHU
de Liège

Citadelle
Hopital

A.**B.****C.****D.**

Take home message

Home-based continuous measure of individual movements

- is applicable to a broad range of conditions**
- allows the evaluation of patients otherwise difficult to evaluate (Angelman, toddlers...)**
- opens the possibility to reduce the number of patients and the duration of trials**
- opens the possibility to individualized monitoring of treatments**
- is not device or algo agnostic.**



The Liege CRMN Team

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Fabian dal Farra

Laurane Mackels

Laurie Medard

Manon Dudos

Laura
Buscemi

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Mélanie
Annoussamy
1974-2023

