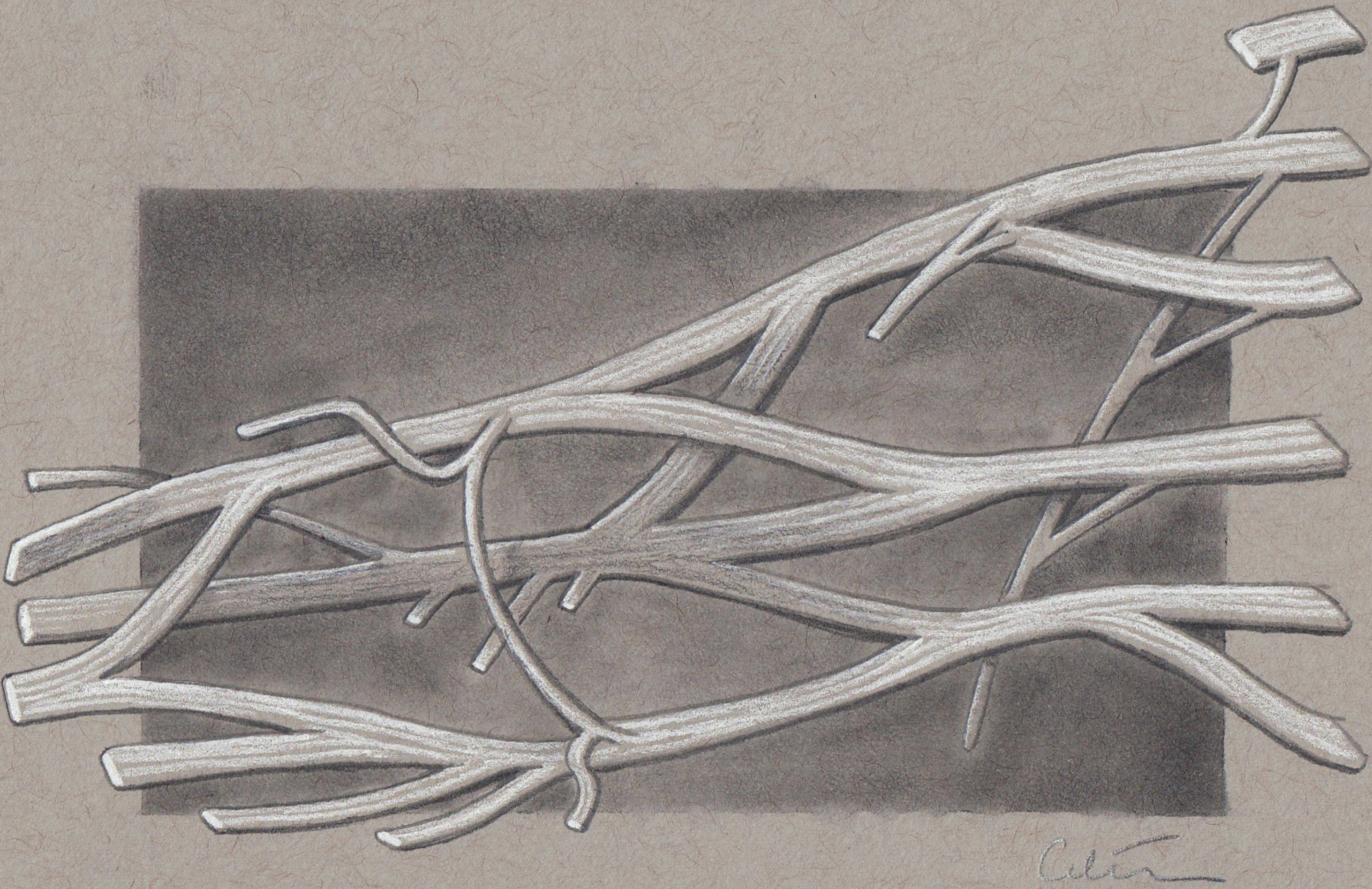
Traumatic
Brachial
Plexus
Injury
James Lind Alliance PSP



Top 10 UK Research Priorities for Traumatic Brachial Plexus Injuries (TBPI)

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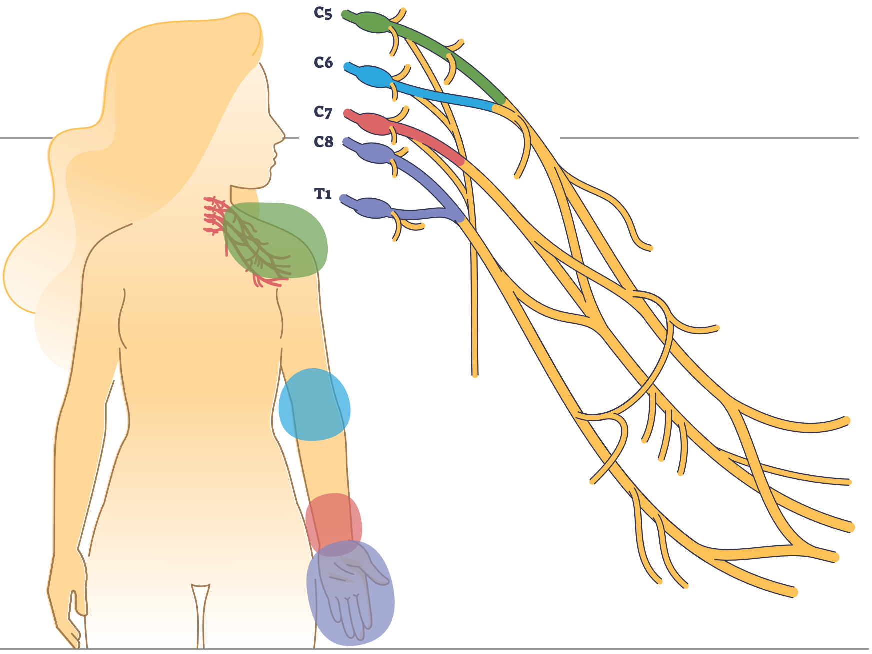
James Lind Alliance
Priority Setting Partnerships

Traumatic Brachial Plexus Injury
James Lind Alliance PSP

Trauma Brachial Plexus Injuries Group
www.tbpi-group.org
Charity Registration No. 1100691

Introduction

Traumatic Brachial Plexus Injuries (TBPI) are life changing and can lead to permanent changes in function of the arm and hand.



The severity of symptoms can vary greatly from person to person, and between different affected nerves and joints. In some individuals, symptoms can be short-term (lasting a few months), whereas most people experience continuous and severe problems for the rest of their lives. Symptoms can include pain, numbness, stiffness, muscle weakness and reduced movement in the shoulder, arm and hand.

Historically, research has focussed on the perceived priorities of researchers. The importance of addressing research towards those priorities identified by individuals with lived experience of TBPI is being increasingly recognised. Involvement from patients, carers and the public as partners in research improves the utility and conduct of research, with further positive impacts on the people involved. A priority setting partnership was therefore developed to set the research priorities regarding the assessment, diagnosis, treatment and care and support of people living with TBPI.

The TBPI PSP team would like to thank the members of the Steering Group, and the James Lind Alliance (JLA) advisers, Nahid Ahmad and Katherine Cowan, for overseeing and guiding this process. We would not have succeeded without their expertise and guidance.

The James Lind Alliance (JLA) brings together patients, carers and health and social care professionals in Priority Setting Partnerships (PSPs) to agree what research matters most in given disease areas.

Acknowledgements

PSP Team

Co-leads:

Hazel Brown

Consultant Physiotherapist working in the South West Plexus Team (SWePT) at Bristol Hospitals. Hazel has a special interest in Adult and Birth Brachial Plexus Injuries. Hazel is also a Doctoral Researcher and Clinical Research Fellow at UCL Centre for Nerve Engineering.

Tom Quick

Associate Professor and a Consultant Surgeon in in the South West Plexus Team (SWePT) at Bristol Hospitals the University of Bristol and Cleveland Clinic London. His clinical interests include Traumatic and Birth Brachial Plexus Injuries and Thoracic Outlet Syndrome. Tom is Clinical Lead for Peripheral Nerve research at the UCL Centre for Nerve Engineering.

SOUTH WEST
BRACHIAL PLEXUS
TEAM

Steering group

We would like to thank and acknowledge the contribution of the TBPI JLA steering group

Charity Partners:

- TBPI-UK Charity
- RNOH Charity

Patient Partners:

- Steve Bloyce
- Phill Burke
- Neil Finney
- Louis James
- Erika Kennington
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Outline of the process

The Road to the Top 10

To identify the Top 10 most important, unanswered questions about Traumatic Brachial Plexus Injuries (TBPI) we followed a priority-setting process.

Autumn 2022

Steering group formed

A group of people with lived experience of TBPI were assembled to work alongside clinical experts from the specialist centres in the UK and the national charity for TBPI.

Spring 2023

Initial survey launched

Summer 2023

Survey results analysed

704 research questions were submitted from 154 respondents from all over the UK.

Autumn 2023

Sorting and refining

Submitted questions were reviewed and themed to reduce the questions down to 68. These 'uncertainties' were checked against the existing evidence base.

3 questions were found to be already answered by research and were removed.

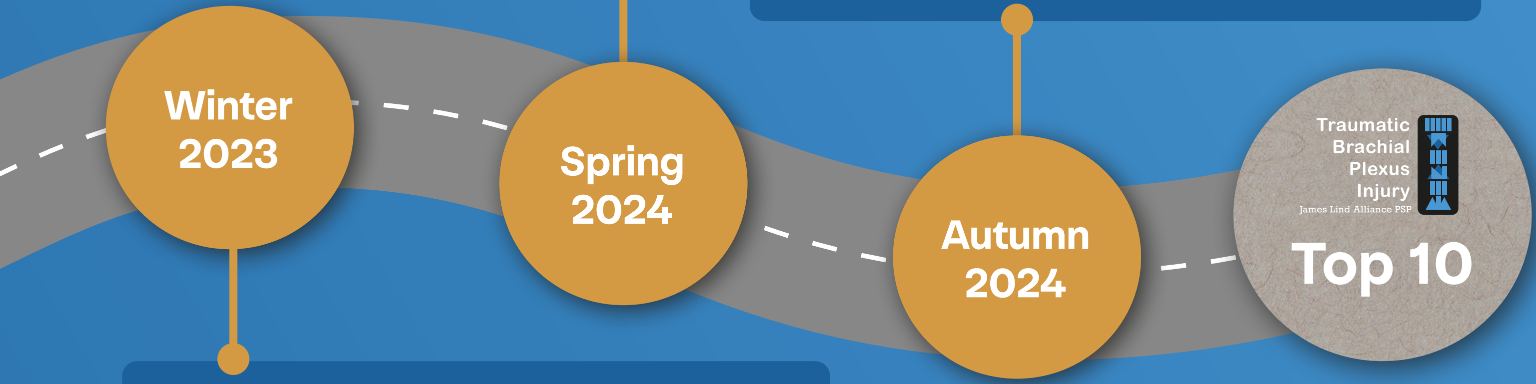
Preliminary ranking

78 people took part in the interim survey. The 22 most commonly voted for questions were identified and taken forward for discussion and prioritising in the final workshop.

Final PSP Workshop

22 questions were discussed and prioritised in a workshop attended by members of the steering group as well as other professionals, patients and family members who were new to the project.

The Top 10 research priorities for TBPI were agreed.



Interim survey launched

65 questions were entered into a second survey. Respondents were requested to vote for their Top 10 most important questions from the list.

The Top Ten priorities for TBPI research

1. Do psychological treatments improve outcomes for people with TBPI. When should they be given and by what methods?
2. What is the ideal care pathway for TBPI (from initial injury onwards)?
3. What are the best occupational and physiotherapy treatment and management strategies for TBPI?
4. Which tests (clinical, imaging, blood tests, nerve tests, biomarkers) are able to identify when surgery may be helpful?
5. How can the results from surgery be better compared to identify: the best time after injury to operate, the best surgical techniques, how well the surgery has worked, and the common risks and complications?
6. What are the best ways to promote nerve recovery and healing?
7. What are the best pain medications, how often should they be reviewed, which have the least long-term side effects, can new therapies be developed?
8. How can muscle fatigue, atrophy and function/control be improved following TBPI?
9. How can we (better) support patients who have gone through life changing injuries?
10. What robotic technology or devices can better assist and support arm and hand function in someone with a TBPI?

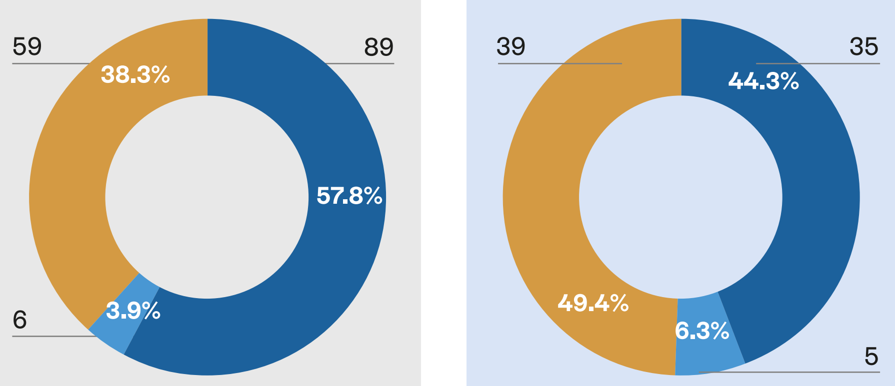
Who Participated?

Demographics from initial and interim surveys

Category	**Initial Survey** (%)	**Interim Survey** (%)
Total responses	154	79

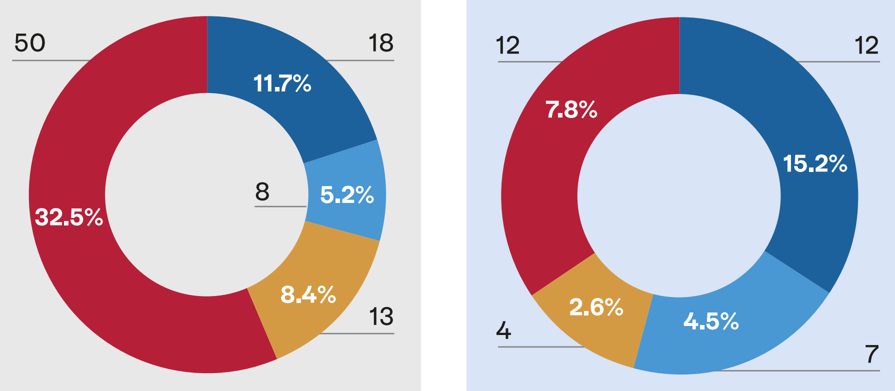
Initial Survey (%) | **Interim Survey** (%)

Respondent type



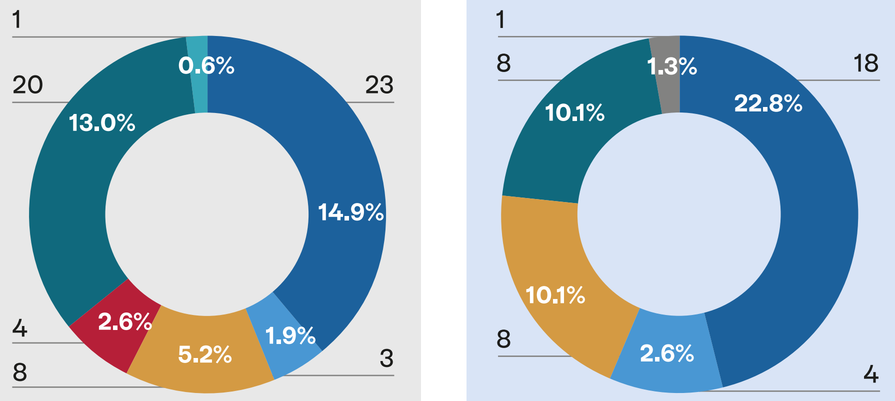
- ● Person with TBPI
- ● Caregiver/family of someone with TBPI
- ● Health care professional

Individual with TBPI - Time since injury



- ● 0-2 years
- ● 2-5 years
- ● 5-10 years
- ● Over 10 years

Health care professionals

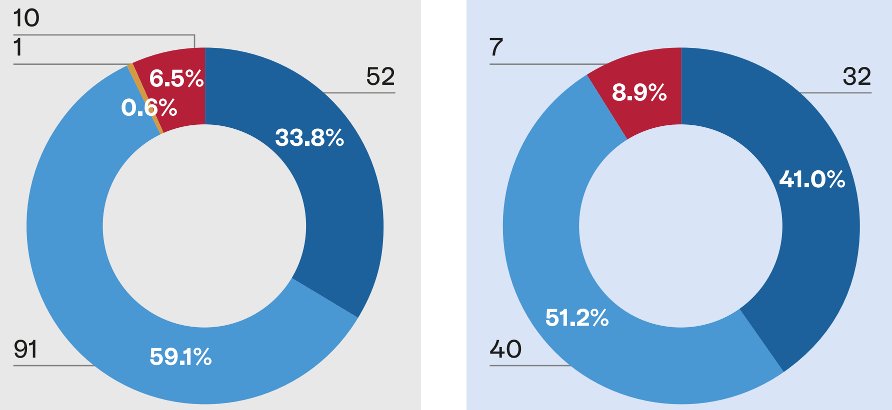


- ● Doctor
- ● Nurse
- ● Occupational Therapist
- ● Orthotist
- ● Physiotherapist
- ● Prosthetist
- ● Support worker

Initial Survey (%)

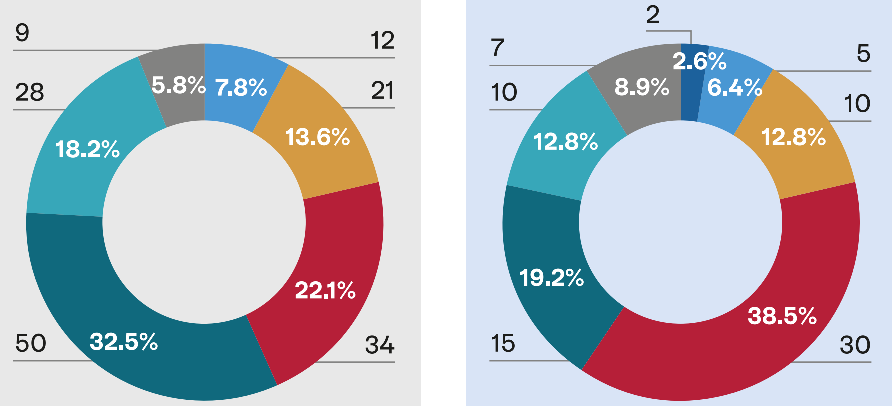
Interim Survey (%)

Gender



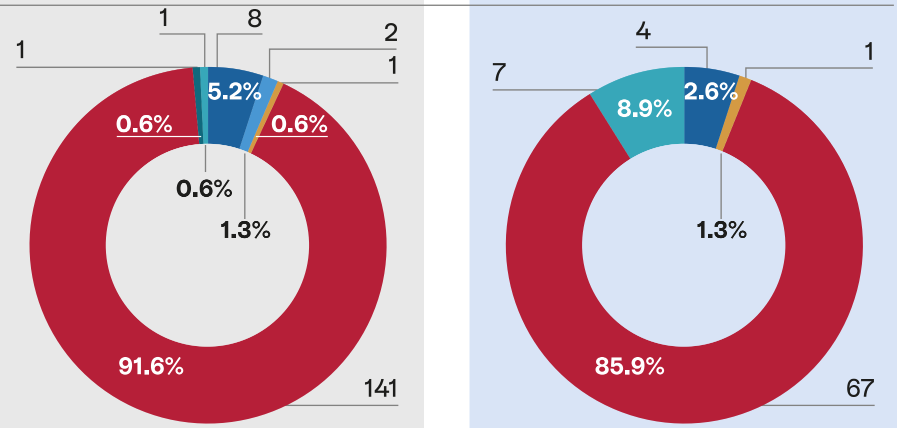
- ● Female
- ● Male
- ● Other
- ● Prefer not to say

Age



- ● Under 20
- ● 20-29
- ● 30-39
- ● 40-49
- ● 50-59
- ● Over 60
- ● Prefer not to say

Ethnicity



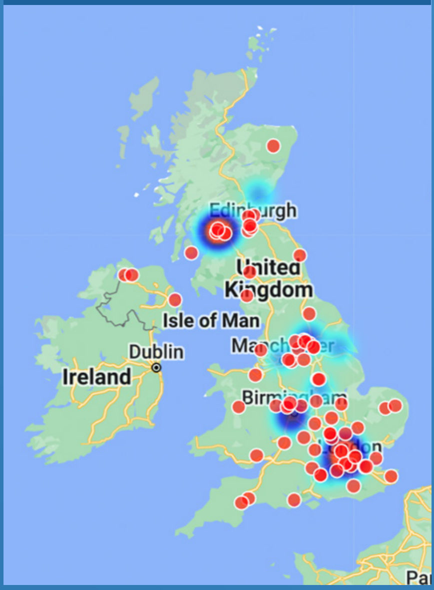
- ● Asian (all backgrounds)
- ● Black (all backgrounds)
- ● Mixed (multiple backgrounds)
- ● White (all backgrounds)
- ● Other
- ● Prefer not to say

There was fantastic participation from individuals throughout the UK with all major regions being represented.

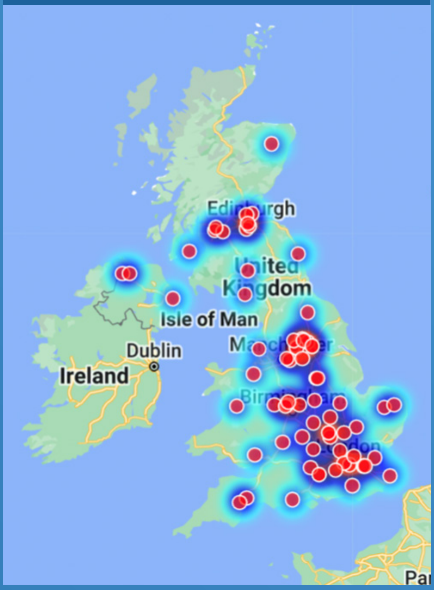
GeoMap of Healthcare Professionals and those with TBPI and their Families/Carers

Healthcare professionals

Those with TBPI and their families/carers (Healthcare Professionals shown in heat map)

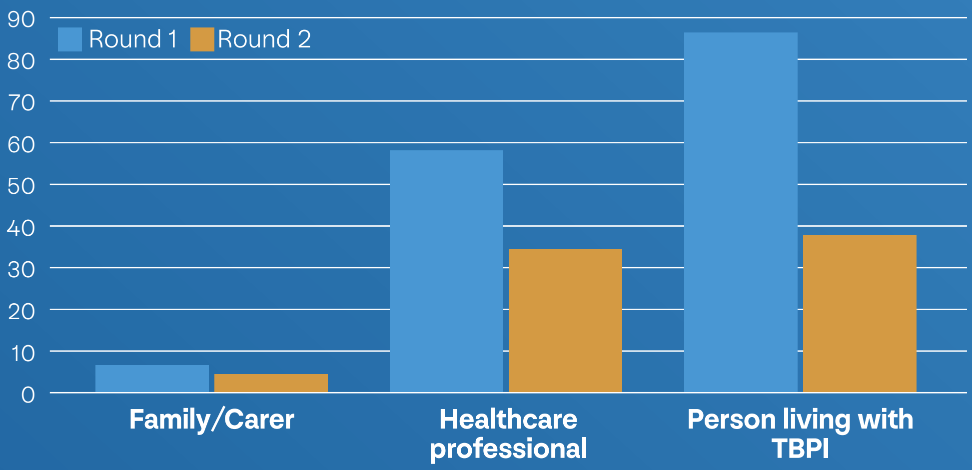


Those with TBPI and their families/carers



*Other Regions Reported: Those with TBPI and Their Families/Carers: Australia, USA, Canada. Healthcare Professionals: Netherlands, Australia.

Participant Role

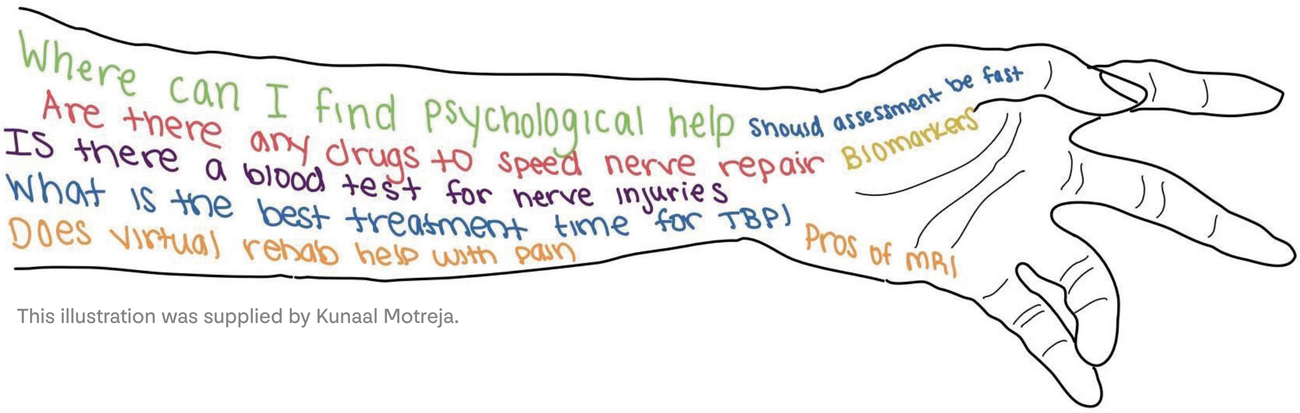


Those who had lived experience of TBPI were the highest responders in both rounds of the survey.

Gathering uncertainties - Round 1 Survey

Responders and uncertainties	Number	Percentage
Total respondents (across all methods)	154	100
Total patients and carers	95	61
Total health and care professionals	59	39
Total number of original uncertainties submitted	704	100
Original uncertainties in scope	641	91
Original uncertainties out of scope	63	9

Responses were reviewed and collated into interim questions to be checked against the evidence base and entered into the prioritisation process.



This illustration was supplied by Kunaal Motreja.

Responders and uncertainties	Number	Percentage
Total number of indicative questions (answered & unanswered)	68	100
Number of verified answered questions	3	4
Number of verified unanswered questions	65	96
Number of verified unanswered questions included in the interim prioritisation	63	Not applicable
Total respondents (across all methods)	79	100
Total patients and carers	44	56
Total health and care professionals	35	44
Number of questions taken to final workshop	22	Not applicable

The final workshop

The final workshop was held in the Queen Elizabeth II Hospital, Birmingham.

22 people attended the final workshop. They included 9 individuals living with TBPI, 2 family members and 11 health care professionals.

Facilitation of the two groups led to lively discussions and the day was expertly facilitated to keep to time and rank all the 22 questions to produce the final Top 10 questions.

There were lots of exchanges of opinions between participants. One centred around the interpretation of how researchers might be able to include the consideration of family members into "how can we (better) support patients who have gone through life changing injuries?"

> "I was pleased to be able to highlight the issues of the impact of the family of the patient, during the sessions. I had several people approach me, after the break out groups, to say they now realise how their parents must have felt and I know that when we switched break out groups some of the people from my original group really pushed to get that question into the Top 10, after seeing the impact on me. I know that the patients' needs will always be the most important, but the family are the ones that support them through and it does have a real impact on us too."

There were several suggestions to merge the wording of the two questions relating to pain ("Can new therapies for nerve pain be developed?" and "What are the best pain medications, how often should they be reviewed and which have the least long-term side effects?") into one question for the final publication of the Top 10 – this would allow another priority to fall within the Top 10. This was voted on by the steering group with 92% agreement.

Feedback received from workshop participants on the Top 10...

> “Whilst sounding quite selfish, the Workshop made it apparent that I was not alone in seeking psychological support, there were others who also recognised its importance. Equally, it was vital that the Workshop priorities recognised all types and stages of care/innovation. The Workshop participants listened to one another and, I believe, achieved that balance.”

> “I found the day very useful and very emotional at times, talking about feelings that I have probably kept to myself since my son’s accident.”

> “I don’t have any strong views on why any of the top 10 is particularly important, just that they all are! What I’ve really liked is that we’ve arrived at them as a collective from so many different aspects of the injury. I thought the workshop was excellent and that although we each may well have chosen a different Top 10 the right result was achieved because of our combination of different angles of looking at the injury.”

Questions 11 to 21 from the final workshop

11 How can we predict how long will it take to recover, and how good the recovery will be, and can this be improved?

12 What is the impact of TBPI on friends and family and how can they be supported?

13 What is the best treatment for total brachial plexus injuries (complete arm paralysis)?

14 How can we better predict outcomes by using nerve tests or measurements during surgery?

15 Which technique(s) can accurately and reliably diagnose a nerve root avulsion (nerves pulled out from spinal cord) and once diagnosed how are these best treated?

16 What functional outcomes are considered when making decisions about surgery?

17 What alternative medicines and supplements (including CBD, medical marijuana, vitamins, animal venoms and compounds) are effective in treating TBPI and its associated nerve pain?

18 What are the long-term effects on the body (e.g. musculoskeletal system, cardiovascular system, skin, other organs, and systems) in a person with TBPI?

19 Would a national database or registry aid monitoring of patient recovery?

20 Does early assessment, diagnosis and treatment improve the chance of normal function?

21 Does the use of a standardised method of assessment improve treatment and outcomes for people with a TBPI?

The importance of the Top Ten

In this section, we tell the stories of each of the Top 10 Priorities. Although the list is numbered the PSP has decided to give equal weighting to each question within the Top 10.

We include the original questions that inspired them, some information on the question and lack of evidence.

Finally, people with a lived experience of brachial plexus injury and people with an interest in research tell us why each priority matters to them.

1

Do psychological treatments improve outcomes (e.g. pain, engagement with treatments, acceptance, coping, anxiety, depression, function, PTSD) for people with TBPI. When should they be given and by what methods?

Original questions submitted related to psychology and brachial plexus injuries included:

1. Does early formal psychology input influence pain and coping strategies?
2. Mental health support as standard and offered long term as needed throughout the full duration of this injury.
3. What are the most effective psychological treatments for adults with BPI?
4. How can we better support people with TBPI who have resulting mental health challenges? (e.g. with education and awareness, a more timely diagnosis, which treatments are most effective)
5. What is the best way to cope with the injury?

Caroline Miller – Physiotherapist and Researcher

I am a Physiotherapist who has treated adults with brachial plexus injuries at University Hospitals Birmingham for many years and I also lead research with adults with this injury. I know that from treating and talking to adults with the injury that it has life changing consequences, not only in terms of physically but also mentally.

Initially, people with the injury may need to address the psychological impact of a severe traumatic incident, which resulted in the injury, when often the medical focus is on helping the arm to move. I have seen how adults with the injury need to deal with the uncertainty of how much they can expect to recover when sometimes healthcare professionals and the research don't have the answers. Additionally, people with a brachial plexus injury may need to adjust both physically and mentally to live in a different way because of the severe pain or the loss of movement or feeling. All too often though, rehabilitation focuses on the physical aspect of recovery.

I am excited that this James Lind Alliance Top Ten has identified that research into psychological treatments should be a key research priority going forward. This means that as researchers we can justify to national research bodies why funding this research is important to patients, their families and healthcare professionals. This will support funding towards researching psychological treatments and ensure we can provide the best possible care for adults with brachial plexus injury in the future.

Phill Burke – Patient Partner

I speak as someone who has lived with a TBPI for almost 20 years, and also in the capacity of my role as a committee member of the TBPI Group charity.

I have first-hand experience of fighting with the injury and the early days/weeks & months of having to wait for any signs of recovery (post-surgery).

This is truly a life changing injury on its own, without the added complication of debilitating pain, and so, it's not the sort of thing that someone can come through the other side of unchanged mentally, and that change starts very early on, unfortunately most, if not all of the focus within the medical world is on restoring or improving function of the affected limb, with the hope that this will restore balance to the patient.

In my experience and seeing it all too frequently in the people I meet through the charity, this is rarely the case.

I was around 6 months in to my 'journey' when my wife started to see the signs of depression in me, it wasn't easy to access the mental health support that I needed, I spoke to the staff that I was seeing frequently, but they regrettably informed me that it wasn't something they could help me with, I would have to start with my GP, this slowed the whole process down. I wouldn't be surprised if it were to take longer now, with the current pressure and workload that our NHS is under.

I truly believe that research into this is desperately needed because this care and support has been missing from the step-by-step treatment of TBPI cases, I'd like to see evidence showing how much better the outcome and recovery of individuals would be if they were in a strong and healthy state of mind. There is already proof available showing how CBT and MBSR can help treat chronic pain, and this natural approach must offer many long-term benefits over medication, but it has to be proactive rather than reactive, my anecdotal evidence suggests that almost all TBPI cases would benefit from it.

2

What is the ideal care pathway for TBPI (from initial injury onwards)?

Original questions submitted related to care pathways and brachial plexus injuries included:

1. What professions should a specialist team be comprised of?
2. What is the best protocol (including clinician reported, patient reported, functional and imaging/neurophysiological/biomarker tests) for the serial evaluation of recovery following TBPI?
3. What does ideal standard of care for TBPI look like (from initial injury to long term follow-up including self-referral)?
4. Does early referral to specialist services affect outcome following TBPI?
5. Is care best provided in specialist/tertiary MDT centres or by local services with individuals with a special interest in TBPI or in private practice?

Grainne Bourke – Surgeon and Researcher

I am an Honorary Clinical Associate Professor and a Consultant Plastic Surgeon in the Leeds Teaching Hospitals Trust. I am the Immediate Past President of the British Society for Surgery of the Hand. I have been treating patients with Brachial Plexus Injuries for 20 years. During this time, we have established a multidisciplinary team of doctors, therapists, psychologists, pain specialists and researchers to help us deliver a better service for patients with nerve injuries. Through our research and listening to our patients, we know that across the UK, patients can have very different experiences. For example, getting to specialist clinics can be a great challenge and be costly when people are struggling financially. However, we also know that early nerve reconstruction and repair (only available at speciality centres) gives the best chance of physical recovery. Some patients really struggle to see a pain specialist or to understand how to get financial or psychological help. There is a lot of variation in the provision of services and patients, families and healthcare professional do not have the information they need to help.

In my opinion, an ideal care pathway is consistent, safe, high quality, evidenced based and cost effective. It supports communication and education for care providers and patients. It encourages healthcare providers to work together with Patient and Public involvement and Engagement to produce a care pathway that is inclusive, equitable, robust, patient centred and that can be monitored and adjusted in real time. This goes hand in hand with data collection, deciding the best way to judge the outcome from surgery or other treatments and improving options for holistic treatments with research and innovation.

Understanding and implementing the ideal care pathway for Traumatic Brachial Plexus Injury is a key question for me in the Top Ten Priorities.

Martin Cawley – Patient Partner

This question means a lot to me. As someone who experienced a life-changing TBPI in 2016 I can say confidently in 2025 that I didn't understand what had really happened to me, let alone the ongoing impact the injury would have. And I still don't. Unlike most common injuries, e.g. a broken wrist, there is no simple way forward with a TBPI. Although I'm sure the different departments involved in my recovery were/are more connected, perhaps more can be done with the patient to set their mind at ease about the pathway. I and friends and family would've felt less anxious just knowing there is something formulated for when patients sustain a TBPI. The road is a long and complicated one, so knowing that scan A will be followed by test B and operation C for example, could bring confidence to an otherwise unfamiliar, uncertain situation. One where the patient might well be thinking "shouldn't I just have this arm amputated?"

3

What are the best occupational and physiotherapy treatment and management strategies (including hand therapy, exercises, hydrotherapy, massage, electrotherapy, scar management techniques etc.) for TBPI?

Original questions submitted related to physical therapies and brachial plexus injuries included:

1. What exercises/exercise approaches work best for restoring function after (any) nerve transfer or reconstruction?
2. What interventions / support favours return to employment for patients with TBPI?
3. What is the most effective treatment for hand stiffness?
4. Gym exercises to improve recovery but also improve lifestyle and quality of life post TBPI. It’s a life changing injury and these could greatly help processing this, improving lifestyle and Mental Wellbeing.
5. How useful is electro stimulation in regards with nerve healing?

Bridget Hill – Physiotherapist and Researcher

Bridget Hill is a Physiotherapist and Early Career Researcher having been awarded her PhD in 2017. She has wide research interests including the development, evaluation and use of outcome measures particularly for the upper limb, and the management of brachial plexus and spinal cord injury.

While it has been fascinating to see the explosion of publications over the last 30 years detailing exciting new surgical approaches to the management of Brachial Plexus Injury, I think that the number of prospective studies that have investigated physio / occupational therapy modalities for this condition can be counted on less than 1 hand. Certainly, we can find several papers that outline good clinical practice based on sound clinical reasoning, but we are yet to see well designed studies that investigate potential treatment regimens when it comes to such a debilitating and lifelong condition.

For me a key to providing the best management strategy starts with therapists who need a very clear understanding and clinical experience of the condition and the myriad of potential modalities that can be utilised. Education is central to therapy at all stages of rehabilitation to provide the person with a TBPI and their family with a clearer understanding of the injury, the expected course of recovery and the potential time frames. In addition, patients must learn how to care for the limb especially if it is flail or sensation is poor. Where possible return work or study (within the confines of any additional injuries) is important throughout rehabilitation and should be encouraged as part of therapy at all stages even pre reconstruction.

Pre reconstruction be it tendon or nerves, therapy should be aimed at maintaining range of movement, be it active or passive, along with a cortical representation of the limb. Home exercise programs are simple to teach along with judicious use of gym programs. Encouraging the use of the limb in 2 handed tasks where the use of aids or compensatory techniques should be encouraged. Positioning the hand so it can be seen and touched while limiting the long-term use of splints or slings that can encourage stiffness and learned non-use. As a lower motor neurone injury functional electrical stimulation does not have a role at this stage.

The immediate post reconstruction phase is aimed at protecting the reconstruction including oedema and wound management, along with splinting as required. Therapists need to have a good knowledge of the surgery provided and post op protocols which will be markedly different for tendon or nerve transfers.

In recent years donor activation focused rehabilitation approach (DAFRA) or induction exercise has been gaining some traction following nerve transfers. Exercising the donor while performing the action of the recipient, DAFRA aims to develop new motor patterns. This can be complemented by using functional electrical stims or biofeedback once volitional movement is seen. Eccentric muscle exercises can also be very useful in the early phase of reinnervation. Hydrotherapy to unweight the limb or the use of slings or slide sheets to reduce friction can all be simple cheap ways of re-educating movement. As with pre surgery using the limb in day-to-day functional tasks is invaluable in helping to re-establish motor patterns and people with TBPI should be encouraged to use their limb whenever possible. Pain can be very debilitating and working with a dedicated pain team is recommended.

Intensive bursts of therapy when change is noted can assist in using the limb functionally and working together as part of a wider multidisciplinary team that includes disciplines such as exercise physiologists, orthotists and psychologists is essential.

Conor Todd – Patient Partner

I suffered a right side TBPI because of a motorcycle accident in August 2022. I have had two operations, in September 2022 (Spinal accessory to suprascapular nerve transfer) and February 2023 (Oberlin transfer). I am seeing improvements in range of motion and muscle strength following my surgeries but still have loss of feeling in my index finger and thumb. I am interested in the improvements of treatments for TBPI and hope that my experience could be of value to others who experience a TBPI. I am a fully trained chef but have moved into management since my injury and surgeries.

As someone who has experienced a TBPI and gone through 2 years of occupational and physiotherapy treatment following my accident, I feel that this a key area to be researched. These areas are vital in recovery process not only from the injury but also from the surgeries I underwent to help repair the damage to my nerves. I will never quite forget the shock of seeing my arm remaining stiff at a ninety-degree angle upon removing my sling six weeks after my first surgery. This is where I first realised how important it was for me to follow the guidance of my Physio and OT.

One of the greatest periods in my physiotherapy journey was the weeklong inpatient rehab program, where I had the opportunity to dive into the tools and aids available to assist me in completing day to day tasks, that I had been finding difficult. This is also where I began my pathway back into the gym as I was able to spend time each day with my PT trying out different equipment to assess what I could do and what would benefit me the most in my recovery. The use of electrotherapy was another great insight for me, both pre- and post-surgery, as I was able to identify the changes in my muscle's response to stimulus. This helped give me a massive boost to push on with my exercises and regain as much movement and function as possible in my affected arm.

Finally, hydrotherapy is for me one of the areas that had has the most impact in my recovery. All the big changes that I have noticed following my surgeries have been when I am in a swimming pool, without gravity to fight against I was able to identify new movement and nerve activation. Once I had mastered the movement trigger and worked on it consistently in the water, I was then able to progress performing the movement against gravity out of the water and eventually progressed to carrying out the movement with weight.

4

Which tests (clinical, imaging, blood tests, nerve tests, biomarkers) are able to identify when surgery may be helpful?

Original questions submitted related to medical tests and brachial plexus injuries included:

1. Improved imaging and neurophysiology to define the severity and extent of injury more accurately.
2. What’s the best way to see the damage?
3. It would be helpful to look at new or improving technologies that could help us with more objective assessments in clinic.
4. How can we more accurately establish where damage has occurred in the brachial plexus and what type of damage?
5. Are there any blood tests/ imaging tests that are biomarkers for recovery?

Ryckie Wade – Surgeon and Researcher

I'm the NIHR Academic Clinical Lecturer in Plastic Surgery in Leeds. Our group is focussed on developing quantitative methods (principally MRI) to measure the health of nerves and end-organs, and changes within the central nervous system following nerve injury. We believe that MRI is the ideal technology because: a) it's biologically safe, b) images of varying contrast with unparalleled fidelity can be acquired without radiation or drugs, c) physiology, structure and function can be measured non-invasively and simultaneously, using d) ubiquitous technology which is present in almost every hospital in the developed world. All of this can be achieved at a lower cost than other medical tests commonly used for the assessment of neuropathy.

Quantitative MRI (qMRI) is a field concerned with generating reliable, repeatable and objective measurements of 'the health of a tissue'. Within peripheral nerves, qMRI parameters are sensitive to axon type, diameter, myelination, density and organisation. Furthermore, we are mapping connectivity, size and shape changes in the brain and spinal cord, and interhemispheric differences in neurotransmitters to identify additional biomarkers and options for adjuvant therapies. In skeletal muscles, we are measuring various parameters which change following injury and compression, which may serve as biomarkers of treatment response.

As qMRI parameters can be acquired rapidly from peripheral nerves, skeletal muscles, the spinal cord and brain at the same time as standard MR imaging, we believe qMRI will add value to treatment pathways. In the future, qMRI may serve as an objective and standardised outcome measure for clinical research i.e., quantifying nerve injury, end-organ change and be used for monitoring recovery. Once mature, qMRI could be used alongside traditional clinical assessments and patient-reported outcomes to help inform and illustrate the nature of the injury to patients, predict which treatments may be most beneficial and so, improve outcomes.

Matt Wilcox – Surgeon and Researcher

Matt is an NHS Surgical Resident and leads research at the UCL Centre for Nerve Engineering focused on developing clinical trials of improved therapies for nerve injured patients.

How do I know if I am going to get better? Are there any therapies that can improve my recovery? These are some of the most common questions peripheral nerve injury patients ask clinicians and are reflected in this JLA list of top 10 priorities for traumatic brachial plexus injury. What if we could answer these questions using a simple blood test or provide patients with images of their muscles as they recover following a nerve injury? A team of clinicians and scientists at the UCL Centre for Nerve Engineering have made important steps towards achieving this.

One approach has been the development of a blood test called neurofilament light chain (NfL) for nerve injury diagnosis and management. With less than 1mL of blood, it has been shown in a laboratory study that it is possible to detect nerve injuries and accurately quantify severity (https://onlinelibrary.wiley.com/doi/10.1111/jns.12576). At only around £30 per test, this offers a cost-effective method to help clinicians diagnose and manage nerve injuries. The team are now exploring the validity of this test in nerve injured patients.

Another approach has been to develop improved imaging assessments of muscles using MRI scans. It has been shown that it is possible to track changes in muscle size and structure after a nerve injury (https://www.nature.com/articles/s41598-021-01342-y). A major benefit of this approach has been the ability to show patients images of changes in their muscles before functional recovery is seen. Patients report that this encourages them to remain engaged with rehabilitative programmes despite not feeling any functional improvement. Researchers are also using this tool to develop studies of therapies which have shown promising laboratory results.

Together, it is hoped these technologies will drive improvements in nerve injury diagnosis, monitoring and treatment.

5

How can the results from surgery be better compared to identify: the best time after injury to operate, the best surgical techniques, how well the surgery has worked, and the common risks and complications?

Original questions submitted related to surgery for brachial plexus injuries included:

1. What is the best technique to conduct exploratory surgery to aid diagnosis?
2. What are common surgical risks and complications and how can these be minimised/prevented?
3. What is the best surgical option for avulsion injuries?
4. What is the best intervention for pan/total plexus injuries?
5. What are the best materials and techniques to repair/reconstruct the nerve?

Tim Hems – Surgeon and Researcher

Consultant Hand and Orthopaedic Surgeon, Scottish National Brachial Plexus Injury, Queen Elizabeth University Hospital, Glasgow, UK. Editor Journal of Hand Surgery European Volume.

Following brachial plexus injury surgery is currently the only intervention which can improve nerve regeneration above spontaneous recovery, although some therapy treatments may aid functional outcomes. There are currently no drug treatments which are effective in enhancing nerve regeneration. Therefore, it is important to know which types of operation are most effective and when they should be performed. Surgical interventions broadly include:

- Decompression of nerves and neurolysis. This surgery involves decompression of nerves entrapped by fractures or scar tissue, but not severed, thereby limiting damage and allowing regeneration to proceed.
- Repair of divided nerves by direct suture or nerve grafts.
- Reconstruction of nerves using nerve transfers. This technique involves connection of a functioning nerve to restore an important function in an injured nerve. Nerve transfers have become more widely used in recent years.

In order to evaluate the effectiveness of surgery it is necessary to collect standardised outcome data from sufficient numbers of patients. Collection of data could be improved by establishing a registry for patients with brachial plexus injury. Ideally randomised controlled trials (RCT) should be set up to compare different surgical repairs or timings of surgery. However, small numbers of similar cases (even with a multicentre study) and the need for consensus of uncertainty in management of a given injury may be impediments to establishing an RCT.

There is a need to identify the best combination of outcome measures to compare treatments. Historically outcomes of nerve repairs have often been reported as strength in reinnervated muscles using an inaccurate scale (Medical research council scale). As well as more objective measurements of muscle strength and coordination, it is imperative to evaluate sensory recovery, pain, cold sensitivity, limitation of activity and participation (using patient reported outcome measures), and psychological effects. Since nerve recovery is a slow process follow-up needs to be long enough to assess the final result, usually a minimum of one year and often two years or more. As well as nerve recovery any complications, e.g. from donor sites for nerve transfers or grafts, should be recorded.

Chris Dy – Surgeon and Researcher

Christopher J. Dy, MD MPH FACS - Dr. Dy (dee) is a board-certified orthopaedic hand surgeon with subspecialty expertise in brachial plexus and peripheral nerve injury. Dr. Dy is currently a tenured Associate Professor of Orthopaedic Surgery at Washington University School of Medicine (St. Louis, Missouri, USA). Dr. Dy's research program has focused on improving delivery of care for patients with traumatic brachial plexus injuries (TBPI), including capturing and sharing the patient experience during their interactions with the healthcare system. Dr. Dy leads a NIH-funded multicentre study at 10 leading academic centres in the United States to prospectively assess both surgeon-graded and patient-reported outcomes after surgical treatment for TBPI. Dr. Dy's body of TBPI research was awarded the 2023 Kappa Delta Young Investigator Award, presented by the American Academy of Orthopaedic Surgeons and Orthopaedic Research Society to persons who have performed orthopaedic research that is of high significance and impact.

In order to more rigorously evaluate prognostic factors after injury, we need to enrol patients in collaborative prospective cohort studies that utilize agreed-upon core outcome measures. Once we are able to combine prospectively collected data, we will be able to gather the sample sizes needed for comparative effectiveness research to examine the ideal timing of surgery and outcomes after different treatment strategies. Building this research infrastructure and encouraging international colleagues to contribute their patients will transform BPI research in a way that raises the methodologic rigor, informs potential randomized trials, and opens the door for clinical collaboration and identification of best practices. Incorporating all domains affected by TBPI, such as patient-reported function, quality of life, and pain, will be critical to ensuring that the collected data comprehensively and accurately reflect the patient experience.

6

What are the best ways to promote nerve recovery and healing?

Original questions submitted related to promoting nerve healing in brachial plexus injuries included:

1. Is there a drug to make nerve injury recovery better?
2. What are the best ways to promote nerve regeneration?
3. What drugs can enhance nerve regeneration?
4. Are there any supplements/vitamins that would help recovery?
5. Is there any evidence to support specific nutrients/diet that improve/impact/speed up or slow down recovery?

James Phillips - Scientist

James Phillips is Professor of Regenerative Medicine at University College London and one of the founders of the UCL Centre for Nerve Engineering. He leads a research group focussed on understanding and repairing the damaged nervous system and has worked in nerve research for more than 25 years. Technologies being developed in his lab include construction of living artificial tissues for nerve repair and novel cell, drug, gene, and biomaterial therapies for nervous system repair and protection.

I was fascinated to see the priority setting partnership unfold and I hope that the questions identified as priorities will help to shape the way research efforts are directed in the future. There is now a reliable set of questions that researchers and funders can use to check whether a proposed research direction aligns with the needs identified by healthcare professionals and people living with TBPI.

Question 6 focuses on identifying the best ways to promote nerve recovery and healing, highlighting the fundamental issue that natural nerve regeneration after TBPI tends to be slow and incomplete. Addressing this question requires researchers from different specialities to work together to understand the underpinning biology and identify innovative new therapies that can enhance nerve regeneration. The enormity of this challenge must not be underestimated; this is a highly complex question and the answers will change as research progresses. Even when interventions are developed in the lab that can potentially improve outcomes, progressing these towards clinical application is a daunting task. Knowing that this question has been identified as a priority will help to motivate researchers and other stakeholders, reassuring them that their commitment to working on this topic is informed by people with lived experience of TBPI.

7

What are the best pain medications, how often should they be reviewed, which have the least long-term side effects, can new therapies be developed?

Original questions submitted related to pain medications and brachial plexus injuries included:

1. Can new evidence such as Duloxetine or medicinal cannabis treating chronic pain and its applicability to BPI be researched?
2. What is the best form of pain relief for phantom limb?
3. Will any research and development be undertaken to stop the pain with avulsion injuries?
4. I would like to know what can be done to help those with chronic pain.
5. How frequently are drugs reviewed to manage pain?

Dennis Hazell - Nurse

As a Clinical Nurse Specialist and independent prescriber working with patients with TBPI I frequently get asked about pain medications. Neuropathic Pain (nerve pain) is a predominant feature of any Brachial Plexus Injury. This type of pain is described as sharp, shooting, burning and difficult to predict. When individuals experience these symptoms, they often are left breathless and unable to participate in conversations or the task that they were completing until it subsides.

NICE guidelines for neuropathic pain medication exist, however these are often not well followed, and even when administered, leave the individual with pain which patients still describe as life limiting and uncontrollable. Therefore, future emphasis on improving and developing pain management systems within this patient group is extremely important. Improved control of pain will enable individuals to better participate in their social networks, as well as giving many a better opportunity to return to employment.

8

How can muscle fatigue, atrophy and function/ control be improved following TBPI?

Original questions submitted related to muscle changes and brachial plexus injuries included:

1. Does EMS preserve muscle which has been deinnervated?
2. Can muscle volume assessments be used to monitor recovery?
3. Can you stop the muscle disintegrating in your arm?
4. Are there ways to prevent muscle atrophy while waiting for nerve recovery?
5. How big is the impact of dysregulated motor control (ie movement technique) strategies in the long term recovery of BPI?

Poppy O. Smith - Scientist

Poppy is a Research Fellow at the UCL Centre for Nerve Engineering. She completed her PhD in peripheral nerve injury and nerve tissue engineering, focusing on the development of an artificial alternative to the nerve autograft. Following her doctorate, Poppy's continuing research interests are in the role of muscle atrophy in regeneration and recovery following nerve injury. She also runs a peer support group for those living with nerve injury, in association with the Brain & Spine Foundation. In addition, she co-founded the Nerve Injury Research Alliance; a co-production group uniting researchers and individuals with nerve injuries to shape research design and direction.

We know that nerve regeneration following injury can take years (Standring, 2022). During this time, the muscle(s) controlled by the damaged nerve(s) do not receive the necessary signals to function properly. This leads to the loss of muscle mass and strength, causing the muscles to look smaller and feel weaker. Muscle atrophy worsens over time, and without nerve stimulation, muscle fibrosis can occur, where muscle tissue is replaced with connective tissue, possibly preventing the regain of muscle function after injury (Carlson, 2014; Mahdy, 2019). Therefore, in addition to considering what research can be done to improve nerve regeneration, it is also important to consider the effects of nerve injury on the muscle and how the muscle could be treated alongside the injured nerve injury to improve functional recovery and the quality of life after injury. This is particularly important in TBPI, which results in the loss of movement of the shoulder, arm and/or hand, resulting in significant debilitating effects on day-to-day life.

Currently, no therapeutic is available to reduce or reverse muscle atrophy beyond physical activity and protein intake, a regime not applicable to those with muscle atrophy caused by nerve injury given the consequential muscle paralysis (Langer et al., 2018; Yadav & Dabur, 2024). Exploring how muscles respond to nerve injury and subsequent nerve regeneration could give us a better understanding of the biological responses which underpin TBPI muscle atrophy. In turn, this will help us develop therapies designed to reduce muscle atrophy and improve muscle function following nerve injury. The selection of this question on muscle function for the top 10 research priorities for TBPI is encouraging and accurately reflects themes regularly raised in my Nerve Injury Peer Support Group and Nerve Injury Research Alliance meetings.

Steve Bloyce - Patient Partner

TBPI injury to c5, c6 and c7 in 2015 with double Oberlin and spinal accessory nerve transfers. Currently studying for a Physiotherapy degree alongside working in the NHS. Former GB para pathway athlete and current team UK Invictus indoor rowing coach.

Physical and mental recovery/rehabilitation following an injury like a TBPI is very complex and requires many factors to be in place. The James Lind Alliance PSP Top Ten results have really captured the broad spectrum of questions that get asked by everyone involved in TBPI.

Having taken part in the JLA process, I feel research questions around improving musculature changes in injured people would offer a further level of support initially. This question works well with question 6 and would offer greater clarity in uncertain times for injured people. I think this area of research is exciting and other areas of exercise, health and wellbeing have opportunity here.

9

How can we (better) support patients who have gone through life changing injuries?

Original questions submitted related to support following brachial plexus injuries included:

1. What is the impact on friends and family? how might this be better supported.
2. How much support do people with TBPI currently receive and from what sources? (health care professionals, TBPI group, social media, family and friends etc)
3. Research into the practical issues that patients have ege.g. getting back to driving and how best to provide info and advice.
4. What are the barriers people with TPBI face in society?
5. How readily can ptspatients access services to return to employment or to seek retraining if they can notcannot return to their previous employment.

Lynne Frewin – Family member

Having watched my son suffer a TBPI, in August 2022 and having provided/continued to provide support to him on a physical and emotional level I have felt there was no support for me as the parent (and I mean that in the most unselfish way). I have and continue to suffer with the emotional trauma of watching somebody I love live day to day with his injury. I feel at a loss to accept that I am unable to ‘fix’ him. As a parent, whatever age your children may be, it is my role to make things better when they are hurting. The inability to do this has impacted my mental health on a daily basis. Just having to put this into words brings me to tears.

Of course the wellbeing of the patient is paramount, but equally I believe that the people who are living/caring for the patient day to day should also have an importance when a care package and support package is being put together. Without the family support the patient themselves would find it much harder to cope day to day and learn to live with their life changing injury.

I was glad to be able to raise this at the Brachial Plexus Injury Workshop, back in October 2024, as it prompted several people, patients, healthcare professionals, researchers to approach me afterwards to express how they hadn’t considered this before and in particular the patients who realised how their own parents/families would have felt.

Neil Finney – TBPI Group -UK

This is an important subject for future research because it is an often-overlooked aspect of the injury. We are fortunate in the UK to have an excellent network of medical experts able to deal as far as possible with the physical side of the injury but there comes a time when patients are faced with the daunting prospect of a future coping with a life changing injury.

Issues with pain and PTSD for example are likely to be ongoing. Employment can be a major concern as can the effect of the injury on relationships and self-esteem. Everyday actions that would previously have been undertaken automatically such as getting dressed, preparing food or attending to housework and gardening often require a great deal of adaption.

This is where a network of people who have already been through the above and more are well placed to advise and guide the newly injured through what is to come. Such a network has been able to flourish since the advent of the internet and future research into improving the lives, post injury, of patients can only be a good thing.

10

What robotic technology or devices can better assist and support arm and hand function in someone with a TBPI?

Original questions submitted related to technology and devices and brachial plexus injuries included:

1. What assisting devices do patients find most helpful when recovering from TBPI?
2. Research into cybernetic prosthesis
3. Is there a role for virtual reality in nerve pain and or recovery?
4. At what point should orthotic intervention be considered?
5. Is there an app or device that can be used on patients’ phones for biofeedback that patients can use?

Mandy Sinforiani – Occupational Therapist

As an Occupational Therapist, with a background in Hand Therapy, I have developed an interest in how robotic gloves may have an impact in reducing hand stiffness, stimulating the small muscles of the hand to promote recovery and facilitating improved upper limb function whilst awaiting recovery. Surgical options for the treatment of Brachial Plexus injuries have shown some success in restoring shoulder and elbow function. However, due to the high level of the injury, by the time the functioning nerves reach the hand there are common issues with stiffness and lack of return of intrinsic hand muscles. A small number of patients have self-funded robotic gloves and have reported some benefits. Patients frequently ask therapists if these gloves are recommended to purchase. However, there is a lack of research to fully support their efficacy. In the current NHS financial climate, a request to purchase a new item, such as a robotic glove, would need to be backed up by evidence.

Recently there have been some developments in the use of soft robotic gloves and exoskeletal gloves that are more compact and user friendly (Wenda et al 2020, Millkvist 2024). A small study in 2024, using a Carbon hand glove (Millkvist et al 2024) looked at a convenience sample of 8 Brachial Plexus birth injuries with promising impacts on elbow flexion strength, grip strength and function. The study by Wenda et al 2020, looks at the development of a glove which is able to perform passive abduction and adduction of the digits as well as several basic daily functional tasks. The aim is to restore functionality of the hand for traumatic brachial plexus injuries. It concludes that the glove will require further testing as Brachial Plexus injured patients are under-represented in robotic research.

I believe further research into this area would be extremely beneficial as the intrinsic hand muscles have a crucial role in the function of the hand and are particularly difficult to restore following Brachial Plexus Injury. The use of robotics may be a route to stimulate this recovery. I would be interested in the possibility of a multi-centre trial that targeted the use of robotic gloves bilaterally; utilising mirror therapy whilst wearing the gloves to target simulation of the intrinsic muscles. This may also have a secondary benefit of reducing pain.

Paul Malone – Surgeon and Researcher

I am a Consultant Plastic, Peripheral Nerve, Spasticity and Upper Limb Surgeon, and also a core member of Birmingham's HaPPeN Research Network. I am routinely involved in the management and care of people with Brachial Plexus Injuries and wish to do all I can to improve standards in the delivery of care.

Robotics have the potential to offer a 'quick win' for patients with an upper limb palsy such as following TBPI. Exoskeletons are ideal for when some sensation has been retained, typically requiring a small amount of retained limb function for electrodes to then activate movements: in a single limb-fitting afternoon a patient with a flail limb can demonstrated meaningful restoration of function, for instance be able to feed themselves, despite having a 'flail limb'. Whilst the body may take many months for an incomplete recovery following nerve surgery, robotics have the power to transform recovery, upgrading a paralysed limb to have meaningful function within as little as a day.

Partial or complete limb prostheses may be used following amputation, either sustained from trauma, or planned following trauma, for instance with an insensate total flail limb.

For robotic devices, options also exist for them to be controlled by electrodes elsewhere on the patient: these can be either surface electrodes or implanted, wirelessly linked. Whilst access is limited and costly within an under-resourced and underdeveloped sector, robotic technology (such as an exoskeleton) has the power to transform the rehabilitation phase and significantly uplift function in absence of a complete recovery.

Impact and Next Steps

The Top 10 list generated from this PSP has identified research questions of significant importance for people with TBPI, their families and the healthcare professionals working with them.

There is a balance regarding questions about all aspects of assessment and diagnosis, as well as those which are concerned about the long-term care and support that patients receive. It reflects priorities of multiple stakeholder groups and will inform researchers and funders to drive meaningful future research and improvements in clinical care for people with TBPI.

The TBPI PSP steering group will continue to draw the attention of the public, academic researchers and funding authorities to the questions selected in this process. The PSP outcomes will be presented at national and international conferences. The results will also be advertised on the PSP and TBPI-UK website and circulated to all its members via a regular newsletter.

This PSP has been seen as an important starting point for the nerve injury research community. All the partner hospital trusts are committed to forming a network to help to tackle the questions posed. In addition, they pledge to foster patient and public involvement in the planning and execution of future studies. The successful completion of this project and its outcomes will support the nerve injury research agenda and direct future research paths, of scientific, clinical and societal relevance; making sure that the needs of end users are properly addressed.

Acquisition of funding is a crucial part of the research process. The establishment of the Top 10 research priorities for TBPI will allow researchers to approach funders and highlight the importance of their research in relation to answering these research priorities which are most important to those who are living with TBPI and those who care for them.

The Top 10 questions will be further analysed by researchers and translated into several research questions and proposals. The PSP steering and expert groups are part of this process but will also encourage other research groups with expertise in individual questions to support this process, bringing in additional ideas and accurately translating questions.

NHS
University Hospitals Birmingham
NHS Foundation Trust

NHS
Royal National Orthopedic Hospital
NHS Trust

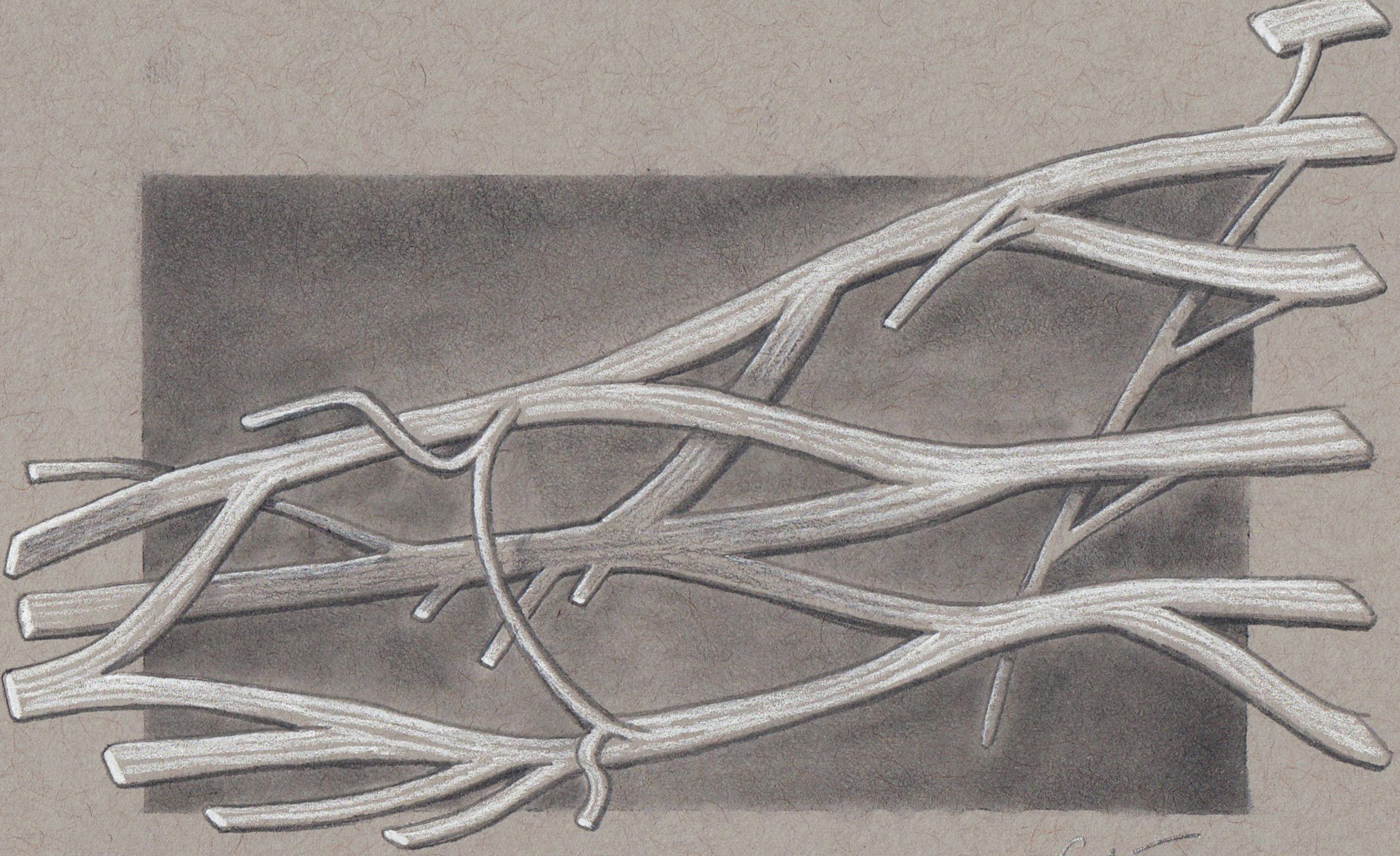
NHS
The Leeds Teaching Hospital
NHS Trust

NHS
North Bristol
NHS Trust

NHS
Greater Glasgow and Clyde

Trauma Brachial Plexus Injuries Group
www.tbpi-group.org
Charity Registration No. 1100691

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Bae Abertawe
Swansea Bay University Health Board



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