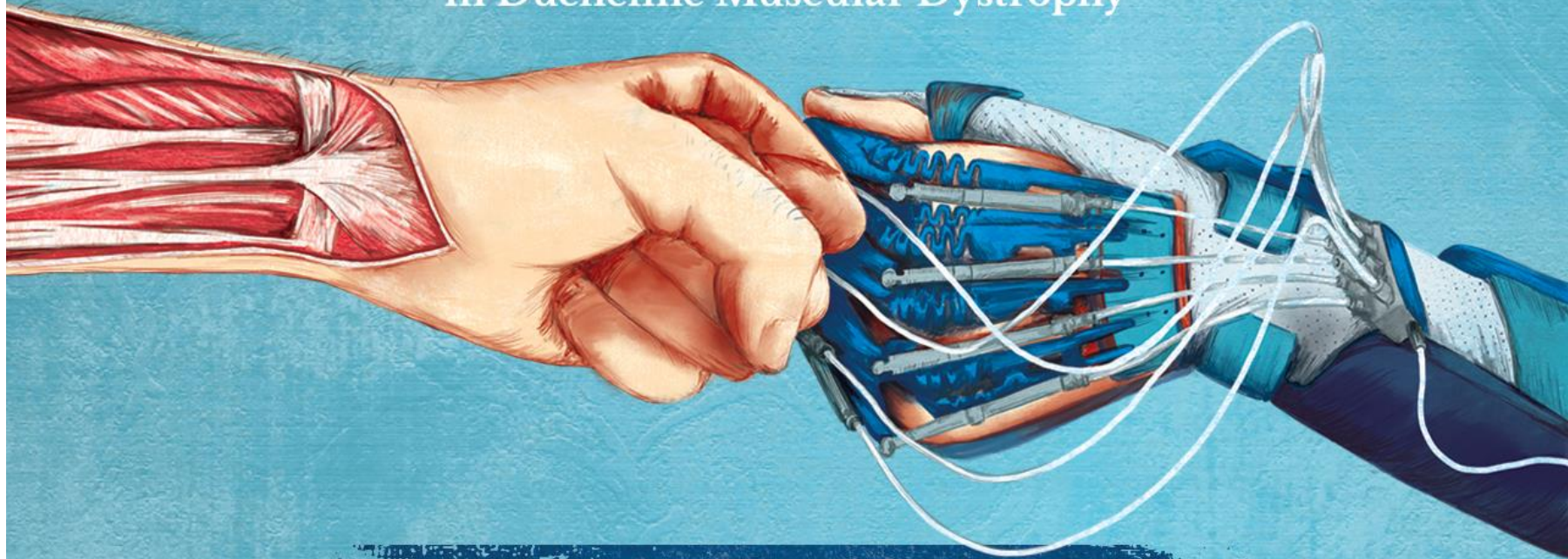


HAND

NEURO-MOTOR CHARACTERIZATION

AND MOTOR INTENTION
DECODING

in Duchenne Muscular Dystrophy



Kostas Nizamis

Duchenne Muscular Dystrophy

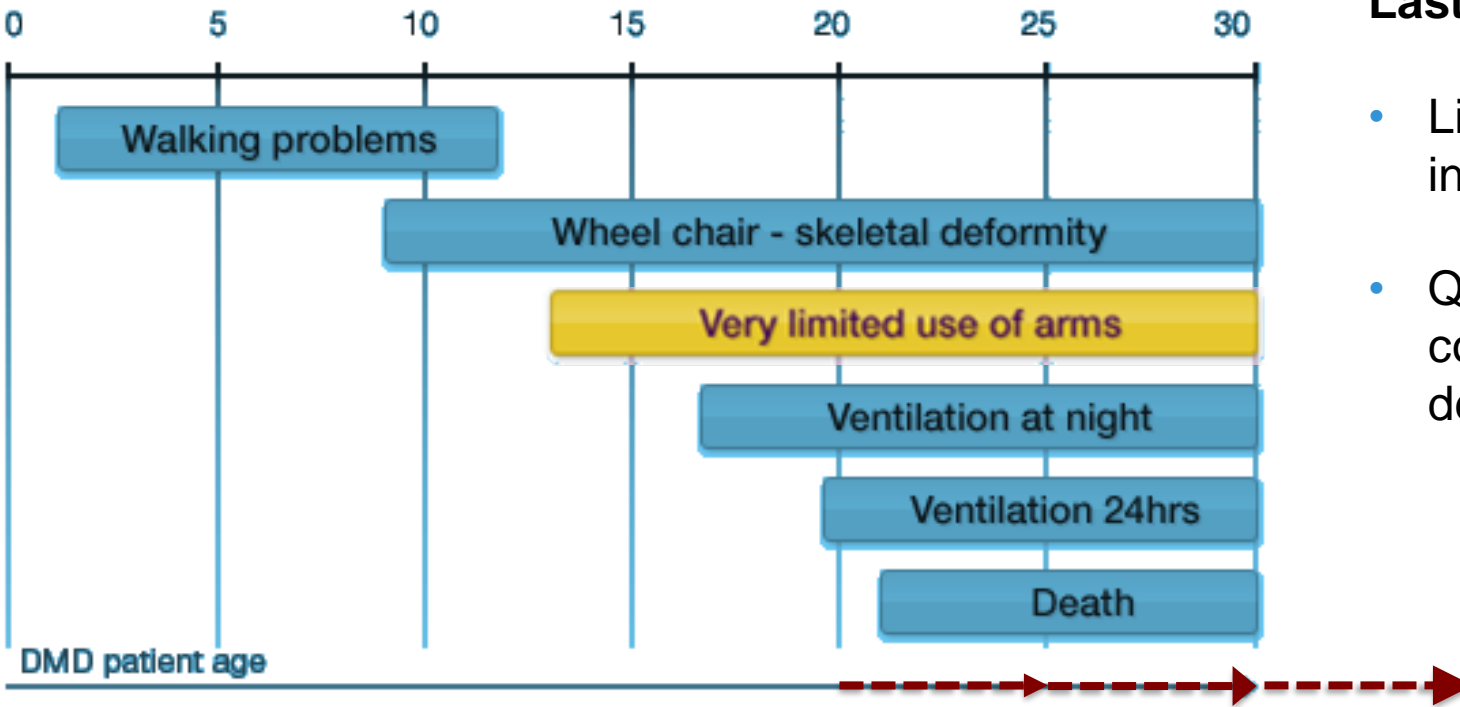


Pathogenesis

- Genetic disease
- Progressive Muscle degeneration
- Incidence 1: 3500 boys

Duchenne Muscular Dystrophy

Progressive Muscle Degeneration:

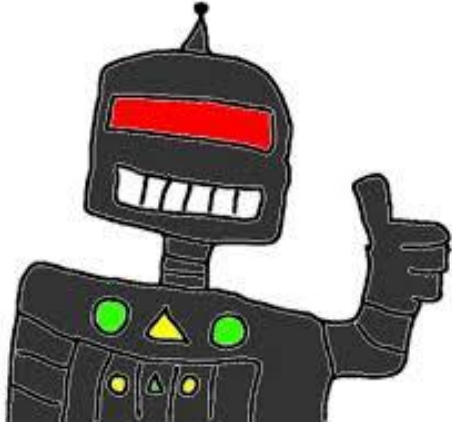
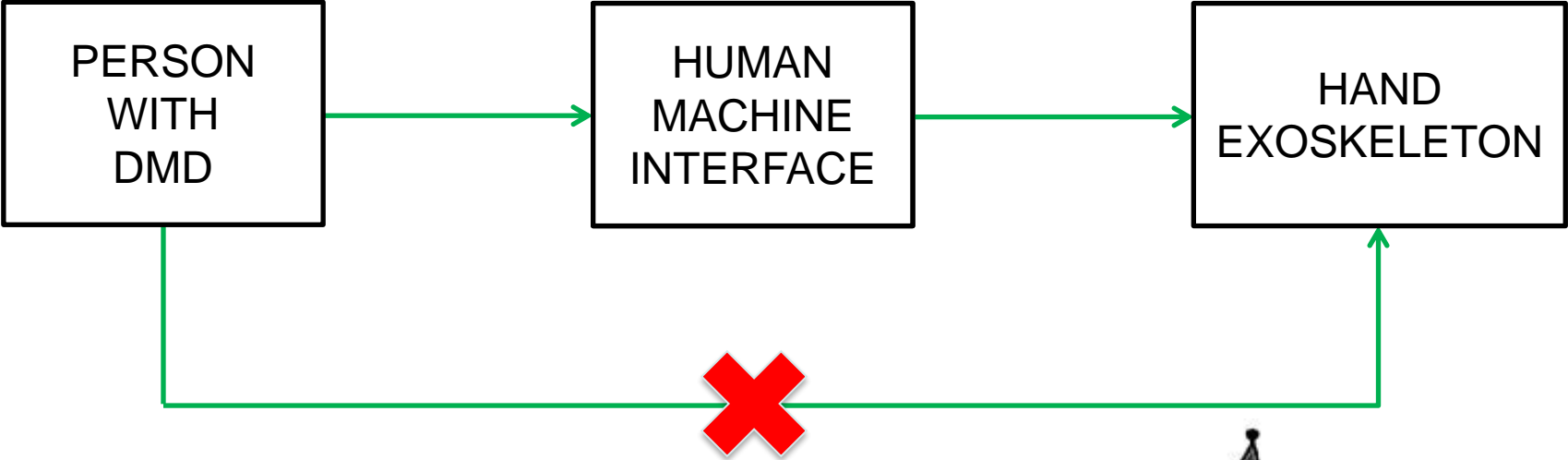


Last 10 years

- Life expectancy increased
- Quality of life continues to decrease

A considerable number of individuals with DMD lives with severe impairments and strong dependency on care

Symbionics 1.3 – Intention Amplifying in Hand Orthosis



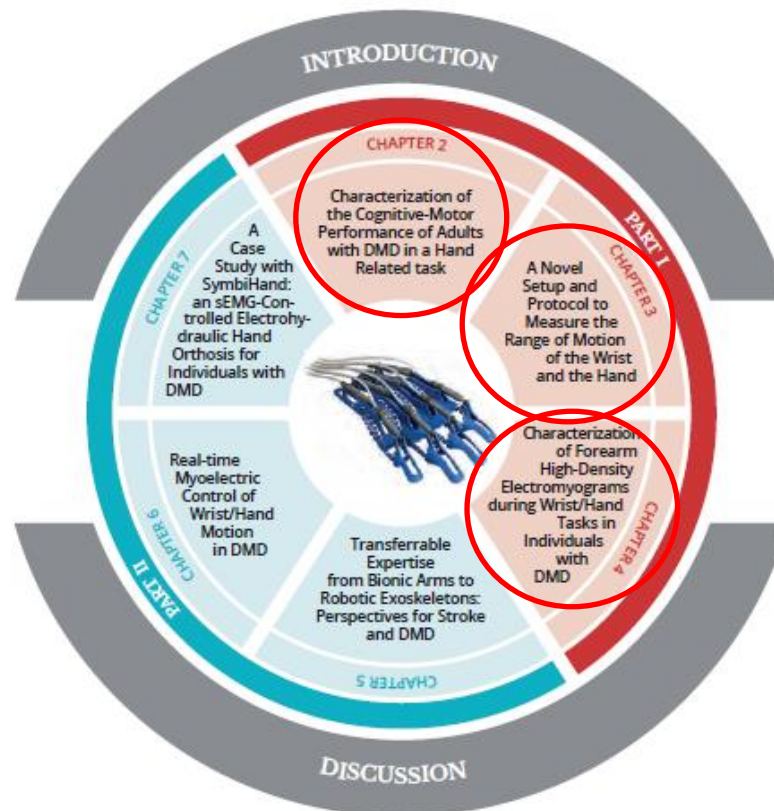
The SymbiHand



PART I

HAND NEURO-MOTOR CHARACTERIZATION IN DUCHENNE MUSCULAR DYSTROPHY

SYSTEM VIEW



PART I

HAND NEURO-MOTOR CHARACTERIZATION IN DUCHENNE MUSCULAR DYSTROPHY

Kostas Nizamis, et al. “Characterization of the Cognitive-Motor Performance of Adults with Duchenne Muscular Dystrophy in a Hand-Related Task”, Plos One

- The data created are shared as a supplement to the paper
- Data include strength, fatigue, age of participants, and condition

Kostas Nizamis et al. “A Novel Setup and Protocol to Measure the Range of Motion of the Wrist and the Hand”, MDPI – Sensors

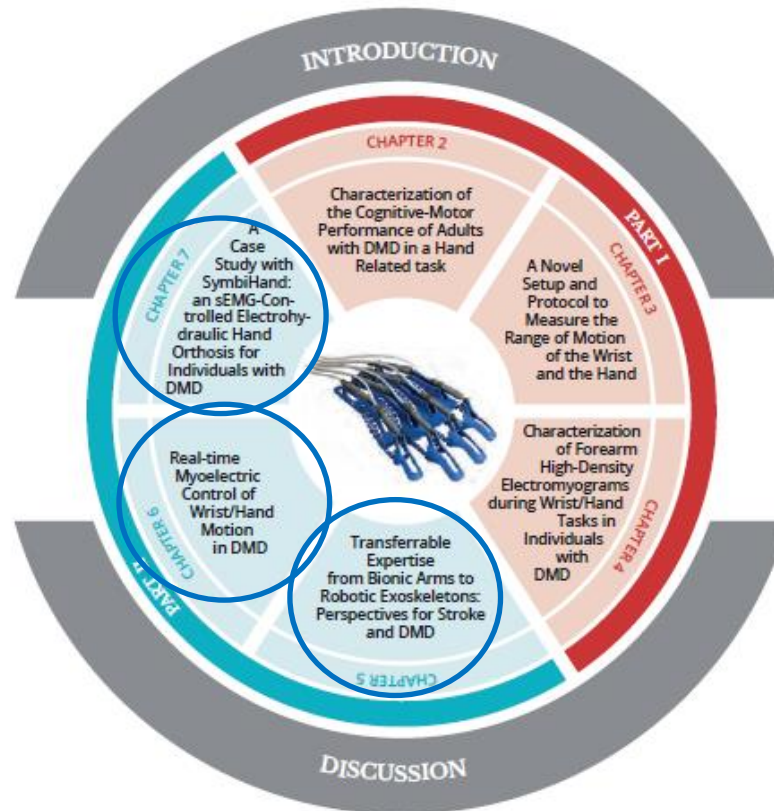
- The data created are shared as a supplement to the paper
- Data include finger position, age of participants, and condition

Kostas Nizamis, et al. “Characterization of Forearm High-Density Electromyograms during Wrist-Hand Tasks in Individuals with Duchenne Muscular Dystrophy” Frontiers in Neurology

- The data created are shared in the 4TU repository
- Data include EMG, arm dimensions, age of participants, and condition

PART II

HAND MOTOR INTENTION DECODING IN DUCHENNE MUSCULAR DYSTROPHY



PART II

HAND MOTOR INTENTION DECODING IN DUCHENNE MUSCULAR DYSTROPHY

Kostas Nizamis et al. “Transferrable Expertise from Bionic Arms to Robotic Exoskeletons: Perspectives for Stroke and Duchenne Muscular Dystrophy”, IEEE Trans. Med. Robot. Bionics

- No data generated

Kostas Nizamis et al. “*Real-Time Myoelectric Control of Wrist/Hand Motion in Duchenne Muscular Dystrophy*”, *Frontiers in AI and Robotics (under review)*

- The data created are shared in Mendeley Data (not yet public)
- Data include EMG, age of participants, and condition

Ronald A. Bos*, Kostas Nizamis* et al. “A Case Study with SymbiHand: an sEMG-Controlled Electrohydraulic Hand Orthosis for Individuals with Duchenne Muscular Dystrophy”, IEEE Trans. Neural Sys. and Rehab Eng.

- The data created are shared in IEEE Dataport
- Data include EMG, fatigue, age of participants, and condition

Incentives

- Sharing data improves the quality of the work, makes it fair and transparent and can result in nice collaborations. High quality work does not fear exposure!
- By sharing data other researchers can reuse it without duplicating efforts and recruiting more human participants. This reduces the time, effort and resources spent by researchers and participants.

Stages of acquiring an METC



IF I FEEL LIKE IM WAITING FOR SOMETHING THAT ISN'T GOING TO HAPPEN.



I can't tell if it's killing me or it's making me stronger.



Relationship between METC writing and actual research



Challenges

- Dissemination and support
- Toolkits for data management
- Data shared in repositories are good, but how do the participants access their data?
- Including data management in Curricula to some extend

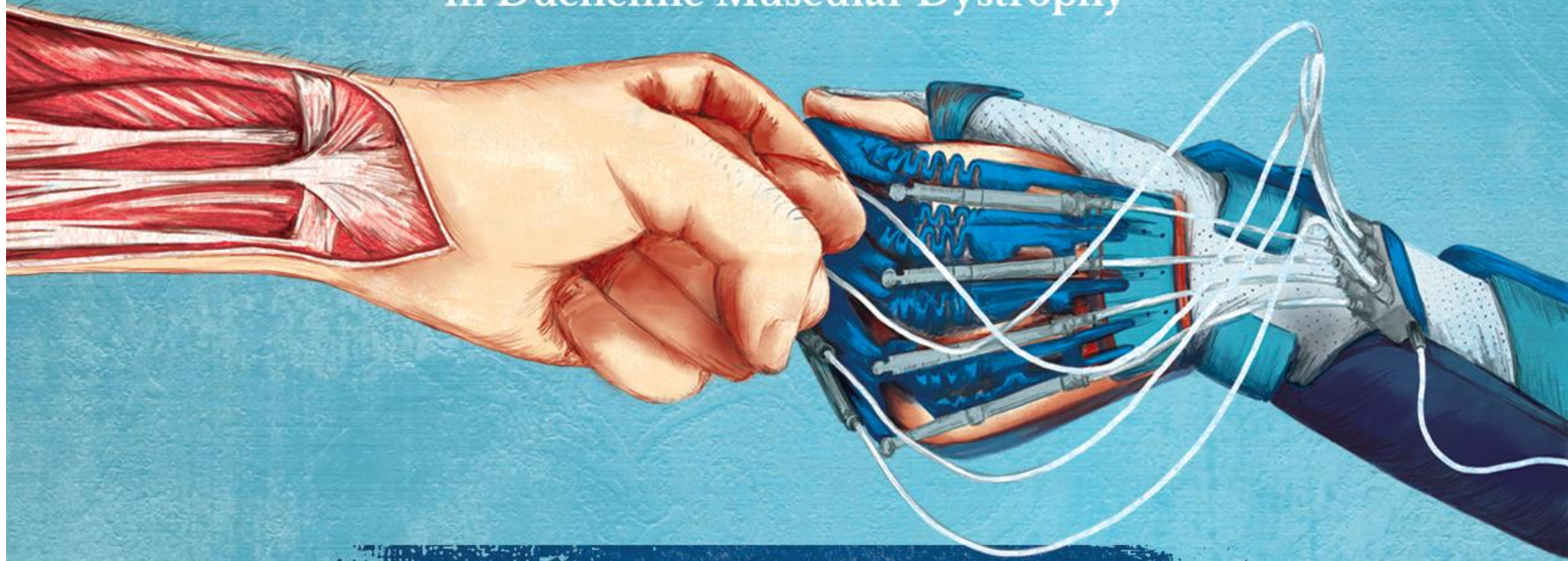
Thank you for your attention!

HAND

NEURO-MOTOR CHARACTERIZATION

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in Duchenne Muscular Dystrophy



Kostas Nizamis