

Think Tank Summary 25/4/23

ISPO Congress Guadalajara

Panel: Dr. Nils-Odd Tønnevold (IC2A, service user, Norway), Christoffer Lindhe (IC2A, service user, Sweden), Prof Laurent Frossard (researcher, Australia) and Beth Sheehan (project manager, Malawi)

Face to Face Attendees: Dieter Juptner (IC2A, service user, Germany), Isabelle Guerrero (IC2A, service user, France), Paulina Chavira (IC2A Inspirational Speaker, service user, Mexico), Didier Cooreman (ICRC, NGO, Switzerland), Ola Kvisgaard (Momentum, carer, Norway), Jessica Broström (Lindhe Extend, supplier, Sweden), Michael Fillauer (Fillauer, supplier, USA), Tom Cacciato (Aether, supplier, USA), Miranda Asher (BACPAR, P&O professional, UK), Mackenzie Gilmore (Operation Go., P&O professional, USA), Maria Valdes (service user, Mexico), Niall Marshall (Koaala, supplier, UK), Bengt Soderberg (SOL, P&O professional, Thailand), Juan Torres (service user, Colombia)

Online Attendees: Ashlie White (Amputee Coalition, NGO, USA), Daniel Messe (Ottobock, supplier, Germany), Lysay Emmrich, (Ossur, supplier, Iceland), Bart & Jack (UMCG, university, Netherlands)

Program

Introduction: President of IC2A Dr. Nils-Odd Tønnevold welcomed the attendees, introduced the panel and gave an overview of IC2A, the vision, mission and the overall achievements and partnerships IC2A has. Nils handed over to Beth Sheehan to introduce the Think Tank and the concept for the Think Tank.

Overview of Think Tank: Beth Sheehan gave a brief history of the previous Think Tanks in South Africa (2017) and Kobe, Japan (2019). Beth introduced the [OneHand project](#) that has helped informed the Think Tank for Guadalajara (featured in the attached presentation).

This year's Think Tank focus was how upper limb patient/prosthetic user journey and outcomes can be improved. The results and discussion of the Think Tank will help to inform the upper limb amputation rehabilitation guidelines for service users as part of the OneHand project, as well as serve as a helpful FAQ document for upper limb prosthetic users and amputees that will feature on the IC2A website (www.ic2a.eu) once compiled.

The attendees in the room were seated at 3 tables with a mixture of upper limb and lower limb amputees, rehabilitation personnel and prosthetic manufacturers to ensure diversity across the discussion. There was also a diverse group participating as part of the online group.

The Think Tank Panel posed four questions, each on an element of upper limb amputee rehabilitation and the user journey. Each table and online group, was facilitated by one of the panel members, with one participant in each group assigned as scribe/presenter of the individual discussions. Each question was given 10 minutes to discuss.

Once all 4 questions had been posed, the group collectively came together to discuss, with Laurent facilitating the discussion and Beth scribing the answers.

Outcomes: Laurent posed each question and asked each group to summarise the most important points from each table. The summary of each group is attached as well as the handwritten notes

from each group for confirmation and reference. Please note group 3's notes are already incorporated into the below summary.

More time was needed for the fruitful discussion due to the amount of depth and topics being covered in each question.

Future: The IC2A team's summary of the Think Tank will support the guidelines for both acquired and congenital limb loss. A summarising document is featured below of the Think Tank and includes summarising statements to help inform the future of upper limb amputation rehabilitation.



Image: Face to face attendees for the 2023 IC2A Think Tank

QUESTION SUMMARY

Question 1: Improvement of quality of care

From user perspective what are the barriers for long term use of upper limb prosthetic devices?

What would you change in order for more people to use upper limb prosthetic devices?

Group 1

- Growing skeletal frame – needs/access/expensive
- Pain wearing socket/prosthesis/harness
- Ongoing therapy – any changes back to the beginning of the process
- Repairs – lack of access to services – need for guardians to understand prosthetic use/repair
- Weight changes

Group 2

- Socket fit
- Volume changes
- Lack of clinician knowledge in terms of fitting / upper limb prosthetics
- Cost and insurance

Group 3

- Time after amputation – the shorter the better
- Burden v solutions leads to the need for an early fitting
- Practicality of use for upper limb
- Michelangelo – too many functions – basic functions (we think too far ahead), clinician driven rather than user driven
- User feedback to change documentation
- Abandonment (10-16yr olds in Germany) – function better without
- Congenital functional without prosthesis – more independent
- Parent / guardian concerns / conceptions / stigma
- Pathway not clear for upper limb rehabilitation (congenital)
- Availability / access – don't or not offered an appealing cosmetic look v function
- Clinicians that have appropriate training
- Can't do certain things due to counter intuit movements = barrier
- Waiting time = barrier = less inclined to accept leading to an increase risk of abandonment
- Understanding pre-care/prosthetic journey and what is to come --- focus on user needs / resources

Group 4

- As quick as possible
- Hard to get back if you haven't used one for a while
- No prosthesis replaces full function of hand
- Need for multiple devices or meets individualised goals
- Critical for training of prosthesis use and ADLs
- Control/speed/learning of device depending on technology

- Lack of expertise in upper limb amputations

Summarising comments:

From a user perspective, like lower limb, prosthetic fit and comfort is still a priority for upper limb and preventing barriers for long term use. Socket fit is reliant on stump size/volume and weight changes as well as pain.

Other key elements for long term use include decreasing the wait time for prosthetic fitting.

The P&O rehabilitation process must also not forget the differences with congenital rehabilitation. There needs to be a clearer pathway for user understanding of the congenital habilitation process. The importance of education and information education for parents as well as the child and understanding that a child's growth may require multiple devices and changes.

A final comment that was felt by all groups was that there is a lack in experienced personnel. Therefore there is need for rehabilitation personal to be experienced in upper limb prosthetics and the rehabilitation journey.

Overall the barriers experienced also inform the change required within the sector to improve the user rehabilitation journey.



Image: IC2A's Think Tank Panel facilitating discussion for Question 1

Question 2: Improvement of clinical pathways and quality of care

Where are the gaps in the continuum of care for rehabilitation pathways or the prosthetic user journey?

Group 3

- Psychology support
- Skin care / irritation care
- Connecting different healthcare professions and knowing who to approach and when?
- Continual care is lost therefore a need for self-driven for follow ups
- Psychology and peer support
- Psychosocial support and family / carer support
- Multiple limb deficiencies but upper limb often neglected
- Wound/skin care – how to clean socket – skin irritation – specialist knowledge about skin scar – understanding the irritation
- How to self care with multiple amputations – documentation and information required.

Group 2

- Right from the beginning – surgery
- Lack of data regarding use of the product
- PT/OT specific to ULA
- Peer support
- Find a champion (i.e. peer)

Group 4

- User at centre of continuum of care
- Changes in life circumstances – understand user journey and need to return to another stage / different prosthesis / training etc – built into life long care
- Motivation to learn new devices / technology
- Understanding options for care / prosthetics etc
- Congenital may not have full disciplinary care therefore a need to increase access to necessary clinicians

Group 1

- Support team – support family
- Parental guidance – everything will be ok – raise them as a child
- Don't pre-emphasise the issue/limb loss
- Self-acceptance
- Understanding someone else 'like me' – having someone in your life that has similar experience / amputation
- Depression which then takes amputees down a different path
- Understanding psychology around limb loss
- Please the parents more than the child, Data base of champions hosted on IC2A

Summarising comments:

One of the main priorities identified in the gaps for the continuum of care for upper limb amputees was the need / lack of peer support offered.

In conjunction with peer support the need for educating and supporting the care givers / parents was also important to include as part of the continuum of care.

A second priority was the inclusion and importance of psychology and understanding the impacts of limb loss both acquired and congenitally.

All of these elements support what has been found as part of the OneHand project and will be included as part of the guidelines.



Image: One group discussing the questions posed by the Think Tank Panel

Question 3: Improvement of standard of care

What are the actions to take to improve standard of care for individuals with upper limb acquired amputation or congenital deficiency?

Group 3

- Education
- Awareness / exposure
- How do you measure and improvement of care
- Clinicians = why do we need a pathway as we have coped without? Need for systemic change and understanding / education
- Information is lost from service users as taken on board initially but not shared across the sector
- Information / literature
- Peer support not offered as regularly
- Alignment needs to be checked like lower limb as it reduces function
- Not being referred appropriately if information not known by clinician
- Individual 'case manager' from beginning – listen to individual case

Summarising comments:

We did not have time to hear from each group on this particular topic but one of the panalists were able to summarise their groups discussion which is featured above. During question 1 and 2 however discussions for improving the standard of care for congenital limb loss were included.

A resounding statement for all groups was that it is important for education to be provided to the parents and care givers, to understand '*all will be ok*' but again well-educated/experienced clinicians in the field of upper limb amputation rehabilitation is required.

Question 4: Improvements of technology advances

What are the obstacles to make the emerging bionics innovations for upper limb extremities accepted as standard of care (3D-printed socket, osseointegration (OI), targeted muscle reinnervation (TMR), regenerative peripheral nerve interfaces (RPNI), haptic feedback)?

- Research knowledge / lack of information for upper limb
- Introducing new ideas regarding technology needs funding support depending on health systems
- Private driven not health system / governmental level
- Cost prohibitive / funding - knowledge what can / can't be accessed
- Lack of equipment to provide/produce to produce new technology
- Knowledge of equipment use - lacking

Summarising comments:

We did not have time to hear from each group on this particular topic it was discussed in the final comments. More research and studies for upper limb is required to be included as part of the standard of care.

Final Comments

- Lack of fiscal studies with bionics (Tom's group)
- Lack of evidence and data
- Lack of experience in upper limb (online group)
- Balancing residual functional limb v using a prosthesis (hard decision) (Ola)
- Standard of care – fit within the individual requirements (Isabelle)
- Peer to peer (user, friends, spouses) how do we disseminate that , access to care, insurance, why do we need this ? Reintegration to community – peer to peer resources demonstrates needs
- Great need for exchange of knowledge
- Every country needs a user organization

Conclusion

Overall, it is clear that upper limb prosthetic users require clearer documentation and resources to support their rehabilitation journey. This also includes information and guidance for their parents and care givers.

Acquired and congenital limb loss therefore require separate documentation to support the rehabilitation verses habilitation journeys.

The need for specialised upper limb rehabilitation personnel is also required. This also aligns with the World Health Organization recommendations for personnel. As part of the rehabilitation journey peer support and psychology should be included at every stage.

One of the most positive things to come out of this Think Tank was that it reinforced what IC2A has already included as part of the guidelines and highlighted other key areas to ensure are documented appropriately for example skin care (not just wound care) and the need to balance the rehabilitation and retraining of the unaffected limb as well as the affected limb.

IC2A looks forward to sharing the guidelines on their website in early 2024.

Image: Two groups discussing the questions posed by the Think Tank Panel

