

NERVE INJURY COMMUNITY DAY EVALUATION REPORT



Background and aims

On Saturday 16th November 2019, Nerve Injury Community Day brought together 58 people living with or working with nerve injury to share and learn over a day of talks, workshops and conversations.

The event was led by the Centre for Nerve Engineering in collaboration with the Wellcome / EPSRC Centre for Interventional and Surgical Sciences, with funding from EPSRC and the UCLH Biomedical Research Centre.

As a centre directly focused on delivering medical and digital health solutions that meet the needs of patients and the public, the event was intended to bring together people working and living with nerve injury to share experiences and learn from each other.

The centre was aware that given the nature of the condition, the nerve injury community is underserved by national organising bodies and charities. The majority of condition-specific charities are local patient-led groups, meaning people can feel isolated and there is a lack of support and advice.

The event's aims, developed in collaboration with people with nerve injury, were to:

- Work collaboratively with research and patient partners, providing all members with the opportunity to contribute to development of a patient event that brings together relevant stakeholders to hold beneficial conversations around nerve injury
- Provide patients and carers with a relevant and engaging opportunity to hear from research professionals, charities and other people dealing with nerve injuries, with a chance to exchange individual insights and stories of their condition
- Provide opportunities for researchers to engage in beneficial conversations, supporting them to design activities that feed into specific research and thinking, as well as feeding into future CNE-wide PPI activity, including further co-development for a future event

Event development

The event was co-produced with a delivery group of patients, researchers, clinicians and professional services, who came together to plan the themes and content, design the event and almost all took part in the delivery and running of the day.

The group met physically twice, with workshops covering all aspects of the characteristics and feel, content, logistics and promotion. The meetings were facilitated by experienced professionals, using groupwork and exercises to allow equal and open contributions.

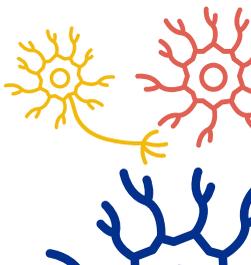
Some of the key insights included:

- the need for a focus on psychological support and pain management
- bringing in carers to contribute and the need for medical professionals to learn too
- designing sessions with and for patients
- how to practically design a nerve injury friendly event

The group continued to comment and feedback between sessions and also volunteered contributions to the event, presenting at talks and workshops.

All the public representatives were reimbursed for their time and travel, including paying those that spoke at the event.

“It’s interesting to learn from the range of experiences, you never meet anyone else that has nerve injury so no one knows what you’re experiencing or has any understanding, even med profs often don’t know. It wasn’t until sitting with other patients that I realised I wasn’t going mad. I think opportunities to talk to other people that have had the same injury is really powerful.”



Event attendance

People came from across the UK, with only 25% of evaluation respondents reporting as being from London and the furthest that people travelled being 582km from Belfast.

Visitors had a range of nerve injury types, with most having experienced brachial plexus injuries, as well as sciatica, Erb's palsy and trigeminal neuropathic pain amongst others.

The event was targeted across types of nerve injury as a way of bringing people together to share their different experiences and share common advice across all. However, we did find this meant content wasn't always relevant for everyone, in particular for Erb's palsy in children.

To help people afford travel we made small bursaries up to £15 available for up to half the participants. However, we found take up wasn't high, with some costs for people being so much higher the bursary seemed pointless, so in hindsight would have provided a higher amount for fewer people.

Format

The day took place at the UCL School of Pharmacy on Saturday 16th November between 11:00 - 16:30.

The space was chosen for being large and easy to access, with all facilities on one floor and split between three large rooms.

The event featured a range of ways to interact and be involved with content, including talks, stalls, Q&As and workshops, purposely done this way to provide different ways to take part, through group or 1-1 interactions, or simply listening to others and information.

Time	Session
10:30 - 11.00	Registration and Stalls
11.00 - 11.45	Introduction Session
11.50 - 12.30	Workshops
12.30 - 13.30	Lunch and Stalls
13.30 - 14.10	Workshops
14.20 - 15.00	Workshops
15.00 - 15.30	Break and Stalls
15.30 - 16.15	Final Session Q&A
16.15 - 17:00	Final Stalls Session



*75% of visitors
came from
outside of
London*

*The furthest
travellers came
from Belfast,
582km away*



Talks

The event started and ended with talks to everyone as a whole, decided on as a chance to set the context for everyone together, then to close the event with a shared exploration of the themes that had come up across the day, posted up by visitors at feedback columns.

Introduction by Dan Taylor, Public Engagement Manager, Wellcome / EPSRC Centre for Interventional and Surgical Sciences

Rebecca Shipley and James Phillips, UCL Centre for Nerve Engineering

The co-directors of the UCL Centre for Nerve Engineering explained the group's work and mission, breaking down how nerve injuries are caused and some of the solutions that the centre and their partners are exploring.

Gary Pearce, Lived Experience of Nerve Injury

A personal account of nerve injury, recounting Gary's own experience of the injury and rehabilitation as well as how the experience changed him and what he learned along the way.

Final Q&A Panel - James Phillips, Tom Quick, Rebecca Shipley and Ed Barnes

Visitors were able to post up their nerve injury questions throughout the event for a mixed panel in our final session to answer and discuss.

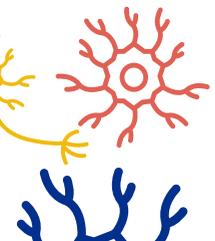
Feedback

Out of our twenty questionnaire respondents 100% rated the talks as 4* or higher out of 5. The majority of comments emphasised the benefit of receiving professional and accessible updates on current research and practice, as well as the real experience shared on stage.

“Well informed specialists and researchers truly wanting to make a difference”

“Great content with a great amount of time allocated for questions”

“Real people sharing real life experiences”



Workshops

Visitors were assigned into three randomised groups as they entered the event, who would stay together throughout the day, forming a cohort who could familiarise with each other as the event continued.

Each group had a member of the UCL Centre for Nerve Engineering team assigned as a guide to direct them to each workshop and become a point of contact throughout the event for advice and support.

Conversations ranged from the psychological effect on those injured and their families through to devices to help butter toast!

Tissue Engineering (Rebecca Shipley, James Phillips & Marilyn Aviles, UCL Centre for Nerve Engineering)

A group discussion about potential future directions of nerve engineering research, exploring people's thoughts and preferences around different, similar potential directions to help the UCL Centre for Nerve Engineering prioritise.

Patient Outcomes (Matthew Wilcox, UCL Centre for Nerve Engineering and Tom Quick, Royal National Orthopaedic Hospital)

Visitors were asked to chart their own journeys of treatment and rehabilitation, opening up conversations about people's priorities for peripheral nerve repair, charting this on large pieces of paper then talking them through together.

Sharing Experiences of Nerve Injury (Steve Bloyce, Lived Experience of Nerve Injury and Ed Barnes, Traumatic Brachial Plexus Injuries Group)

Two members of the co-production team each hosted a table at this workshop to open up conversations about people's personal experiences of nerve injury, inviting people to share the issues they've faced and solutions they've found.

Feedback

The sessions received really strong feedback, especially for being the main time in the event in which visitors could talk and learn from each other and from UCL staff and students.

“Really good and useful to hear other people's point of view and to share mine”

“It was like group therapy – loved every minute of it”

“It’s nice to be asked and listened to”

Stalls

The stalls area was beside the refreshments and lunch area as a chance for visitors to explore topics at their own leisure and to set up 1-1 conversations for those that preferred to have conversations that way or to go into more specifics and depth.

The area featured stalls run by researchers, clinicians, charities and patients across a range of themes and topics. The science-based stalls also featured animations and activities to break down complexity, including a ‘stitch a noodle’ activity to see how nerves are repaired.

Feedback

The stalls were the lowest rated aspect of the day (70% rated them 4 - 5 out of 5), with good feedback about the discussions at these but with many feeling there were barriers to approaching the stalls themselves.

This was part of our learning from the event, as a group of people that rarely get to meet to share experiences and advice, visitors appreciated the breaks much more as a chance to share with each other rather than explore more topics.

Given the informal feel of the event this part could also feel quite daunting, having to approach stallholders, and the area could have done with more clearly marked time, descriptions and space.

“Enjoyed the opportunity to discuss new research and possible surgical techniques”

“Didn’t really get the time to speak to many people on the stalls”

“For an initial event the stalls were good however going forward it would be better having a wider selection and have people approaching us rather than making the daunting task of going to them”



“Enjoyed the opportunity to discuss new research and possible surgical techniques”



Evaluation and Feedback

We evaluated the event using event feedback forms and using a graphic facilitator, Jenny Leonard, who was able to spend more time discussing key questions with visitors as well as a debrief with event contributors.

Visitor Experience

The responses allowed us to gauge that as a whole the event had succeeded in our second aim.

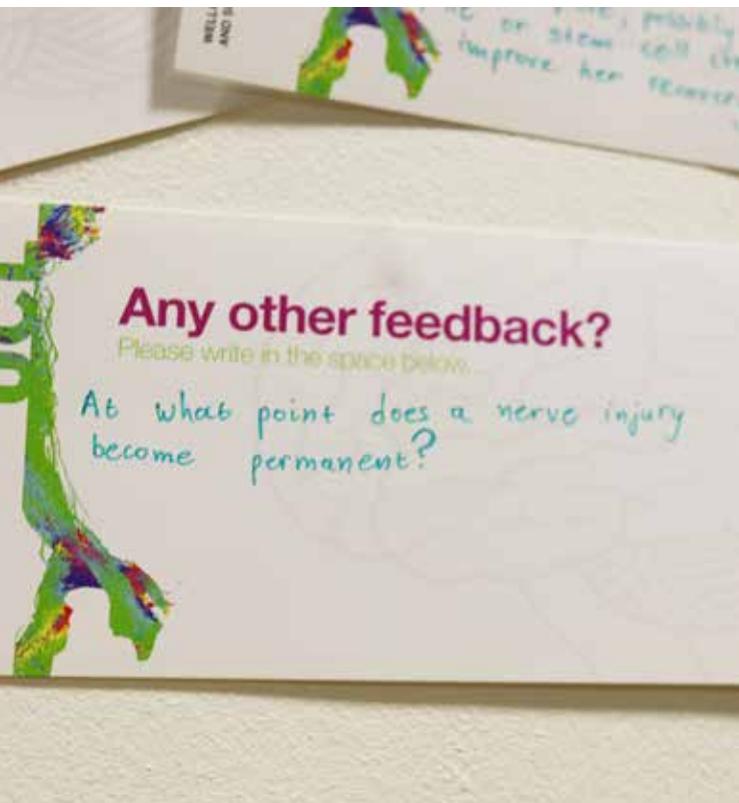
The main thing people felt they got from the day was information and meeting professionals working in the area, the use of ‘speaking to’ and ‘talking to’ indicates that it was the one-on-one opportunities that appealed rather than professionals as speakers.

Visitors also really appreciated the chance to talk about their own experiences and hear from others, feeling valued and comforted by this. There were a lot of comments about the benefits to meeting people with similar journeys and experiences and how this has helped. A lot of visitors mentioned the nice people and new connections they made.

Of the things to be improved, there were mainly comments about the content, asking for other topics to be incorporated and suggesting other specialisms for speakers. The main request for consideration in the design was changing how the stalls were incorporated into the event, which will be considered for next year.

“It was a really positive event and you deserve enormous credit for pulling everything together – everyone that I spoke to got a lot from the day. Well done!”

– Gary Pearce, Lived Experience Member of the NICD Delivery Group



“The information and workshops have been great! Knowledge really is power and this event left me more confident”

Contributor Feedback

The group felt that the overwhelming positive experience from the development of the event was working with the co-delivery group, getting a lot from the patients themselves and learning about their priorities and ideas.

The conversations throughout the event's development and delivery were useful for developing ways of better explaining science to new and relevant audiences, while a lot of conversations helped to identify and prioritise topics of interest and learn where new research connections could usefully be sought.

It was also a motivating experience for the academics involved as visitors seemed to be very interested in the topics and genuinely valued the day and chance to learn from the UCL team and each other.

Looking back though the team felt that the aims for the overall event could have been more clearly communicated to participants, helping to specify the content and its relevance, as well as managing expectations of visitors so they knew exactly what they were coming for and would get out of the day.

While developing the event the contributors also felt progress wasn't always communicated clearly, partly as there was one main contact organising the logistics. For the next event we will standardise feedback on progress and development, as well as splitting tasks more equally across the group.

Next steps

The team are planning to make Nerve Injury Community Day a regular event, building on the connections and feedback from the event to design something even better for 2020/21.

The key considerations will be how the event structure can be improved to give more time for exploring key topics and for discussion between visitors. We will also work more with people leading workshops to better define their aims and how to facilitate responses, these weren't always clear, making it difficult to evaluate the success of those sessions

In the meantime, the UCL Centre for Nerve Engineering team were inspired by the discussions and need from the nerve injury community for more communication and are developing a newsletter as a way to continue discussions and connections between events.

Co-Delivery Group Contributors

Rebecca Shipley	UCL Centre for Nerve Engineering
Despoina Eleftheriadou	UCL Centre for Nerve Engineering
Victoria Robertson	UCL Centre for Nerve Engineering
James Phillips	UCL Centre for Nerve Engineering
Simao Laranjeira Gomes	UCL Centre for Nerve Engineering
Matthew Wilcox	UCL Centre for Nerve Engineering
Tom Quick	Royal National Orthopaedic Hospital NHS Trust
Hazel Brown	Royal National Orthopaedic Hospital NHS Trust
Dan Taylor	Wellcome / EPSRC Centre for Interventional and Surgical Sciences
Marilyn Aviles	UCL Institute of Healthcare Engineering
Alice Hardy	UCL Institute of Healthcare Engineering
Steve Bloyce	Lived Experience of Nerve Injury
Gary Pearce	Lived Experience of Nerve Injury
Jenny Thompson	Lived Experience of Nerve Injury
Michaela Havelkova	Lived Experience of Nerve Injury
Ed Barnes	Traumatic Brachial Plexus Injuries Group
Neil Finney	Traumatic Brachial Plexus Injuries Group
Martin Hill	Traumatic Brachial Plexus Injuries Group
Karen Hill	Carer supporting someone with nerve injury

Other Contributors

Jenny Leonard	Graphic Facilitator
The Samaritans	
Mark Agathangdon	West Euston Patient Pain Support Group
Rebecca Powell	UCL Centre for Nerve Engineering
Suzette Lust	UCL Centre for Nerve Engineering
Papon Muangsanit	UCL Centre for Nerve Engineering
Maria Sasaki	UCL Centre for Nerve Engineering
Simon Kellaway	UCL Centre for Nerve Engineering



NERVE INJURY

COMMUNITY DAY

ACCEPTANCE & MOVING ON!
AND HOW TO DO THIS!

FINDING WAYS OF COPING
COMING OUT OF DENIAL & DEPRESSION

NOT EVERYONE WILL HAVE THE SAME JOURNEY!

STRESS EFFECTS PAIN AWARENESS

MULTI-MODES OF THERAPY FOR THE INDIVIDUAL!

TALKING THERAPIES

WE NEED TO THINK MORE ABOUT THE MENTAL HEALTH SIDE OF IT!

CENTRAL NERVOUS SYSTEM (CNS)
PERIPHERAL NERVOUS SYSTEM (PNS)



IT'S GOOD TO MEET PEOPLE IN PERSON

TO MEET OTHERS IN THE SAME SITUATION!

WHAT HAVE YOU FOUND INTERESTING AND USEFUL ABOUT TODAY?

WE NEED EASY & ACCESSIBLE SUPPORT FOR THE PSYCHOLOGICAL CHALLENGES!

AWARENESS OF THINGS THAT MIGHT HAPPEN LATER DOWN THE LINE!

THERE IS A LOT OF 'PRESUMED KNOWLEDGE'

MORE DOORS OPEN TO FIND SUPPORT!

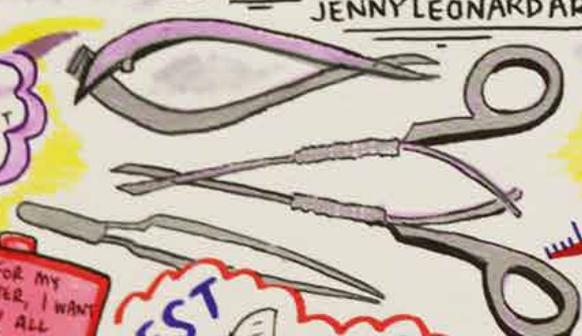
MORE TALK ABOUT

E.G. MUSCULAR IMBALANCE

NERVE DAMAGE



ARTWORK BY JENNY LEONARDART.



WHY DID YOU COME TODAY? AND WHAT WOULD YOU LIKE FROM AN ONGOING...

NERVE INJURY COMMUNITY OF:
RESEARCHERS
PATIENTS &
MEDICAL PROFESSIONALS

TO TRY TO GET MORE INFORMATION SPECIFICALLY ON

WHAT FUTURE TREATMENT OPTIONS ARE THERE?!

TO FIND OUT FOR ME
WHERE TO NEXT?

TO FIND OUT MORE ABOUT MY...

FOLLOWING LIMITS... RESPONSIBLY HOW MUCH TO PUSH YOURSELF?

RECOVERY

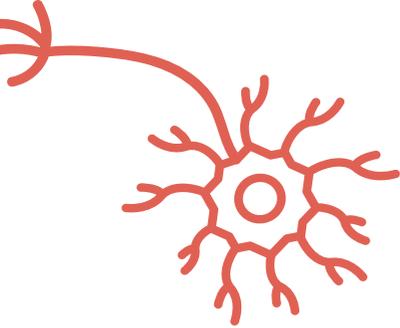
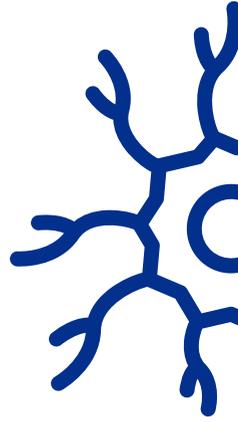
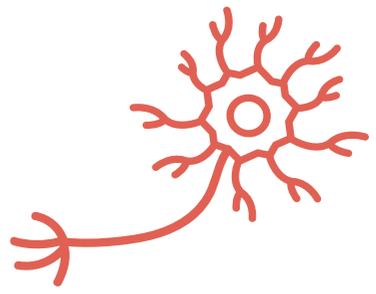
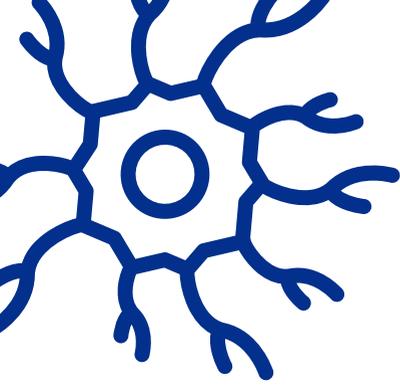
BECAUSE MY RECOVERY HASN'T GONE TO PLAN!

I LEARNED FOR MY DAUGHTER, I WANT TO KNOW ALL ABOUT...



LONG TERM





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