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Workshop report

1st Workshop on Upper-Extremity Assistive Technology for People with Duchenne: State of the art, emerging avenues, and challenges April 27th 2015, London, United Kingdom

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1. Introduction

1.1. Workshop theme and participants

The 1st workshop on Assistive Technology for People with Duchenne Muscular Dystrophy (DMD) was held in London (United Kingdom), on April 27th 2015. The primary goal was to bring people from different disciplines together and discuss opportunities to accelerate the development of upper-extremity assistive technology for enhancing the functional abilities of non-ambulant men with DMD. The topics of the workshop included the state of the art, emerging avenues and challenges of upper-extremity assistive technology. Twenty-four participants representing parents, experts in user requirements, human-machine research, electrical and mechanical engineering, and clinicians involved in the care of children with Duchenne muscular dystrophy from Denmark, the Netherlands, the UK and the USA, participated in the workshop. Key results included the identification of the need for comparative studies based on standard requirements and outcome measures, and the low acceptance rate of commercially available devices. Advanced robotic arm supports are still in experimental phase. Finally, focus groups were initiated on (1) evidence based user requirements and acceptance, (2) assessment protocols, (3) modular technology, and (4) accessibility and reimbursement.

1.2. DMD and assistive technology

DMD is a progressive muscle disorder, characterized by muscle wasting and weakness. The first signs of the disease is ambulatory delay, with 50% of DMD boys starting to walk after 18 months [1]. DMD leads to full time use of a wheelchair in the mid-teens, loss of upper-extremity (UE) function in the late-teens followed by the development of cardiomyopathies and respiratory failure [1,2]. Currently, there is no cure for DMD, and treatment is mainly aimed at delaying disease progression and preserving functional abilities. Due to these new treatments (including nocturnal ventilation), life expectancy in boys with DMD has increased from 14 years of age in the 1960s to 25 years of age in the 1990s [3,4]. Currently, the median survival of boys with DMD is estimated to be over 30 years [5,6] and it is expected that the life expectancy will continue to increase. Because of the prolonged life expectancy, the number of individuals living with DMD is increasing. This group of young men lives with impaired UE function for more than 15 years, which severely limits the performance of basic activities of daily living (like self-feeding and personal care) and restrict social participation. It is generally accepted in the DMD community that early and combined efforts of steroids and bracing to preserve leg strength are rewarded by a longer ambulatory period. There is also evidence that suggests that certain assisted arm training delays the progression of muscle weakness in the arms [7]. The use of assistive devices has the potential to improve the quality of life for people with DMD, by enabling them to continue performing activities of daily living and participate in

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social activities. Between 1936 and 2011 [8], more than 100 UE assistive devices have been developed. Most of them are intended for rehabilitation to regain strength and motor control, and few are designed to assist during activities of daily living. UE assistive devices for daily use are also known as dynamic arm supports. Despite all the developmental efforts, few devices are commercially available. Van der Heide et al. [9] concluded that only a few number of dynamic arm supports that have been developed have also been evaluated. Most of the studies that they found examined the effects of dynamic arm supports on body functions, activities, and participation under laboratory conditions. Although, in general, these studies report positive outcomes, the number of users of dynamic arm supports appears to be low. Researchers have mentioned various possible reasons that could be the cause of the low number of users: preference of compensatory movements over using an assistive device, large dimensions of the devices that stigmatize the user, difficulties in adjusting the device, clinical deterioration and expense. Besides efficacy evaluation under laboratory conditions, a much better understanding of effectiveness of using dynamic arm supports in daily life is needed [9].

2. User requirements

2.1. Patients' perspective

Elizabeth Vroom presented what the highest priorities are for young men with DMD. In order to improve quality of life for those living with Duchenne, independence and participation must be facilitated. For young men, it is important to be able to participate in work and social activities. While privacy is indicated as being important, socialization and employment are priorities as well. In 2007, the Dutch Duchenne Parent Project organized a workshop to determine whether improving arm or leg function should be prioritized. The outcomes of this workshop were that young men considered arm function as the highest priority. The loss of lower extremity function can be compensated fairly well by using a wheelchair, but compensating the loss of arm function is less evident [10]. Although complete loss of arm function arises at the late-teens, it has been shown that performing activities with the arms is already limited in the late ambulatory stage and that participating in school activities is also restricted because of these limitations [10].

When young men with Duchenne were asked what a new drug should gain in terms of daily activities, the responses were related to the activities that can be achieved with the arms: touching the face, self-feed, personal care such as brushing teeth, toileting, use of computer, and the ability to maneuver wheelchair are considered of high value. Individuals with DMD expressed an urgent need for privacy, which becomes impossible as weakness increases. Two user requirements studies have been performed to determine what activities are considered to be most important. Annie Kennedy presented the results from a study performed by the PPMD in the USA. The results from focus groups sessions were combined with an online survey that was distributed in the USA (N = 19), to determine priorities of ambulant and non-ambulant people with DMD. The priority activities for the ambulant group were stand up, pick up objects from the floor and walk upstairs. The priority activities for the non-ambulant group were repositioning at night, bring hands to mouth, shift while seated, using joystick and using the keyboard of a computer.

Imelda de Groot presented the results from a World-wide survey. In this survey, 213 individuals (age ranging from 1.5 to 35.2 years old) with DMD participated, of which 95 were ambulant and 118 non-ambulant. From this survey, it was concluded that the main priority is to eat independently and prepare food. Subsequently, activities that were indicated to be important by the ambulant respondents were getting dressed, reaching objects or lifting objects and writing. Activities that were indicated being important by the non-ambulant respondents were personal hygiene, drinking and using a computer [10].

2.2. Discussion and future actions

- Arm function is highly important. More insight in ADLs that should be supported and what people require from an arm support is needed. Current surveys address what young men value (e.g., use of computer). It is important to reach out more broadly in getting input into device design – it might just be that we are currently sampling a small portion of the population who is willing to test a novel device. It is also important to consider potential users in the full range of the progression, from early through late loss of ambulation.
- Studies on technical requirements are needed (e.g. required movement speed, number of degrees of freedom, range of motion of each joint). While there is a considerable variety of upper-extremity assistive devices, there are few studies that investigate the user requirements. One example is the study by Ramanathan et al. [11], which analyzes the arm trajectories of healthy subjects during ADL to find what are the movements that an arm support device should assist.
- The use of two arms may be preferred over one arm, since a lot of ADL are bimanual tasks. Current devices are essentially for one arm; therefore, bimanual application doubles the price. Insurance companies typically reimburse at most one arm support.
- Patient organizations have a crucial role in putting patients first, encouraging collaborations, recognizing unmet needs, determining which initiative has the highest priority, gaining leverage for research funding, stimulating regulatory approval, improving the access of technology and advocating for the reimbursement of devices.

3. Evaluation of arm function

In order to optimize devices and assess effectiveness of devices, quantitative and objective evaluation methods are needed. Quantitative data comprises kinematic parameters, such as the range of motion of supported arm movements and the muscle effort that is needed to using a particular type of arm support. Individuals with DMD need relatively more effort in all directions in order to perform the same movements as healthy controls. Also, they recruit more muscles simultaneously for all motions. One key question is whether muscle activation requirements or the amount of energy required to perform a specific activity will become lower by using the assistive device.

3.1. Disease progression and training effects

In the same World-wide survey (N = 213) that was presented by Imelda de Groot, changing patterns of arm function during the course of DMD were investigated. The questionnaire included the domains of pain and stiffness in the arms, activity limitations and restrictions in social participation. In general, pain, stiffness, and activity limitations increased with disease stage. The researchers found that activity limitations in the arms already occurred in the early ambulatory stage, and that these limitations affected their social participation. About 70% of the respondents experienced limitations when performing social activities. Only 9% of the respondents on the other hand used supportive aids [10]. Progressive muscle weakness results in reduction of physical activity and disuse of the musculoskeletal and cardiorespiratory systems, because performing activities cost more and more energy [12]. In addition, the use of a motorized wheelchair and a sedentary lifestyle further restricts the arm function, resulting in secondary physical deterioration and disuse. To decrease the deterioration due to disuse, arm training is considered [13]. There is evidence that assisted bicycle-like motion training of the legs and arms is feasible and safe for both ambulant and wheelchair-dependent children [7]. Recently, a training study in DMD was conducted, in which participants received a training program with a dynamic arm support. The training was based on a virtual reality computer game, in which participants had to perform several ADL while using dynamic arm support. Six boys finished the study and in four of these six boys, the trained arm retained more motor function than the untrained arm. These preliminary findings may indicate that boys with DMD can safely train their arms with dynamic arm support [14].

3.2. Range of motion

Jay Han presented part of his work on measuring reaching workspace. In order to quantify the reachable workspace, various methods can be used. One promising method is the Kinect-acquired reachable workspace measure, developed at the University of California. This method comprises a scalable and affordable sensor-based upper extremity reachable workspace assessment system using a Kinect sensor [15,16]. This quantitative reachable workspace outcome measure has demonstrated applicability as a novel surrogate marker of upper extremity function in DMD and Becker Muscular Dystrophy (BMD) [17]. In a series of preliminary studies, the reachable workspace outcome measure has shown its validity, reliability, and sensitivity, as well as clinical-meaningfulness by correlating strongly with person-reported activities of daily living (ADL) function. Additionally, the Kinect-acquired reachable workspace measure demonstrated its utility in both ambulatory and non-ambulatory individuals as well as pediatric and adult populations with DMD/BMD, providing for the first time, a means to follow progression of the disease through important clinically-meaningful functional milestones, such as both the loss of ambulation and ability to self-feed, through the lifespan of an individual with DMD or BMD. The impact of the novel upper extremity assessment tool and outcome measure will be most directly felt in clinical trials where it will facilitate: 1) access to clinical studies for non-ambulatory individuals, 2) reduction of study participant burden, 3) improvement in efficiency through automation, 4) home-based data collection via internet-connected sensor, and 5) better evaluation of efficacy for interventions; all contributing to potentially transform the way clinical trials are conducted in DMD/BMD. However, improved quantitative measurements of upper extremity with its correlative clinical data will also have implications for intervention development in the robotics field. The kinematic and dynamic parameters obtained across a large cohort with a spectrum of disease severity and functional levels can be used to inform design of assistive devices, robots, and exoskeletons. The data will also be informative in general model building as well as refining models of upper extremity function. Identification of individual requirements/needs and functional parameters will contribute to a more 'personalized' and prescriptive robotic system that will be optimized and tailored to individual functional needs.

3.3. Discussion and future actions

- Arm function progression studies: Monitoring the disease progression is needed so that engineers know what level of assistance is needed as a function of time (per day, per year) in arm supports. To this end, modeling may be useful to estimate individual muscle function.
- How much support is needed: A current problem is that the arms are often disused, which results in deterioration of muscle capacity. Once people with DMD lose ambulation, the arm use is reduced. The general consensus was to keep using the arms, but also that overuse should be avoided. There is a need to address upper extremity function, with titrating how much assistance is given. Although it is not scientifically clear when there is overuse, fatigue, pain and no functional return the next day are associated with upper extremity overuse and can be used to help titrate the amount of assistance required.
- There is a need for outcome measures to evaluate arm function in a daily life setting: Currently, insufficient objective data are available to evaluate how much the arms are used/burdened during the day. Also, longitudinal studies are missing.
- Therapeutic effects: Pilot studies suggest that there may be a therapeutic effect when a person regularly uses an arm support. How does this therapeutic effect relate with the quality of life of the users? Is it necessary to prevent overuse of the arms?

4. State of the art and current research

4.1. Commercial arm supports

The first arm supports were developed in the 1960's [8]. While the first designs only supported eating movements, current devices assist a wide range of ADL. Up to date, there is a large number of UE assistive devices that have been developed, but only few are intended for daily use, commercially available and used by people with DMD. Extensive reviews can be found in References [8] and [18]. Dynamic arm supports can be divided into two subcategories [15,16], non-powered (also called passive, or body-powered devices) and powered devices (also known as active or externally-powered devices).

Non-powered arm supports use elastic elements (i.e. springs) to compensate the weight of the arm. Tariq Rahman, Paul Verstegen and Blake Mathie presented the developments of the WREX, the arm supports of Focal Meditech and the X-Ar respectively. The WREX (JAECO Orthopedic, USA) [19] and the TOP (Focal Meditech BV, the Netherlands [20]) arm supports are non-powered arm supports that have been in the market for more than 20 years. The WREX (JAECO Orthopedics, USA) is now available in two versions: the metal version that attaches to the wheelchair or to a table, and a wearable version that combines 3D printed plastic parts and metal parts, known as Baby WREX, for ambulatory children [21]. More recent commercially-available non-powered arm supports include the SLING, the Dowing and the Balancer (Focal Meditech BV, the Netherlands [20]), the VERTICAL M.A.G (Proteor, France), the Nitzbon Mobility Arm (Nitzbon, Germany), the Saebo MAS (Saebo Inc., USA) and the X-Ar (Talem Technologies, USA [22]).

Powered arm supports use motors to change the settings of the gravity compensation mechanism or to move the arm in the vertical or horizontal plane using a joystick or buttons. The TOP arm support can be extended with an actuator, called HELP, to provide active support in the vertical direction to assist persons with more severe muscle weakness. Beside the TOP/HELP, Focal Meditech has developed the active version of the Sling, Darwing and the GoWing. Other powered arm supports include the Armon (Micrograviity Products, NL) [23], the Zonco Mobile Arm Valet (ZoncoArm, USA) [24], the DAS (Exact Dynamics, the Netherlands) [25] and the Neater Arm support (Neater Solutions, UK) [26].

A recent systematic review on the effect, effectiveness and usability of arm supports concluded from the results of 47 evaluation studies that there was an increased ability to perform activities of daily living and user satisfaction when using an arm support, but that the use of dynamic arm supports at home was low [9]. A recent study of a questionnaire-based evaluation of the WREX concluded that the WREX made a significant improvement in arm function for users while performing everyday tasks. Sixty percent of the 55 users included in the study continued to use the WREX at the time of the survey. Sixty-nine percent of wheelchair-mounted WREX users continue to use it, and 48% of body-mounted continue to use it. Reasons for abandonment included weight, interference with other activities, joint contractures, and imprecise gravity compensation. Users showed more improvement of arm function with the wheelchair-mounted WREX than the body-mounted model. Aesthetics, fitting, and reimbursement were identified as areas for improvement [27]. Furthermore, a user evaluation study with the Neater arm support concluded that the use of the Neater arm support by adults and teenagers with neuromuscular disorders could greatly improve their independence, confidence, and ability to engage in social situations [28].

4.2. Current research on arm supports

In addition to currently available devices there are several initiatives that aim to develop solutions that better suit the needs of young men with DMD. Among these initiatives are: the A-Gear project (DPP-Flextension, The Netherlands), the ReachABLE project (New Jersey Institute of Technology, USA) and the Patient@Home project (Aalborg University, Denmark).

Micha Paalman and Joan Lobo-Prat presented the work done in the Flextension A-Gear project. The **Flextension A-Gear project** started in 2011 with the goal of developing an inconspicuous arm support that could adapt to the growing needs of people with DMD. The development towards the ultimate arm support was divided in two separate functional prototypes: the Passive A-Gear and the Active A-Gear, which are directly related to two levels of assistance. The Passive A-Gear is intended for younger individuals that are still able to perform activities of daily living when the weight of the arms is compensated. The Passive A-Gear, in contrast to the existing arm supports, has a mechanical structure that closely follows the biomechanics of the arm and trunk, uses a novel spring configuration to balance the weight of the arm, and has a hip joint incorporated to allow flexion/extension movements of the trunk [29]. When the support provided by the Passive A-Gear becomes insufficient, the Active A-Gear will provide the extra assistance in weaker individuals with DMD using motorized joints. In order to operate active arm supports, the user needs to communicate his motion intention to the device through a control interface. The selection of the control interface in response to specific user needs and capabilities is a crucial determinant of the usability of the arm support. In previous studies, we have shown that the use of electrical activity of arm muscles (known as surface electromyography, sEMG) or the measurement of small forces that are still generated by the muscles, are both suitable signals to derive the motion intention of the adults with DMD with very limited arm function and control active arm supports [30]. When using force-based control it is crucial to accurately distinguish the voluntary forces from the intrinsic forces of the arm such as gravity, inertia or stiffness forces. Especially for persons with a severe muscle weakness, the intrinsic forces of the arm have to be compensated. An alternative method is EMG-based control. Although the use of muscle activity is less intuitive, the EMG signals are not affected by the intrinsic properties of the arm such as stiffness, and therefore directly represent the motion intention of the user. On the other hand, disadvantages of EMG-based control include the poor long-term signal. In Reference [30] we found that while movements with the force-based control were smoother and faster, EMG based-control was perceived as less fatiguing.

Madeline Corrigan gave an overview of the **Reach*ABLE* project**, which is carried out by the New Jersey Institute of Technology (NJIT). This project aims at developing a wheelchair mountable admittance controlled arm support to increase independence for activities of daily living for individuals with DMD. A proof-of-concept prototype has been developed to demonstrate the feasibility of implementing force-based control with motorized antigravity assistance to provided intuitive, compliant, and inherently safe user control [31]. Force-based admittance control allows the minimization of the friction and inertia that opposes the user's movements, which decreases the overall force required to control the device. Admittance control allows the intuitive use of residual muscle strength to operate the device. The use of residual muscle strength has the potential to reduce disuse atrophy and the development of contractures. Because admittance control involves modeling the device as a small point mass, the device can be tailored to the functional status of each individual. The mass can be decreased as the strength of the user decreases over time to continue to allow control of the device despite the change in muscle capacity. Conversely, the mass can be marginally increased, as needed, to promote use of the muscle strength that remains in order to promote use of residual strength that can potentially reduce disuse atrophy [31].

Musculoskeletal models have been widely used to investigate the upper-extremity biomechanics. Musculoskeletal models can be implemented to objectively analyze the interaction between the user and the arm support. The manufacturing of an upper-extremity assistive device is an expensive process and patient-specific musculoskeletal models hold a large potential for design optimization of such devices. By co-simulating musculoskeletal model and orthosis dynamics, the properties of the orthosis can be adjusted to obtain an optimal design to augment the residual capabilities of a specific patient. However, to achieve this, a patient-specific model that takes into account the properties of the musculoskeletal system, including the pathology, must be developed and validated. Miguel Nobre Castro presented part of his work in which he modeled the upper-extremity of a patient with idealized brachial plexus injuries (BPI), from which paralyzed/atrophied muscles were known. This model contains 10 joints and 134 muscle-tendon units and by using inverse dynamic analysis, internal forces (muscles and joint reactions) were estimated [32]. The co-simulation of the patient model with a passive orthosis model was performed, taking advantage of patient's residual muscles function during a 'pick a cup and drink' task. This study suggested that a BPI patient with an idealized C7 nerve root lesion could be assisted by an orthosis whose set of springs' stiffness was optimized. Design optimization promotes experimentation and design maturation before the manufacturing stage as long as the subject and orthosis models are accurate. Clinical validation of these prototypes is mandatory to assess the function of the orthosis under operating conditions.

4.3. Discussion and future actions

- The adoption rate of commercially available arm supports is low: There are several potential reasons that limit the user's acceptance of arm supports: current devices have large dimensions, which compromises their attractiveness and they do not provide enough support for the weaker users. It is important to determine the variables behind the adoption or rejection of arm supports and how to weigh those variables in the design and deployment process. There is a need of studies that investigate which user requirements are not met. There is also a need to incentivize the use of arm supports to preserve arm function.
- **There is a need for evaluation of current arm supports.** There are several arm supports on the market and it is not clear what are the capabilities and limitations of each of them. A quantitative and objective evaluation of the performance of each arm support and their working principles could result in a set of guidelines for choosing which arm support is the most suitable for a specific user.
- **It is not clear whether users prefer wearable devices or devices that require wheelchair attachment:** Both wearable and wheelchair based devices present advantages and limitations. Most of the commercially available devices are wheelchair bound and new developments are focusing on wearable arm supports.
- **A clear image of certification and reimbursement in various countries is needed**: To get devices reimbursed, cost-benefit studies are needed. Although it is difficult, quality of life and costs need to be justified. Such cost-benefit studies are needed from both the individual using the device and their caregiver. One of the challenges is to progress from anecdotal feedback to reliable statistics.

5. Emerging avenues

5.1. Soft robotics

Conor Walsh presented his vision on the next generation wearable robots, in which he foresees use of soft materials such as textiles and elastomers to provide a more conformal, unobtrusive and compliant means to interface to the human body [33–36]. These robots will augment the capabilities of healthy individuals (e.g. improved walking efficiency, increased grip strength) in addition to assisting patients who suffer from physical or neurological disorders. Various projects focus on the design, fabrication and control principles that are required to realize these systems. An example is a soft exosuit that can apply assistive joint torques to restore mobility of those with physical disability [33,34]. Advantages of this suit over traditional exoskeletons are that the wearer's joints are unconstrained by external rigid structures, and that the worn part of the suit is light, which minimizes the suit's unintentional interference with the body's natural biomechanics. It has been demonstrated that healthy subjects required 7% less muscle activation when they used the exosuit. A second example is the development of a soft robotic glove for hand rehabilitation that consists of a wearable textile with attached elastomeric fluid-powered actuators specially designed to match the natural movements of the fingers and thumb [35,36]. A similar glove is also being tested at usability in persons with muscular dystrophies. Part of the technology is open source available via a Soft Robotics Toolkit.

5.2. Shell-based mechanisms

Just Herder shared his vision on the possibilities of compliant shell-based mechanisms (or shell mechanisms for short), a class of mechanism between conventional linkage based exo-robotic systems and soft robotics, in body support devices. Shell mechanisms is the extension of the idea of statically balanced compliant mechanisms [37–39] into the third dimension in the form of spatially curved shells that are to be designed for specified stiffness. This technology bears the promise of true exoskeletons that could be wearable underneath regular clothing. This means that the functionality of exo-robotic systems, which tend to be bulky and stigmatizing, needs to be fitted into a design space of around 10 mm around the body contour. Statically balanced shell mechanisms are excellent candidates for achieving this challenging goal. Herder and his team is currently working in this direction by developing dimensional optimization methods based on isogeometric analysis, and semi-automated graphical synthesis methods. The initial results are promising although there are still challenges to be overcome. Future developments include extension of shell-mechanisms to distributed mechatronic systems where motion, actuation and sensing are distributed over the surface of the shells.

5.3. Control modalities

Aldo Faisal gave an overview of the possibilities of eyetracking as control modality for assistive devices. He explained that the pursuit of an effective brain machine interface holds the hope to enable patients with severe motor disorders to interact with their surroundings. Different approaches can be categorized as non-invasive cortical interfaces (e.g. EEG), invasive cortical interfaces, e.g. implanted multi-electrode arrays (MEA), or non-invasive and non-cortical interfaces (e.g. EMG). The clinical aim, however, remains the same: to extract an intention signal from a patient, for which conventional approaches such as joystick, mouse movement or sip and puff control are not possible. Present 'assistive technology' interfaces can serve most of its possible users. Operating, however, is still as slow as 10–15 years ago (e.g. abundant use of scan systems that almost always solve the problem, but inhibit speedy task performance), not intuitive or too complex. The use of a combination of intention signals for example eye movements and muscle activity has the potential to realize fast and easy to learn control interfaces with a very little latency. Based on the idea 'Seeing is moving', Faisal and his collaborators applied an eye-tracking based control interface into the control of a wheelchair. In the European project ENHANCE, similar approaches are used to develop control interfaces for active arm and hand support devices.

5.4. Trunk, head and hand support

Bart Koopman and Arno Stienen presented some of the latest developments in trunk, head and hand support devices. Persons with DMD often have instability of the trunk and head leading to balance problems while sitting. Scoliosis is often present and negatively affects trunk posture. Control of trunk posture is not only essential for respiration and to avoid swallowing problems, but also for optimal function of the arm and for positioning of the head to make visual control of the arms possible. Arm support enables persons with DMD to continue use of the arms and hand by being able to position the hand in a larger area around the body. However, bringing the arm further away from the body destabilizes trunk posture, which limits use of the arm support. Given these problems, stabilization of the trunk is often necessary. However, stabilization currently involves restriction of the degrees of freedom of the trunk and hence arm/hand function. In addition, current trunk stabilizing braces and supportive devices are often uncomfortable, cause pain and induce respiratory problems, feeding problems, and potentially pressure sores. New solutions are required that stabilize trunk and head postures while allowing the user to choose postures that support optimal performance of hand/arm activities. It is crucial that the assistance provided by devices is adapted to actual needs of those with Duchenne. Too much help may have the price of adding to muscle loss, so help has to be titrated carefully. Beside the importance of adaptive trunk and head support, adaptive support of hand function may be essential for persons with DMD in late non-ambulatory state.

In order to realize such adaptive supports, control of the device and minimal dimensions are important factors. A good understanding of the progression of the weakness in different muscle groups is needed to build better devices. Biomechanical models may also be useful. It is however difficult to develop a kinematic model, so it is important to collect lots of date which is made available for the community.

5.5. Discussion and future actions

- Are the expectations from robotic solutions realistic?: While emerging technologies are very attractive from a technical point of view, it is important to keep in mind that there is a need for functional, robust and affordable assistive devices. The high rate at which these emerging technologies are advancing is a clear indication that there is global interest in developing better assistive devices that can improve the quality of life of people with DMD.
- Share best practices, and things that did not work: A mailing list involving the workshop participants and others interested, that is updated (with a résumé) regularly, including new publications and products.

6. Conclusion

At the end of the workshop, John Porter and Just Herder gave a summary of the workshop's contents and chaired the discussion between the workshop's participants. The workshop addressed the user requirements, the current methods for the evaluation of arm function, the commercially available arm supports, the current research projects towards active arm supports, and emerging technologies that could be useful for the future development of assistive technology for people with DMD. Based on these discussions, six clusters of action points were identified. These are (a) identifying user and caregiver needs and acceptance, (b) assess performance of user and caregiver before and after fitting of a device, (c) develop lab and ambulant testing metrics and protocols, (d) gather data on use of device, (e) develop modular technology and (f) work on accessibility and reimbursement in different countries. These action points were distributed over four focus groups, namely on (1) evidence based user requirements and acceptance, (2) assessment protocols, (3) modular technology, and (4) accessibility and reimbursement. The ambition of these groups is to accelerate progress in these focus areas by coordinating cross-border research and development efforts and identify opportunities for governmental and industrial funding.

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