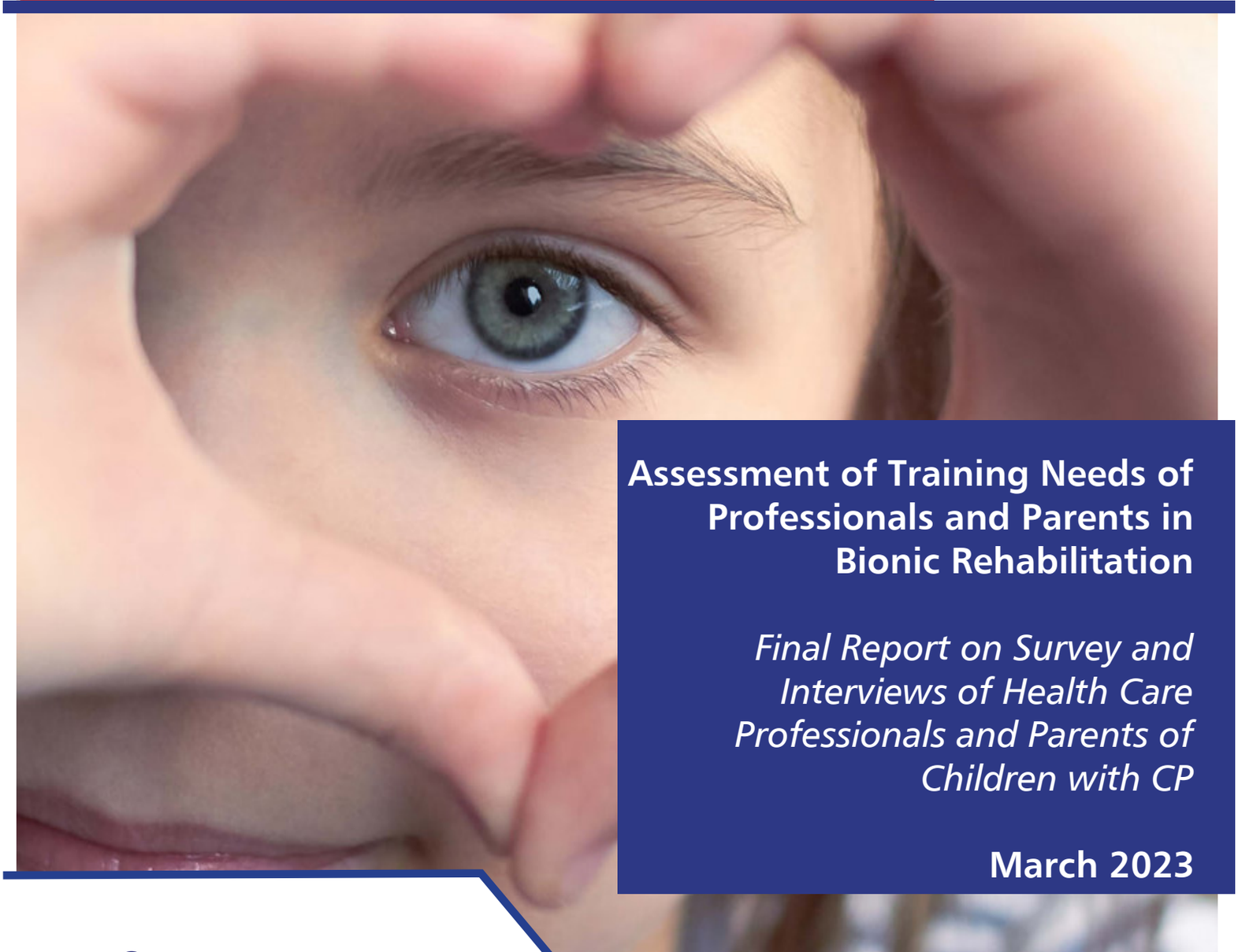
M.O.T.I.O.N.

Mechanised Orthosis for Children with Neurological Disorders



Assessment of Training Needs of Professionals and Parents in Bionic Rehabilitation

Final Report on Survey and Interviews of Health Care Professionals and Parents of Children with CP

March 2023

Canterbury Christ Church University

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Mechanised Orthosis for children with neurological disorders

FOREWARD

The Canterbury Christ Church University (CCCU) Team led the Assessment of Training Needs of Professionals and Parents in Bionic Rehabilitation (WP 3.2.1), an integral part of the Mechanised Orthosis for Children with Neurological Disorders (M.O.T.I.O.N.) project. This report presents the survey findings of the study which was conducted in 2020-2022 for this deliverable, across the UK, France, Belgium and the Netherlands, by M.O.T.I.ON partners. Results from the surveys informed the development of training for health care professionals and parents on the use of robotic rehabilitation technology in practice.

The report is divided in two sections. Section 1 contains presentation of findings from the survey conducted with healthcare professionals and Section 2 presents the findings from the survey and telephone interviews with parents of children with CP.

We would like to acknowledge CCCU team members for their valuable contribution to this work: Dr Damian Coleman, Dr Mathew Brown, and Markus Hunt, School of Psychology and Life Sciences; Dr Raymond Smith, Andy Buttery, and Prof Debra Towse, Faculty of Medicine, Health and Social Care; Maggie Gurr, Private Physiotherapist and CCCU Disability Officer.

Activities of this report took place in cross-border collaboration with project partners from all countries (UK, France, Belgium and Netherlands) and stakeholders from relevant internal and external organisations. We would like to acknowledge M.O.T.I.O.N. partners who have contributed to the development and conduct of the surveys in all project sites:

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EXECUTIVE SUMMARY

Designing high quality training around new assistive technology is a vital part of its development. Understanding contextual, personal, social and service level factors and developing comprehensive, relevant and accessible education, training and ongoing support are critical to the successful adoption of Robotic Assistive Technology (RAT) devices.

Online surveys and telephone interviews were conducted with healthcare professionals and parents of children with cerebral palsy to understand their knowledge, experience, attitudes, and training needs on Robotic Assistive Technology (RAT), with particular reference to Lower Limb RAT for use with adults and children. Key findings for both groups and below are highlighted below.

For Healthcare Professionals:

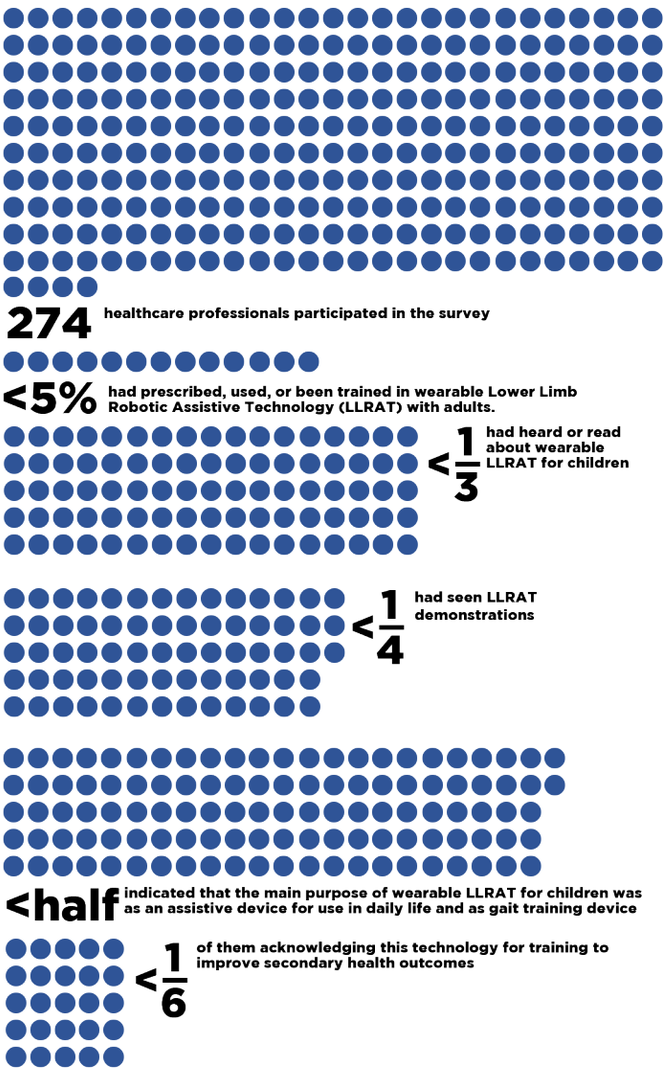
- 274 healthcare professionals participated in an online survey of training needs assessment in bionic rehabilitation across four coutries: UK, France, Netherlands and Belgium. Most of the them were physiotherapists or physical therapists. They were mainly working in community-based services or acute/hospital-based services and tended to be highly experienced with most having been practicing 11-13 years+.
- Less than 5% of the survey respondents had prescribed, used, or been trained in wearable Lower Limb Robotic Assistive Technology (LLRAT) with adults.
- Almost a third of the respondents had heard or read about wearable LLRAT for children however, less than a fourth had seen LLRAT demonstrations and even fewer respondents had prescribed, used or been trained in the use of wearable LLRAT with children.
- Almost half of healthcare professionals indicated that the main purpose of wearable LLRAT for children was as an assistive device for use in daily life and as gait training device, with less than a sixth of them acknowledging this technology for training to improve secondary health outcomes.
- Levels of confidence in the ability to use wearable Lower Limb RAT varied across countries however few respondents in any country (<3 respondents) said they were ‘very confident’.
- Respondents agreed with a wide range of potential benefits for children from the use of wearable LLRAT. Gait training, joint mobility, extension of independent walking, independence and participation in activities and quality of life and self-esteem were the most important benefits recognised by survey participants.
- Most survey respondents in all countries wanted to know more about wearable Lower Limb Robotic Assistive Technology.
- Most respondents in all four countries identified lack of funding for training and costs of the technology as potential barriers to training professionals.
- Information on safety issues, contraindications of use, adjustment of devices to individual needs and information about how LLRAT works are the key areas that most respondents, across all four countries, see as essential to include in training.
- A mix of online and face-to-face training was the preferred approach to LLRAT training by the majority of respondents.

For Parents of Children with Cerebral Palsy:

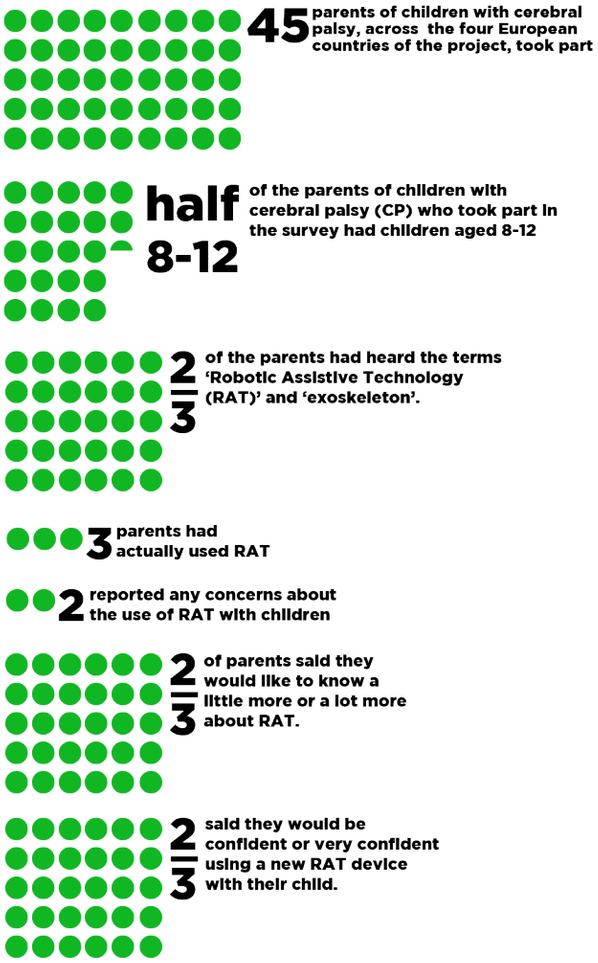
- 45 parents of children with cerebral palsy, across the four European countries of the project, took part in a survey of knowledge, experience and training needs in Lower Limb Robotic Assistive Technology.
- Half of the parents who took part in the survey had children aged 8-12, which was the target age group for the trials of the MOTION wearable LLRAT devices that were developed during the project.
- Half of the respondents were looking after children with CP could not walk independently. Cerebral palsy was reported to affect their children’s lives in terms of eating and nutrition, vision, cognition and behaviour problems. Almost all children were receiving some form of rehabilitation therapy, mostly physiotherapy alone or in combination with other therapies, and half of them were receiving therapy twice or more frequently per week.

- Almost two thirds of the parents had heard the terms 'Robotic Assistive Technology (RAT)' and 'exoskeleton'. Most had also heard of, read about or seen/seen a demo of RAT. However, only three parents had actually used RAT.
- Only two parents from any country reported any concerns about the use of RAT with children. These concerns were related to the weight and attachment of the devices and what precautions were in place to manage breakages/ errors.
- Two thirds of parents said they would like to know a little more or a lot more about RAT.
- Two thirds of parents said they would be confident or very confident using a new RAT device with their child.
- The top scoring topics for parents' training were: benefits of using wearable LLRAT, how it works and how to use it effectively; and where to find ongoing training and support.
- Parents' preferences for the format of training were mainly in-person, either one-to-one or in groups and, on average, half of them indicated that they would prefer online training.

Healthcare Professionals



Parents



Key Key Survey Findings across all project countries

1. ONLINE SURVEY OF HEALTH CARE PROFESSIONALS

1.1. Aim of the study

The aim of the study was to understand the experience, knowledge and training needs of health care professionals in wearable, Lower Limb, Robotic Assistive Technology (LLRAT) for children.

1.2. Methodology

A survey methodology was adopted to address the study aim, using a self-completed online questionnaire to assess knowledge, experience, attitudes and training needs of healthcare professionals in the use of wearable, Lower Limb Robotic Assistive Technology.

Participants

Survey participants were healthcare and other professionals working with children in rehabilitation services, who would be likely to benefit from the future use of bionic rehabilitation technology in their therapeutic practice with children. This professional group included occupational therapists, physiotherapists, paediatricians, speech and language professionals and other staff working in rehabilitation services in clinical and community settings for children with CP, such as care assistants, and paediatric consultants.

There was a purposive trget sample of 50-60 professionals per country, based on feasibility of recruitment in the time available for the study. An actual overall sample of 274 healthcare professionals was recruited to the study (Netherlands n=42; Belgium n=72; France n=7; UK n =153).

Recruitment

Survey participants were recruited mainly through partners' networks in all project countries. There was some variation per country, depending on the partners' access to professional networks. Participants were invited by email with the link to the online survey through:

Professional networks such as the Dutch Paediatric Physical Therapy association, CP-net, and Society for Movement Analysis Laboratories in the Low Lands (SMALLL) in Netherlands; Association of Paediatric Chartered Physiotherapists (APCP) in the UK and partners' local health networks of occupational therapists, physiotherapists and paediatricians in France.

Rehabilitation services such as Pulderbos - Revalidatiecentrum voor Kinderen en Jongeren in Belgium; Sint Maartenskliniek, Radboudumc, rehabilitation centres Roessingh, Klimmendaal and Tolbrug in Netherlands; Chailey Clinical Services, Sussex Community NHS Foundation Trust and other NHS Trusts in the UK.

The survey was also disseminated through social media in all countries. Each cross-border partner was responsible for distribution of the survey and collation of data in their country. Once collected, data were sent to CCCU for collation and analysis.

Survey Questionnaire

The MOTION online surveys for both health care professionals and parents were developed collaboratively across the cross-border team. Survey questions were designed by the CCCU team drawing from existing survey tools in Assistive Technology (AT) (Arthanat et al, 2015; Liddell et al, 2008; Menard et al, 2020) and with reference to other literature on effectiveness and outcomes of the use of wearable, Lower Limb, Robotic Assistive Technology (LLRAT) (Jans and Scherer, 2012; Scherer and Craddock, 2002; Widehammar et al, 2017) as well as including additional, bespoke items which drew upon the expertise of cross-border partners.

There was cross-border collaboration in developing survey questions and deciding on key terminology which would be relevant cross-nationally; for example, the use of 'wearable, Lower Limb Robotic Assistive Technology' (LLRAT) to describe the devices of interest to the project and those being developed by the MOTION partners and ensure that clarity of the technology being referred to. Feedback was also received by practicing professionals and parents to ensure that questions were clear, concise and relevant to professionals and parents they intended to use them with.

The English version of the survey was translated to French and Dutch. A copy of the English survey questionnaire for healthcare professionals is provided in Appendix 1 of this report.

Participants were asked to give their consent at the start of the survey which was a prerequisite to continue to the main part of the survey. The survey had 27 main questions, mostly closed response items with a few open-ended questions to provide further information.

There were four main survey sections:

- **Background information** - profession, sector worked in, years in practice, region
- **Experience of Lower Limb Robotic Assistive Technology with adults and children** - prescription, use, training in and other knowledge of LLRAT; having seen, heard about or used
- **Attitudes to the use of wearable Lower Limb Robotic Assistive Technology with children** - perceived purpose of LLRAT for children; perceived benefits and concerns around use; perceived confidence in using LLRAT; satisfaction with level of knowledge in area of LLRAT
- **Training issues related to the use of wearable Lower Limb Robotic Assistive devices** - perceived barriers to training; importance of different types of information in training; preferred form of training.

The survey was administered via the Online Surveys platform in the UK, Castor EDC in the Netherlands, QUALTRICS in Belgium and Google Docs in France. Each platform was the preferred package for the institutions involved, for secure data collection and storage in accordance with General Data Protection Regulation (GDPR) and the Data Protection Act (2018), as well as other individual institutional data security requirements. All platforms were compatible with Excel and this was used to collate the anonymous data into a single dataset for transfer to SPSS for further statistical and thematic analysis.

The survey was piloted in the UK with a range of Health Care Professionals (HCPs) for clarity and acceptability and to check that technical aspects of the survey were working correctly. There were no significant recommended changes to the survey.

Ethical Approval

Cross-border partners each sought appropriate ethical (or management) approval in line with their country and organisation-specific requirements.

The English version of the survey was granted ethical approval via the CCCU Faculty of Medicine, Health and Social Care Ethics Committee in January 2020. It was also submitted for approval from the NHS Health Research Authority (HRA, Project ID 285909). This was required in order to allow further professionals to be recruited via NHS services. In France, according to regulations for research involving human participants, the study did not require ethical approval, as advised by the French ethics committee (Comité de Protection des Personnes), which are governed by le Décret n° 2016-1537 du 16 novembre 2016 relatif aux recherches impliquant la personne humaine (Legitfrance 2016). In Belgium, the study was granted ethical approval via the Ethics Committee Research (EC Research) of University Hospitals Leuven (UZLeuven) on 30th November 2020. In Netherlands, the study was reviewed and received favourable opinion by the Medical Ethics Committee region Arnhem-Nijmegen (dossier number: 2020-6836).

Data Analysis

Partner countries coded and translated responses according to a coding plan developed by the CCCU team, which coordinated data collation and analysis across the four partner countries and authored the report. Analysis was

undertaken on SPSS v26. Data were mostly nominal and ordinal level with a small number of free text, qualitative responses. Frequencies and descriptive statistics were calculated where appropriate along with graphs and tables. Free text, qualitative responses were analysed thematically through a basic content analysis to detail and explore key issues and themes.

1.3. Survey Findings

Demographic characteristics of participants

Most respondents (65%) were physiotherapists or physical therapists. The second largest group across the whole sample was occupational therapists (17.5%) (Figure 1). Physiotherapists were the largest group responding in all countries (Netherlands 57%; UK 60%; Belgium 85%) with the exception of France, where the 'other' professions group was the largest (43%), specified as exercise therapist or kinesiologist, paediatric physician, orthopaedic or orthopaedic surgeon, and teacher.

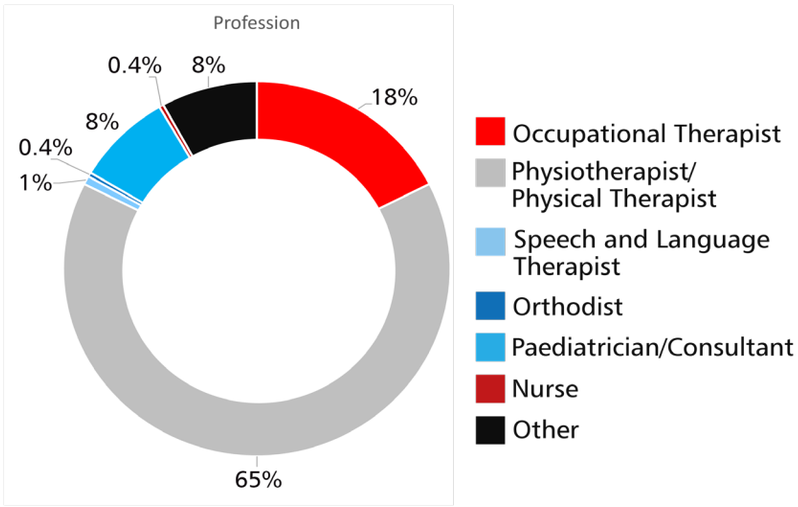


Figure 1: Main Profession of Healthcare Professionals responding to the survey

Respondents across countries worked mostly in community-based services (50%) and acute/ hospital-based services (33%). 'Other' sectors specified by respondents (8%) included special needs education provision, private companies, day care centres, multifunctional centres, university, university hospital and charities (Figure 2). There was some variation per country; most respondents were working in acute/hospital settings in the Netherlands (88%), and France (43%) while most respondents were working in community-based/local authority services in UK (66%) and Belgium (43%).

In all countries, most survey respondents had over 11 years practice experience either with adults (France 86% Netherlands 74%; Belgium 68%; UK 67%) or with children (Netherlands 67%; Belgium 65%; UK 56%, France 43%).

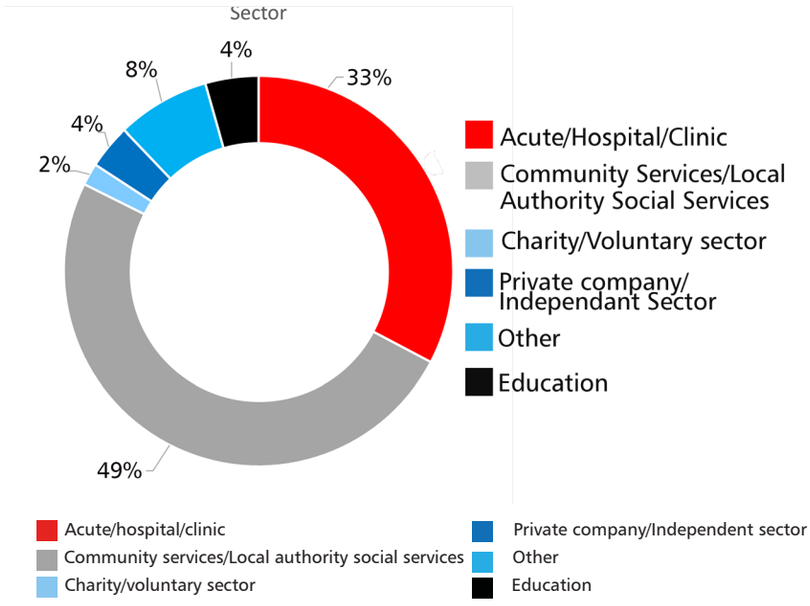


Figure 2: Healthcare Professional Respondents' Place of Work

Experience with Wearable LLRAT for Adults

Only a very small number of the healthcare professionals respondents in any country had prescribed LLRAT for adults and less than 5% had used it in practice or had been trained in using it. Almost one fifth (18%) had seen a demonstration of this technology (Netherlands 14%, UK 16%, Belgium 21%) with the exception of France (57%). Almost half of respondents (44%) in all countries had heard or read about it (Netherlands 43%, UK 46%, Belgium 35%) with the exception of France where all respondents had heard or read about LLRAT, although this was the smallest country sample.

Experience with Wearable LLRAT for Children

As with the experience with wearable LLRAT for adults, only 3% respondents had prescribed LLRAT for children, only 6% had used it in practice and 2% had been trained in the use of wearable LLRAT with children. Around a fifth of respondents across countries had seen a demonstration of this technology (total: 18% - Netherlands: 19%, UK: 14%, Belgium: 24 %; France: 29%), and almost a third of respondents had heard or read about wearable LLRAT for children in most countries (total: 32%; Netherlands: 31%, UK: 30%, Belgium: 14%) with the exception of France with a higher number of respondents indicating this (71%).

Types of AT devices known to respondents

Healthcare professionals reported having some experience or knowledge of the LLRAT devices used currently in practice as shown in the Figure 3. Not all reported devices would be classified as Robotic Assistive Technology, however the variety of the devices is indicative of the varied level of knowldge of healthcare professionals.

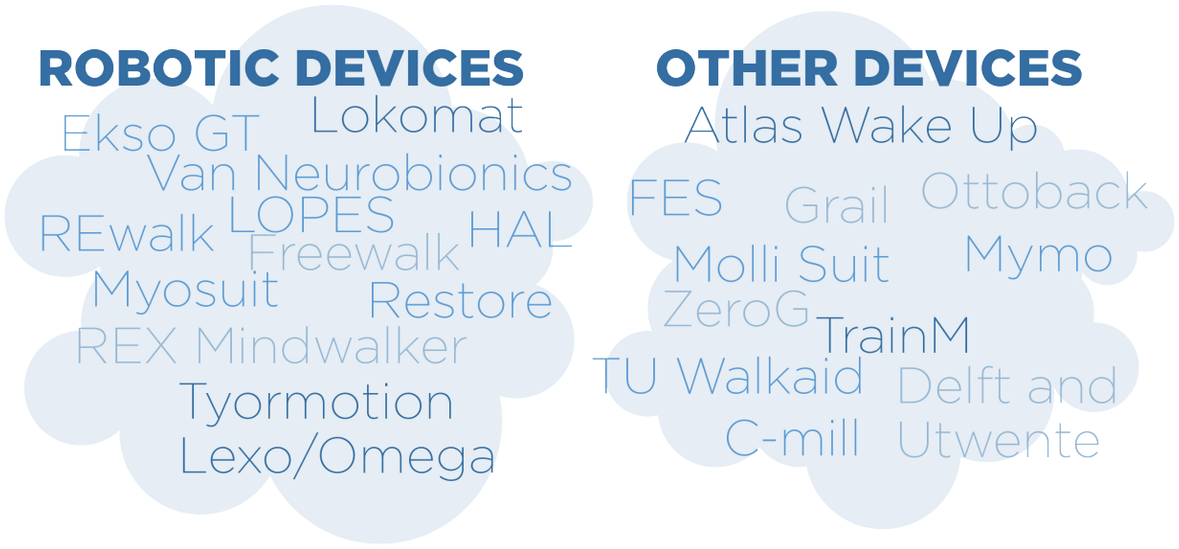


Figure 3: Types of Assistive Technology devices reported by respondents

Perceived Purpose of Wearable LLRAT for Children

Respondents agreed with more than one stated purposes of using wearable LLRAT for children. Most agreed that the main purpose was as an assistive device for use in daily life (44%) and as for training to improve gait functions (43%). The third suggested purpose, as a training device to improve secondary health outcomes, was chosen by less than a third of the survey respondents across the countries (13%) (Figure 4).

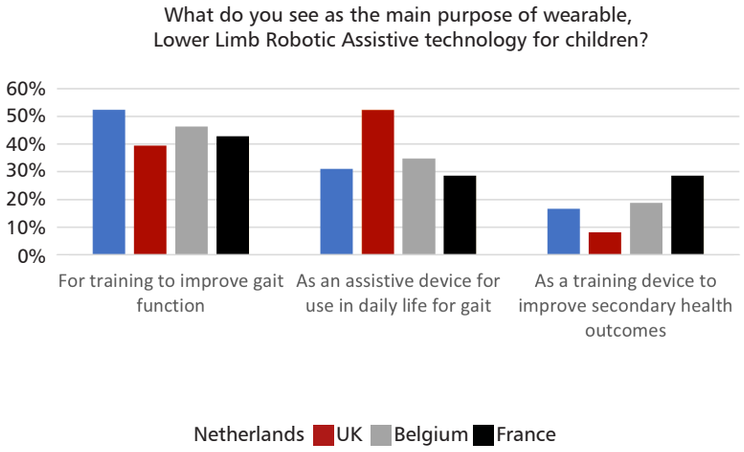


Figure 4: Perceived Purpose of Wearable LLRAT for Children by country

Satisfaction with Knowledge of Wearable LLRAT for Children

Very few healthcare professionals felt that they knew enough about LLRAT for children; only 2 respondents across the overall sample (1 each from Netherlands and Belgium). Most of them wanted to know more about this technology (France – 100%; UK - 94 %; Belgium - 54%; Netherlands - 38%).

Level of Confidence in Ability to Use Wearable LLLRAT with Children

Overall, very few respondents agreed they were 'very confident' in their ability to use LLRAT for children (n=5, 2%). The levels of confidence vary per country however most of them were still showing low levels of confidence (UK - 90%; Netherlands – 48%; Belgium – 57%) with the exception of France where the majority indicated they were 'fairly confident' (71%) (Figure 5).

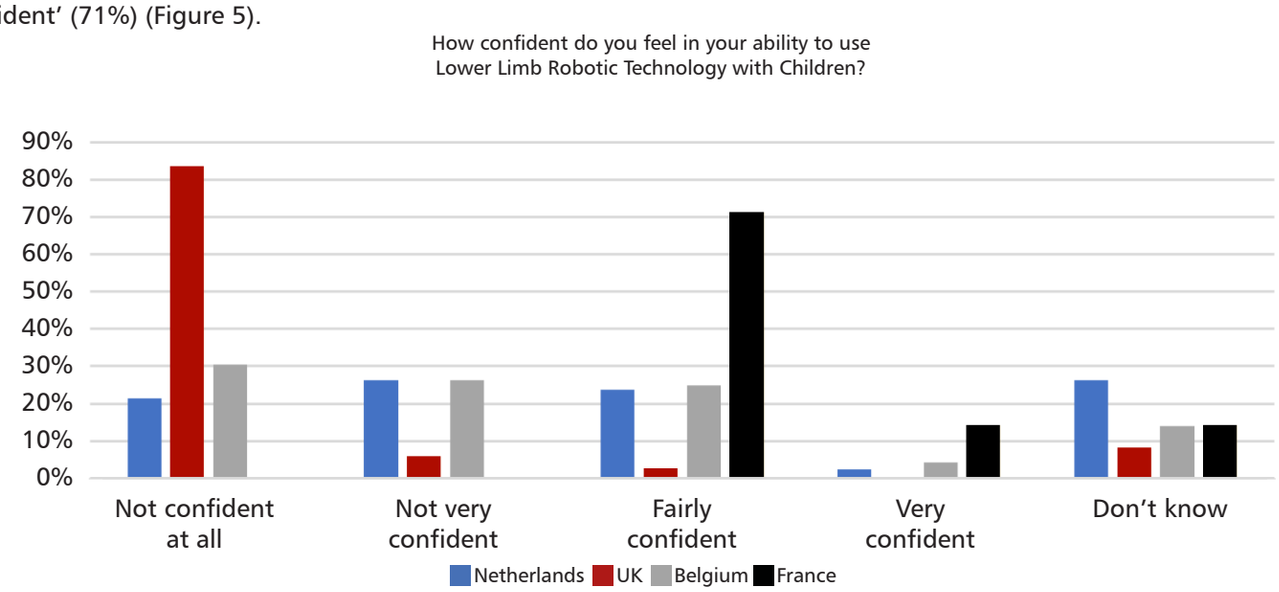


Figure 5: Level of Confidence in Ability to Use LLLRAT with Children by Country

Perceived Benefits of Wearable LLRAT for Children

Respondents agreed that there was a wide range of potential benefits for children from the use of wearable LLRAT when they were asked to indicate their agreement of a list of possible benefits of LLRAT which was drawn from existing research evidence. The top five benefits (highest agreement per country) were :

Other benefits

- New form of therapy giving extra motivation for child and therapist
- Improving equality with peers, taking into account the judgements of others and the influence on yourself
- Teaching a motor program
- Training in daily activities, so no extra time is needed for therapy and the child is better able to be a child
- Motor planning for the lower limbs

Concerns Relating to Wearable LLRAT for Children

A major concern relating to the use of LLRAT for children, which cut across all countries, was the potential cost of the device and how it was going to be funded. In the UK, for example, the focus of concern was whether or not the NHS could afford an expensive device and if this could be a barrier to implementation. This was reflected in comments from one of the French participants. Concerns for the need for the device to be child friendly and safe to use in this population were reported more often by respondents in the Netherlands and Belgium. Whereas in the UK, concern regarding a lack of knowledge and the need for adequate training to increase safety of use was more often stated. Respondents from the Netherlands were less likely to report having concerns about the use of LLRAT devices for children.

Perceived Barriers to Training Professionals in the use Wearable LLRAT

The majority of respondents across the total sample thought that lack of funding for training (75%) and the costs of the technology (75%) could be barriers to training professionals. When asked about potential barriers to training professionals in the use of wearable LLRAT, around 70% of respondents in all four countries identified lack of funding for training and costs of the technology could be significant barriers to professionals' training. Other factors that most respondents identified as barriers were: uncertainty about the extent to which the technology would be available for use in services/to prescribe, lack of availability of ongoing training and support, lack of locally available training courses and uncertainty over the benefits of wearable LLRAT over other assistive technology. 12% of the total sample felt that there were no specific barriers to professionals' training.

Content of Training for Professionals in Wearable LLRAT for Children

Information on safety issues, contraindications of use and adjustment of devices to individual needs were the key areas that most respondents, across all four countries, identified as essential to include in the training.

Particular topics were identified per country which could suggest potential gaps in these local contexts. For example, information on how LLRAT works (Netherlands); assessing suitability of LLRAT for a child; practicalities of use (e.g manual handling); information on prescribing and funding; fitting, adjusting and customization to individual client needs; and how to evaluate the impact and outcomes of LLRAT use (UK); practicalities of use; suitability to different client groups and fitting, adjusting and customization to individual client needs (Belgium); management of expectations from parents/carers (France).

Given these differences, it is recommended that each country uses training materials with a view to covering agreed 'core' information but with possible variation on some other elements, to ensure that information is relevant and of interest to participants. This might be achieved by a modularised approach where different elements can be selected from a menu of information/resources.

Additional Content to Include in Training for Professionals

Respondents were asked to suggest if there was any additional information or skills that should be included in

training for professionals in LLRAT, over the topics listed in the questionnaire. In the most part, respondents said that the list of areas suggested was extensive and covered what might be included in training well. A small number of other responses were given to this question. These included:

- Different uses of exoskeletons;
- Health insurance;
- How gait analysis is quantified;
- How equipment is maintained and whether it can be used for more than one client;
- Infection control and cleaning;
- How long and how may times a week it may be used for;
- Peer support for families;
- Making sure that the materials developed are accessible to families
- Making sure professionals could easily update knowledge where there were gaps between clients who might benefit from LLRAT;
- How commissioning of these devices is supported and what kinds of devices are already in use in different health systems.

Format of Training for Professionals

A mix of online and face-to-face training was preferred by most respondents (81%) across the total sample. This was much higher than the preference for face to face only training (36 %) and online only training (7%). There was also cross-country agreement on a 'blended' form of training, with over 70% of respondents in all four countries considering that training that combined both online and face to face elements would be useful for professionals.

1.4. Implications for Development of Training

Professionals are likely to hold positive views towards wearable LLRAT but lack confidence in their ability to use this currently. Assessing confidence in use following completion of training modules is likely to be a key measure in the evaluation of the success of these materials.

Face to face and online materials will need to be sufficiently detailed to allow professionals to see how wearable LLRAT can be adapted to different client needs and environments. For example, it could be helpful to show use within different health services-this might be achieved by a series of case studies that look at different ways the devices might be employed with clients with different needs.

The inclusion of clear, and honest assessment of the pros and cons of use and best practice protocols will be beneficial. These could be guidelines developed by practitioner organisations and associations-if such guidelines exist at the time of delivery-or bespoke material developed by the team. This would need to draw on intelligence related to the devices and review of clinically relevant literature on use of similar technology.

Practical, day-to-day information on device use-for example, on cleaning and maintenance could be beneficial.

Ensuring that the training and materials developed are dynamic and can link to ongoing training for professionals is important. Materials should enable an 'easy refresher' for staff who may have undergone training but have an extended gap between this and actually working with a client who would benefit from wearable LLRAT.

Material that addresses managing client expectations and ensuring that clients can be signposted to relevant peer and other support groups could be useful and therefore work exploring and linking with other support for children with CP and their families could be a valuable part of developing training and materials online.

2. SURVEY AND TELEPHONE INTERVIEWS WITH PARENTS OF CHILDREN WITH CEREBRAL PALSY

2.1. Aim of the Study

The aim of the study was to understand the knowledge, experience, attitudes and training needs of parents and carers with wearable, Lower Limb, Robotic Assistive Technology (LLRAT) for children.

2.2. Methodology

A survey methodology was adopted to address the study aim, using structured telephone interview and an online self-completed survey questionnaire to assess knowledge, experience, attitudes and training needs of parents of children with cerebral palsy in the use of wearable, Lower Limb Robotic Assistive Technology.

Participants

Participants were parents and carers of children under 18 years with cerebral palsy, who might benefit from wearable Lower Limb Robotic Assistive Technology. Participants were recruited via rehabilitation clinics and services and parents' and charity networks in each country.

There was a purposive target sample of 10-15 parents per country, based on feasibility of recruitment in the time available for the study. An actual overall sample of 45 parents was recruited to the study (Netherlands n=10; Belgium n=10; France n=15; UK n=10).

Questionnaire/interviews

The survey questionnaire for parents was an adapted version of the survey questionnaire for professionals and it was developed by the CCCU team in collaboration with project partners. Participants provided information about their child's health condition and how this affects his/her daily life and functioning. These questions were derived from scales commonly used for assessing the child's functionality, i.e. the Gross Motor Function Classification Scale-GMFCS (Palisano et al, 2008). Survey questions covered parents' knowledge, experience, attitudes and training needs around LLRAT with children with CP.

The survey covered the following areas:

- **Knowledge of parents of children with cerebral palsy in wearable, Lower Limb Robotic Assistive Technology for children**
- **Level of confidence in the use of wearable, Lower Limb Robotic Assistive Technology with children**
- **Topics to be included in parents' training in LLRAT and format of the training**
- **Perceived barriers to training parents in LLRAT for children with CP**
- **Perceived benefits in the use of LLRAT for children with CP**

Data Collection

The approach to data collection varied per country, based on practical and capacity considerations as COVID 19 pandemic restrictions required flexible, less time-consuming methods of data collection with parents. Telephone interviews were selected for use in the UK and France where participants were first recruited via partners' networks. In addition, in the UK, an online self-completed questionnaire was also offered as an alternative to provide flexibility to parents who had limited capacity to arrange telephone appointments. Project partners in Belgium and Netherlands recruited participants in clinical practice and invited parents attending their services to complete the online survey questionnaire, supporting them with completion if required.

Ethical Approval

Cross-border partners each sought appropriate ethical (or management) approval in line with their country and organisation-specific requirements.

In the UK, the study was granted ethical approval via the CCCU Faculty of Medicine, Health and Social Care Ethics Panel in January 2020, and also received approval from the NHS Health Research Authority (HRA, Project ID 289281). This was required in order to allow parents and carers recruited through NHS sites to be able to participate. In France, there was no requirement to obtain ethical permission for this type of study. In Belgium, the study was granted ethical approval via the Ethics Committee Research (EC Research) of University Hospitals Leuven (UZLeuven) on 30th November 2020. In Netherlands, the study was granted ethical approval by the Medical Ethics Committee region Arnhem-Nijmegen (dossier number: 2020-6836).

Data Analysis

As with the healthcare professionals' survey, partners collected data in the four countries, coded and translated interview/questionnaire data according to a coding frame devised by the CCCU team, who coordinated the data collation and analysis for the whole sample. Analysis was undertaken on SPSS v26. The data were mostly nominal and ordinal level with a small number of free text, qualitative responses. Frequencies were calculated and are presented in this report. Free text, qualitative responses were analysed thematically through a basic content analysis.

2.3. Findings

Participant Demographics

Overall, parents participating in the survey, except one, had a child with a diagnosis of cerebral palsy. Half of these children were aged 8-12 years (total sample - 53.3 %; Netherlands – 50%; France - 47%; Belgium – 30%; UK – 80%).

Half of the children across the total sample could not walk independently however there were country differences as this was the case in the UK and Belgium however in France the majority of parents were looking after a child with no independent movement whereas all the parents in Netherlands indicated that their child could move independently. Cerebral palsy was reported to affect children's lives severely in terms of eating and nutrition (38%), vision (29%), cognition (33%) and behaviour problems (13%).

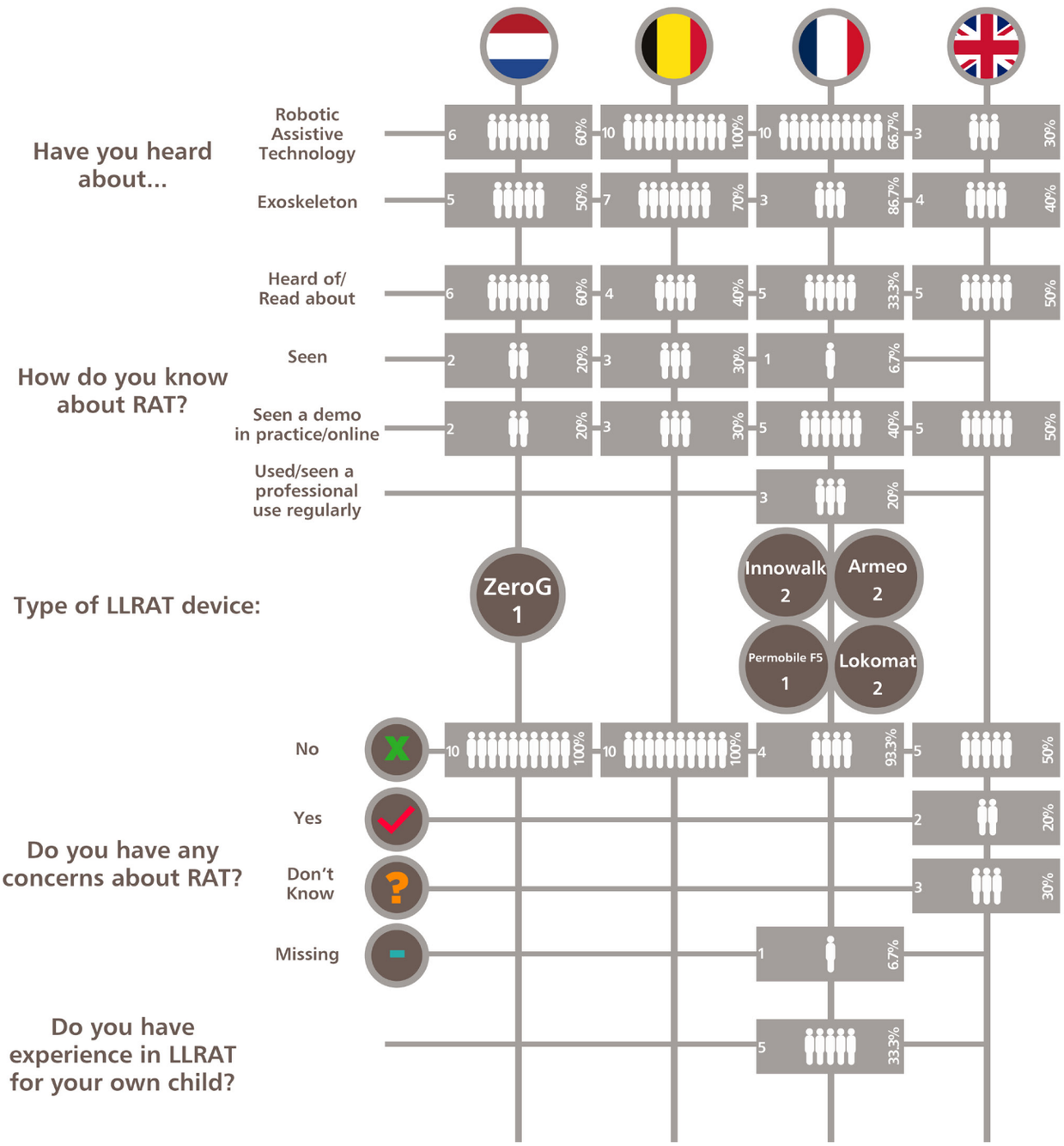
Type, Frequency and Location of Therapy Received

Most children in the sample (93%) were receiving some form of rehabilitation therapy, mostly physiotherapy alone or in combination with other therapies such as occupational therapy, speech and language therapy and psycho-motivity. Two thirds of children (55%) received therapy twice a week or more frequently. This was predominantly received in a clinic or therapy centre.

Knowledge and Experience of, and attitudes to, Robotic Assistive Technology, Exoskeletons and Lower Limb Robotic Assistive Technology.

Parents were asked a range of questions to gauge their current knowledge and experience of Robotic Assistive Technology. Most of them had heard the terms 'Robotic Assistive Technology' (64%) and 'Exoskeleton' (66%). The majority had also heard of, read about or seen/seen a demo of RAT (80%). However, only 3 parents (out of 45) had actually used RAT.

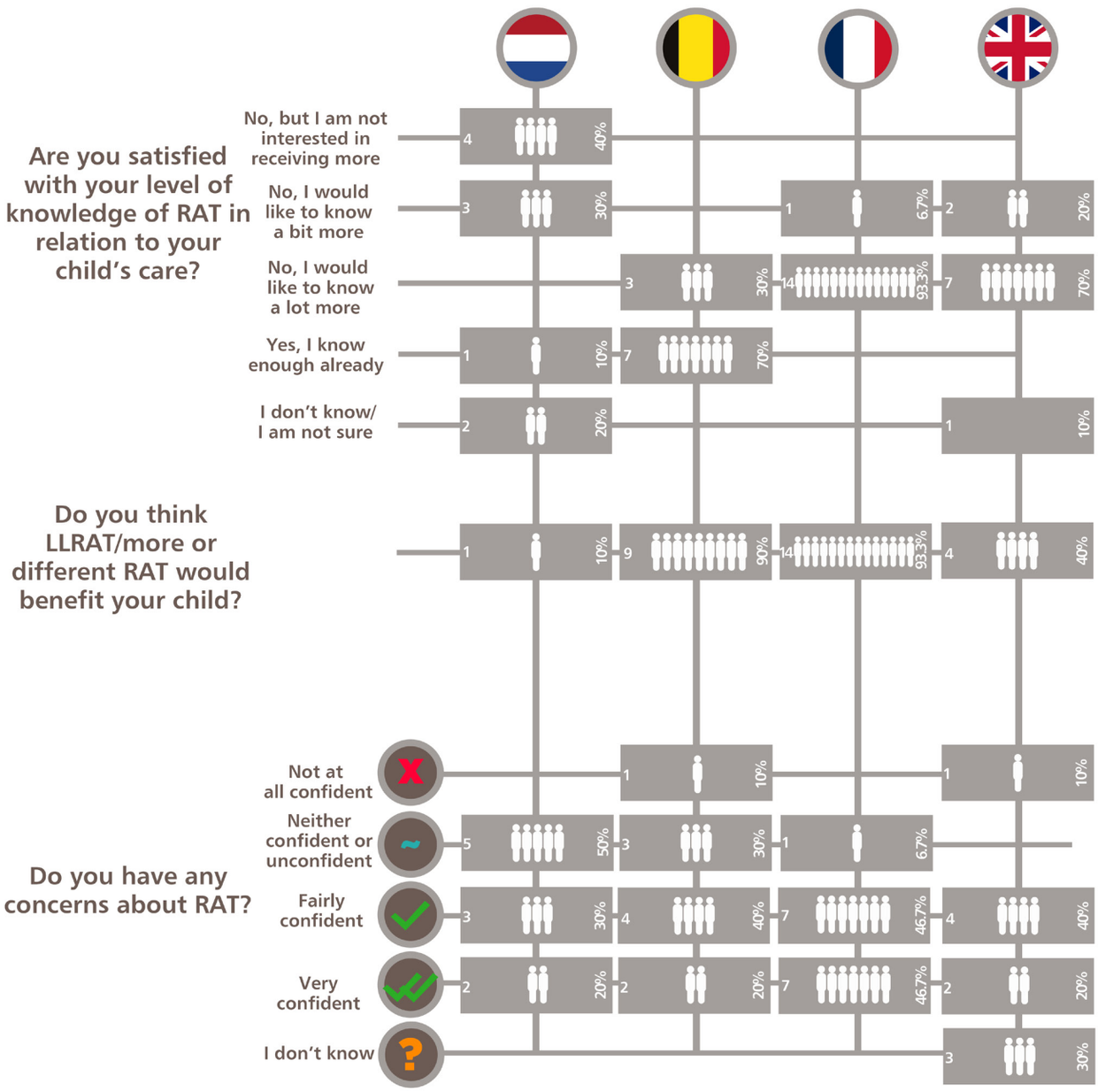
Table 1: Parents' experience, views on and confidence in LLRAT by country



Most parents would like to know a little more or a lot more about Robotic Assistive Technology (67%) and agreed they would be fairly confident or very confident using a new RAT device with their child (69%).

Responses varied between countries due to participants' prior engagement and experience with LLRAT. For example, four of the French parents said they had training, professional expertise or some other professional experience that related to RAT/AT/rehabilitation-mainly due to their healthcare professional background or training and this was reflected in their level of knowledge reported. The French parents were more likely to have actually used RAT or seen a professional use RAT with their child or somebody else than parents from other countries. Innowalk, Lokomat, Armeo and Permobile F5 were mentioned as types of RAT French parents had seen.

Only two parents from the total sample reported any concerns about the use of RAT with children. These related to the weight and attachment of the devices to the child and what precautions were in place to manage the device breaking and errors if they occurred.



Content and Format of Training

Parents were asked which of a list of training content would be important to include in training in LLRAT. The top scoring content to include in training, in terms of percentage agreement across the whole sample, was: clinical social and psychological benefits of using LLRAT (84.4 %); how LLRAT works (84.4 %); how to use LLRAT effectively (84.4 %); and where to find ongoing training and support (80 %).

Parents' preferences for the format of training across the total sample were: in person, individual (88.9 %); in person, group (75.6 %) and online (46.7 %). A variety of cross-country differences can be seen in Table 2, below.

Table 2: Content and Format of Training Considered Most Useful for Parents

	Netherlands (n=10)	Belgium (n=10)	France (n=15)	UK (n=10)
Topics to be included in training				
The clinical, social and psychological benefits of LLRAT	10 (100%)	10 (100%)	12 (80%)	5 (50%)
How LLRAT works	10 (100%)	10 (100%)	13 (87%)	5 (50%)
How to use LLRAT effectively	10 (100%)	8 (80%)	14 (93%)	6 (60%)
How to use LLRAT safely	10 (100%)	8 (80%)	13 (87%)	4 (40%)
Where to find ongoing training and support	10 (100%)	8 (80%)	14 (93%)	4 (40%)
How to communicate with children and keep them engaged	10 (100%)	5 (50%)	13 (87%)	3 (30%)
How to use LLRAT alongside other AT	9 (90%)	6 (60%)	13 (87%)	4 (40%)
Signposting to online resources, books and other materials	10 (100%)	5 (50%)	13 (87%)	5 (50%)
How to use the technology on a practical level	10 (100%)	8 (80%)	14 (93%)	3 (30%)
Format of training useful to parents				
Online training	5 (50%)	2 (20%)	10 (67%)	4 (40%)
In-person, group training	7 (70%)	6 (60%)	15 (100%)	6 (60%)
In-person, one-to-one training	10 (100%)	9 (90%)	13 (87%)	8 (80%)

Also, parents provided further suggestions and ideas about training content and delivery as presented below:

Accessible Information about LLRAT and Communication to others:

'It's important to get a good explanation and to be able to reread it so that you can share it with, for example, family'

'How do you talk to the health professionals who take care of the child every day. Are they seeing this as a gadget?'

'Sharing between families after use, sharing secular knowledge, findings, including with professionals'

'Take action on professionals as few know about these technologies'

Impact/Outcomes of LLRAT use:

'[After the training] *Be able to discuss with other families and professionals on the use and advantages / disadvantages of this technology and the progress seen in our children'*

'Share experience, statistics, feedback on clinical results'

'Capture results of improvements with the child, then [do] further development of the technology'

'Know that it's not always going to work first time, every child is different, [you] *need to adapt* [LLRAT] *to individual children'*

'Understand of the commitment involved: what are the benefits and what is the commitment from the child to see them? How many weeks, years of use? What is the commitment from the providers that RAT will be available to the child for the duration required?'

Costs of LLRAT:

'Examples and insight into production and costs etc'

Ongoing support with LLRAT:

'A support at home!'

'Practice with a person nearby to be well trained. A hotline in case of problems. Video tutorial for the first steps with devices'

Fit of LLRAT with other therapy the child is receiving:

'How does this orthosis fit into the overall care?'

Technical details/how LLRAT works:

'I would like to know how it's designed and how it works, I can't wait for this technology to be available!'

'[Be able to] *see demos and explanations on the uses'*

'[My child has] *trouble with visual stimulation, and localization. Add an auditory support to comfort [support] the child who sees badly or does not see or is suffering from cortical blindness'*

2.4. Implications for Development of Training

Parents in the sample held positive views towards wearable LLRAT and its benefits for health. Although for some, this technology was not seen as being likely to benefit their own child - where children were more independently mobile - parents expressed an openness to trying anything that would help support their child. They were relatively confident in their perceptions of their ability to use wearable LLRAT, despite relatively little personal experience of its use. Although a small sample, this suggests parents to be open to learning about wearable LLRAT, where they can see a use for it with their child.

Parents expressed an interest in learning about how wearable LLRAT technology works. This information should be included in the training, possibly tailored to different levels of interest so that parents who are most interested could be provided more detailed information or given signposting to recommended resources for further reading/ information.

Personalised information where possible and child-centred information to help parents see how the devices could be used in everyday life with their children would be valuable.

Embedding resources into a wider and ongoing training and support network for parents will be important. Peer support may play a role in this ongoing support as well as professional support. A good range of signposting to other support services and training in the materials produced is likely to be valued by families.

Parents would value in person training, particularly individual training. This suggests that training and information should be provided, where possible, with online training either taking a secondary role or ensuring it can be tailored to parents whose children have differing needs and/or supplemented by future in person training.

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APPENDIX 1

Online Survey for Healthcare Professionals (English version)

MECHANISED ORTHOSIS FOR CHILDREN WITH NEUROLOGICAL DISORDERS (MOTION)

SURVEY OF TRAINING NEEDS OF HEALTHCARE PROFESSIONALS IN THE USE OF ROBOTIC ASSISTIVE TECHNOLOGY FOR CHILDREN WITH CEREBRAL PALSY

INTRODUCTION

Thank you for your interest in this survey, hosted by **Canterbury Christ Church University (CCCU)**. CCCU is one of 15 partners working on a cross-Europe project called **MOTION (Mechanised Orthosis for children with neurological disorders)**. The project focuses on children with Cerebral Palsy (CP). The study is being conducted in the UK, France, Belgium and the Netherlands.

It is estimated that 46% of the children with CP might benefit from innovative wearable, lower limb robotic assistive technology. Robotic assistive technology devices can sense, and process sensory information, and perform actions that benefit people with disabilities. Wearable, lower limb exoskeletons that assist standing, walking and rehabilitation, are an example of robotic assistive technology.

MOTION aims to develop a wearable, lower limb exoskeleton and associated technology for this and train professionals and parents and carers in its use. Part of the project is to survey healthcare professionals-particularly those who work in Kent, Sussex and Surrey- who work with children about their use, knowledge and training needs in wearable, lower limb, robotic assistive technologies like exoskeletons. The questionnaire has been designed to build on current research knowledge on wearable, lower limb robotic assistive technology. The questions include validated measures used in previous research studies and a range of bespoke questions designed by the study team to help us understand more about training needs in this new and emergent area of assistive technology.

The survey takes approximately **20 minutes**. It is anonymous and your personal details or any other identifying information will not be used in any published reports, articles or presentations. The answers will be compiled into a report on the general knowledge, experiences and training needs of healthcare professionals, across the UK, France, Belgium and the Netherlands and used in future publications about the findings of the project.

By completing this survey, you are giving consent for the data you provide to be used for the purposes of this part of the MOTION project. You can withdraw at any time you wish. All data and personal information will be stored safely and securely within Canterbury Christ Church University premises in accordance with the General Data Protection Regulations 2018, Data Protection Act 1998 and the University's own data protection requirements. Data will only be accessed by the researchers working on this project. All data will be deleted after a period of 5 years following the end of the MOTION project, i.e. they will be deleted in 2027, as per funders' requirements.

INSTRUCTIONS FOR COMPLETION

This survey comprises 4 sections:

1. Information about you

2. Your experience of Lower Limb Robotic Assistive Technology with Adults and Children

3. Your views on the use of Wearable, Lower Limb Robotic Assistive Technology with Children

4. Issues related to the use of wearable lower limb robotic assistive devices

Please complete all the questions as much as possible to enable the research team to compile a comprehensive picture of your experiences in this area. Sections will be prefaced by instructions for completion. Please read and follow these carefully.

If you have any questions please contact the MOTION team at CCCU, at motion@canterbury.ac.uk.

This work is carried out as part of the INTERREG MOTION project-https://www.interreg2seas.eu/nl/MOTION The Interreg Programme is a European Territorial Cooperation programme funded by the European Regional Development Fund (ERDF).

CONSENT TO PARTICIPATE

I confirm that I have read and understood the information above and have contact details of the research team if I have any questions. YES NO

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
YES NO

I understand that any personal information that I provide to the researchers will be kept strictly confidential.
YES NO

I agree to take part in the survey. YES NO

1. **INFORMATION ABOUT YOU**

In this section, we would like to know more about your background as professionals, to understand how your profile may be relevant to the way you answer the questions of the survey.

What is your main profession?

- Occupational Therapist
- Physiotherapist/Physical Therapist
- Speech and Language Therapist
- Orthotist
- Pediatrician/consultant
- Nurse
- Other – please specify:……

How many years have you been practicing?

- < 2 years
- 2-4 years
- 5-7 years
- 8-10 years
- 11-13 years
- 14+ years

How many years have you worked with children?

- < 2 years
- 2-4 years
- 5-7 years
- 8-10 years
- 11-13 years
- 14+ years
- I don’t work with children

Which sector do you work in?

- Acute/hospital/clinic
- Community services/Local authority social services
- Charity/voluntary sector
- Private Company/Independent sector
- Other – please specify:……

What is the location of your workplace (region)?

- Kent
- Surrey
- Sussex
- Other –please specify: ……

2. YOUR EXPERIENCE OF LOWER LIMB ROBOTIC ASSISTIVE TECHNOLOGY WITH ADULTS AND CHILDREN

In this section, we would like you to answer questions that relate to your experiences with Lower Limb Robotic Assistive Technology devices for Adults and Children.

Which statement best describes your previous experience with Lower Limb Robotic Assistive Technology **with Adults**? (please tick)

- I have prescribed Lower Limb Robotic Assistive Technology YES NO
  - Which device/s you have prescribed? ……..
- I have used Lower Limb Robotic Assistive Technology in practice YES NO
  - Which device/s you have used? ……..
- I have been trained in the use of LLRAT but not used it in practice YES NO
  - Which device/s you have been trained to use? ……..
- I have seen a demonstration of LLRAT use in practice/online YES NO
  - Which device/s you have seen a demonstration of? ……..
- I have heard/read about LLRAT and know a little about its use YES NO
  - Which device/s you have heard of or read about? ……..
- I have no previous experience of, or knowledge related to LLRAT YES NO

Which statement best describes your previous experience of the use of Lower Limb Robotic Assistive Technology **with Children**? (please tick)

- I have prescribed Lower Limb Robotic Assistive Technology YES NO
  - Which device/s you have prescribed? ……..
- I have used Lower Limb Robotic Assistive Technology in practice YES NO
  - Which device/s you have used? ……..
- I have been trained in the use of LLRAT but not used it in practice YES NO
  - Which device/s you have been trained to use? ……..
- I have seen a demonstration of LLRAT use in practice/online YES NO

- Which device/s you have seen a demonstration of? ……..

- I have heard/read about LLRAT and know a little about its use YES NO
  - Which device/s you have heard of or read about? ……..
- I have no previous experience of, or knowledge related to LLRAT YES NO

Which statement best describes how you feel about your level knowledge of Lower Limb Robotic Assistive Technology with Children? (please tick only one answer)

- I feel I know enough already
- I would like to know a little more
- I would like to know much more

How confident do you feel in your ability to use LLRAT with Children? (please tick only one answer)

- Very confident
- Fairly confident
- Not very confident
- Not confident at all
- Don't know

3. YOUR VIEWS ON THE USE OF WEARABLE, LOWER LIMB ROBOTIC ASSISTIVE TECHNOLOGY WITH CHILDREN

This section asks about your views on using **wearable** lower limb Robotic Assistive Technology with **children.**

What do you see as the main purpose of wearable, Lower Limb Robotic Assistive technology for children? (please tick only one answer)

- For training (in hospital or at home) to improve gait function
- As an assistive device for use in daily life for gait
- As a training device to improve secondary health outcomes

Which, if any, of the following do you think could be potential benefits for children in using wearable, lower limb, robotic assistive technology for rehabilitation? (please tick all that apply)

- Improved **cardiovascular** health
- Improved **respiratory function/breathing**
- Improved **digestion**
- Improved range of **joint mobility**
- Improved **bladder** health
- Improved **skin** integrity
- Improved **bone** density
- **Gait** retraining
- Improve **muscle strength**
- Decrease **spasticity**
- Reduced **pain**

- Possible extension of **independent walking**
- Upper body **motor control**
- Opportunity for **change of position**
- Improved **speech/communication**
- Greater **independence/participation** in activities
- Improved **quality of life** and **self-esteem**
- **Curiosity/interest generated**, 'cool' use of technology
- **Other**-please specify: ……..

4. ISSUES RELATED TO THE USE OF WEARABLE LOWER LIMB ROBOTIC ASSISTIVE DEVICES

This section asks about your views on training in wearable, Lower Limb Robotic Assistive Technology.

Which, if any, of the following do you think could be barriers to training professionals in the use of wearable, lower limb, robotic assistive technology **with adults or children** (please tick all that apply)?

- Lack of **locally available training** courses
- Lack of **nationally available training** courses
- Lack of **funding to support training**/study/prioritizing other training
- Lack of **availability of ongoing training/support** in their use
- Lack of **available online resources**
- Lack of **published resources** (text books, journals)
- Lack of **skilled trainers**
- **Confidence** around learning to use the technology
- Concerns around **using** the technology **effectively with adults**
- Concerns around **using** the technology **effectively with children**
- Concerns around **using** the technology **safely with adults**
- Concerns around **using** the technology **safely with children**
- Concerns around the **costs** of the technology
- Uncertainty about the extent to which it will be used in services/**available** to prescribe
- Uncertainty around the **benefits over other assistive technology** or devices
- There are **no barriers**
- **All of the above**
- Other – please specify: ……

Do you have any concerns relating to the use of wearable, lower limb, robotic assistive technology with **children**? Please explain ……

How important do you think it is to include information on the following in training for professionals in wearable, Lower Limb, Robotic Assistive Technology use with **children**?

Please do not select more than 1 answer(s) per row.

	NOT IMPORTANT	QUITE IMPORTANT	VERY IMPORTANT	ESSENTIAL	DON'T KNOW
The **clinical**, **social** and **psychological benefits** of use					
Assessing the suitability of wearable, Lower Limb, Robotic Assistive Technology for a child					
Information on **how** wearable, Lower Limb, Robotic Assistive Technology **works**					
Information on **how to use** wearable, Lower Limb, Robotic Assistive Technology **effectively**					
Information on how to use wearable, Lower Limb, Robotic Assistive Technology **safely**					
Practicalities of use e.g. manual handling					
Information on **where to find ongoing training/support**					
Information on **prescribing and funding**					
Best practice in **communicating with children** around the use of wearable, lower limb, robotic assistive technology					
Best practice in **communicating with parents/carers/ family** around the use of wearable, lower limb, robotic assistive technology					
Feedback from users on use					
Best practice in ensuring **child's engagement** through diversification of use, fun and motivational approaches					
Information on how wearable, Lower Limb, Robotic Assistive Technology could be **used alongside other AT**					
Information on the **benefits over other assistive technology or devices**					
Contraindications of use					
Suitability to **different client groups**					

Signposting to **online resources**					
Signposting to **published resources** (text books, journals)					
Preventing abandonment/refusal to use					
Use in **different settings and environments**					
Fitting, adjusting and **customization** to individual client needs					
Managing the child and parent's/carer's **expectations** around wearable, lower limb, robotic assistive technology					
Legislation, regulation and policy related to use					
Evaluating the outcome/ impact of use					

Is there anything else you think should be included in training for professionals around the use of wearable LLRAT?

What form of training do you think would be most useful for professionals (please tick all that apply)?

Online Face-to-Face/Experiential Both Online and Face-to-Face/Experiential

Please use this space to add any other comments you have about wearable Robotic Assistive Technology or this survey.

Thank you very much for your interest in this study

APPENDIX 2

Telephone Interview Schedule/Survey Questionnaire for Parents of Children with Cerebral Palsy (English version)

MOTION (Mechanised Orthosis for Children with Neurological Disorders):

Assessment of training needs of healthcare professionals and parents and carers in the use of Robotic Assistive Technology for Children with Cerebral Palsy

INTRODUCTION

The researcher/interviewer will:

- Introduce themselves to the interviewee and check that it is still convenient to conduct the interview [date and time of the interview will have been suggested by interviewee on the consent form, along with contact details].
- Describe the purpose of the project, and who the funder is. Explain that the study is being conducted in the UK, France, Belgium and the Netherlands.
- Say: *The project focuses on children with neurological conditions such as Cerebral Palsy (CP). It explores parents' or carers' views on what we call 'wearable, lower limb, robotic assistive technology' or robotic AT. Robotic assistive technology devices can sense, and process sensory information, and perform actions that benefit people with disabilities. Wearable, lower limb exoskeletons, like the one in the logo on the information sheet you were sent, are an example of robotic assistive technology. These are robotic assistive walking and standing devices used in rehabilitation. The Motion project aims to develop an exoskeleton for children with CP and train parents and carers and professionals in its use. Part of the project is to ask parents and carers about their use, knowledge and training needs in robotic assistive technologies like exoskeletons.*
- Check that all interviewees have received the information sheet and consent forms and/or any other documentation or process required for the researcher's institution/local/national ethics and any other regulation have been followed.
- Ask if the interviewee has any questions about the project or interview and answer these.
- Explain the length of interview and broad areas that will be discussed.
- Describe the confidentiality of interview, that there are no right or wrong answers, that the information will not be shared with any third parties, government or other services or organisations outside of the research team, that we are acting as an independent research organisation and answers will not affect any services or benefits received by the interviewee, child/ren or their family. Explain how data will be stored and for how long.
- Emphasize the right for the interviewee to stop the interview and withdraw at any point without having to give a reason and the right to not answer any question if they wish.
- Check that consent is given to participating in and to audio-recording the interview or written notes being taken.
- Ask if the interviewee is happy to start the interview.

1. Information about parents/carers

Which area do you live in?

- Kent
- Surrey
- Sussex
- Other – please specify: ……

Do you have any medical or health professional training or other work-related experience related to robotic assistive technology or assistive technology and rehabilitation in general?

NO
YES [add details]

2. Information about their child/ren with CP

Now can I ask some questions about your child or children with Cerebral Palsy?

How many children do you have with Cerebral Palsy?

Can you tell me how old this child is/these children are?

Child 1: 0-2 yrs 3-7 yrs 8-12 yrs 13-17 yrs

Child 2: 0-2 yrs 3-7 yrs 8-12 yrs 13-17 yrs

Child 3: 0-2 yrs 3-7 yrs 8-12 yrs 13-17 yrs

Add as needed

The next question is about your child's level of mobility. I am going to read a list of different levels of mobility. Can you tell me which ones apply to your child? (read list and tick all that apply)

- My child can walk independently without a walking aid
- My child can walk with a walking aid (frame or stick)
- My child uses a walking aid (frame or sticks) indoors only
- My child uses a walking aid (frame or sticks) both in and outdoors
- My child uses a walking aid (frame or sticks) in therapy sessions only
- My child can sit independently
- My child can weight bear to transfer independently
- My child can weight bear to transfer with carer support
- My child needs lifting or hoisting for transfer
- My child can maintain head position in supportive seating independently
- My child is unable to maintain head position without support

I am going to ask you some questions about how much CP affects your child in day to day life. Can you answer –never, sometimes, often, always. How much does CP affect your child in terms of:

- Eating and nutrition (never, sometimes, often, always)
- Vision ever, sometimes, often, always)
- Cognitive problems never, sometimes, often, always)
- Behaviour problems (never, sometimes, often, always)

Does s/he currently receive rehabilitation therapy such as Occupational Therapy and Physiotherapy?

NO
YES [add details-which type of therapy is received]
If yes, how often does s/he receive this therapy and where?

3. Knowledge of Robotic Assistive Technology

This next section is about robotic assistive technology. As mentioned, robotic assistive technology devices can sense, and process sensory information, and perform actions that benefit people with disabilities. Wearable, lower limb exoskeletons, like the one in the logo on the information sheet you were sent, are an example of robotic assistive

technology. These are robotic assistive walking and standing devices used in rehabilitation.

Had you heard of any of the following terms before participating in this study?

- Robotic Assistive Technology

  No

  Yes – please give details, what had you heard about robotic assistive technology?

- Exoskeleton

  No

  Yes – please give details, what had you heard about exoskeletons?

Which statement best describes your knowledge of robotic assistive technology

- Heard of/read about
- Seen
- Seen demo in practice or online
- Trained in their use
- Use/see professional use regularly with your child or someone else

Do you feel you have sufficient knowledge about Robotic Assistive Technology in relation to your child's care?

- No, but I'm not interested in receiving
- No, I would like to know a bit more
- No, I would like to know a lot more
- Yes, I know enough already
- I don't know/I am not sure

4. Experience of Lower Limb Robotic Assistive Technology

Would you say you have any experience in the use of Lower Limb Robotic Assistive Technology for your child's care or for anyone else?

- No
- Yes please give details

What types of Robotic Assistive Technology, if any, have you used with your child/children?

5. Attitudes to Lower Limb Robotic Assistive Technology

Do you think Lower Limb Robotic Assistive Technology [or more robotic AT/different robotic AT] could benefit your child? Why?

- No – please explain
- Yes –lease explain

Do you have any concerns about Robotic Assistive Technology?

- No –please explain
- Yes – please explain

How confident would you feel about using a new robotic assistive device with your child?

- Not confident at all
- Not very confident

- Neither confident/nor not confident
- Fairly confident
- Very confident

6. Training needs in Lower Limb Robotic Assistive Technology

Have you had any training in the use of robotic assistive technology?

- No – please explain
- Yes – please explain

Can you tell me what you think is important to include in training in wearable, lower limb robotic assistive technology for parents

a) The **clinical, social and psychological benefits** of using wearable, lower limb, robotic assistive technology

b) Information on **how wearable, lower limb, robotic assistive technology works**

c) Information on **how to use** wearable, lower limb, robotic assistive technology **effectively**

d) Information on **how to use** wearable, lower limb, robotic assistive technology **safely**

e) Information on **where to find ongoing training/support**

f) How to communicate with children around the use of wearable, lower limb, robotic assistive technology and **keep them engaged**

g) Information on how wearable, lower limb, robotic assistive technology could be **used alongside other AT**

h) Signposting to online resources, books and other materials

i) How **to use technology on a practical level?**

Is there anything else you think should be included in training for parents, carers and family members of a child with a neurological disorder around the use of robotic assistive technology.

What form of training do you think would be most useful for parents, carers and family members of a child with a neurological disorder (tick all that apply):

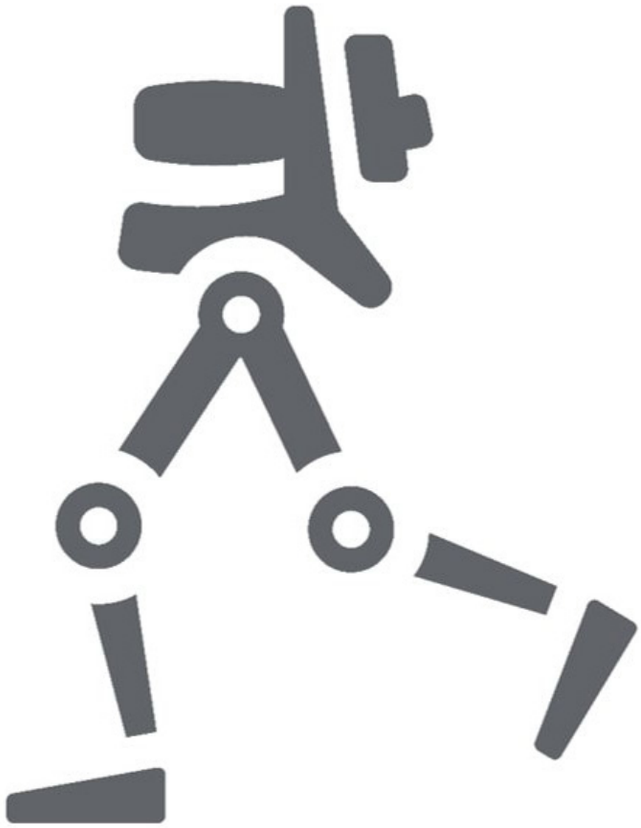
- Online
- In person, group
- In person, individual

Is there anything else you would like to tell us about Robotic Assistive Technology, this interview or this study?

Researcher/interviewer to say that is the end of the questions and the interview, thank the interviewee for their time and switch off the audio-recorder and tell the interviewee they have done this. They then ask them if they have any further questions and answer these or direct to the Motion website. They should let them know of any next steps for the research and ways they can find out more/find out the main results of the study and when.

M.O.T.I.O.N.

Mechanised Orthosis for Children with Neurological Disorders



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