

NEUROENDOCRINE CANCER UK

QUARTERLY NEWSLETTER

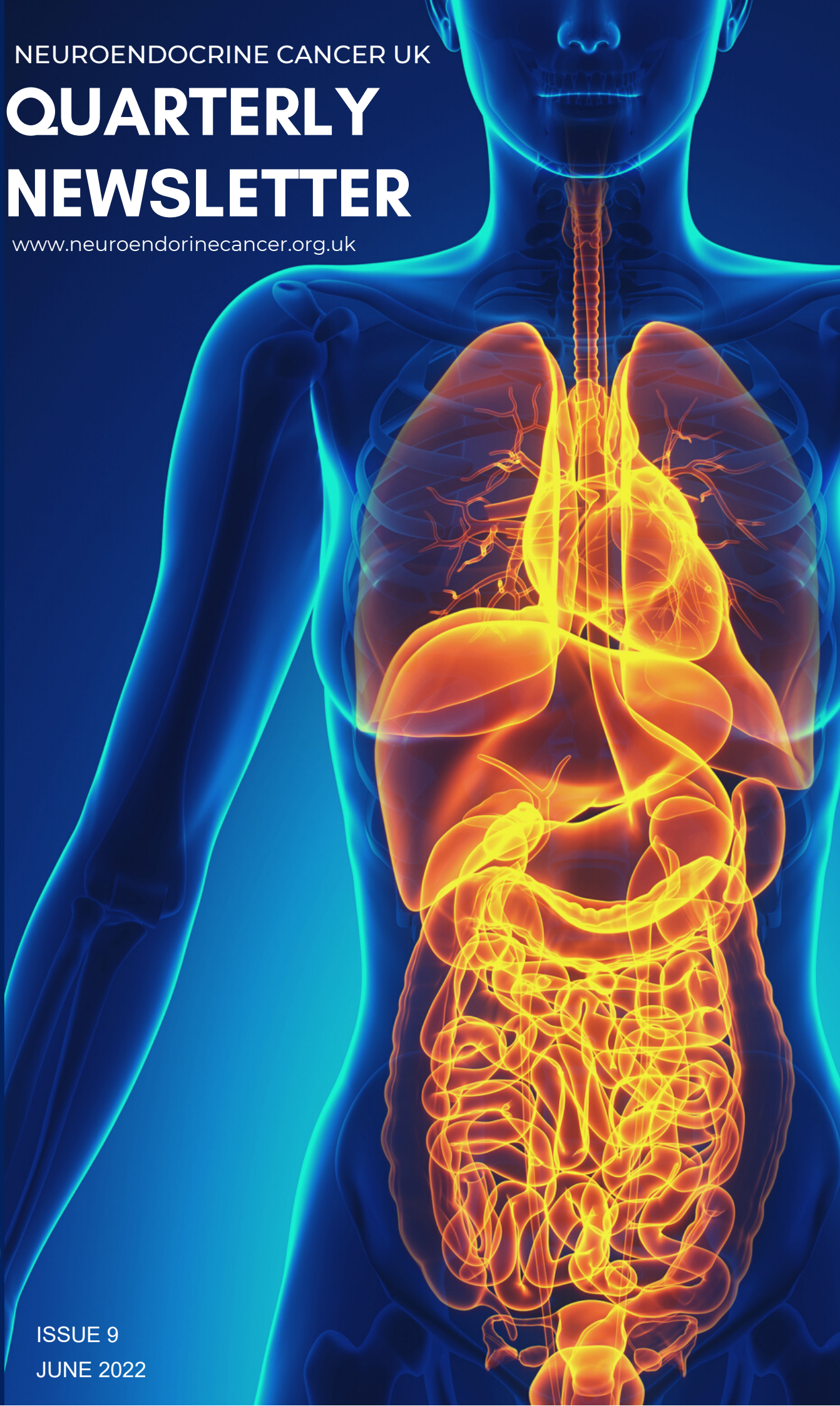
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NOT JUST NE CANCER



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NEUROENDOCRINE CANCER UK

Our Mission

Our purpose is to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes.



WELCOME FROM THE CEO

WELCOME to the first of our new monthly newsletters - designed and produced to keep our Neuroendocrine Cancer community up to date with new developments and projects. Thank you for your feedback on how you would like to receive news from us.

NCUK exists to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes. We exist because Neuroendocrine Cancer is Not just NE Cancer.

As we shared in our January newsletter, 2022 will be a year of firsts

For example this year we will see:

1. The launch of the first National Neuroendocrine Cancer Day on June 11th
2. The launch of our new NCUK handbook and virtual toolkit
3. The development of a patient care pathway with a multi stakeholder group in collaboration with the Health Policy Partnership.

The month of May introduces 3 new staff here at NCUK who are all going to be integral in ensuring we can offer you the best services we can. The whole team here at NCUK are here for you, so please stay in touch and together, we can change attitudes towards and assumptions made about Neuroendocrine Cancer.

I would just also like to express my heartfelt thanks to all of the wonderful humans that support our work, as an HCP, a Fundraiser, an NCUK Ambassador, a Natter coordinator, an Advisory Board member, a Committee member, a Twitter advocate, a Project supporter/partner or an Awareness raiser.

THANK YOU so much.

Cathy x

WELCOME!! NEW TO OUR TEAM

Lisa Walker - Campaigns Officer

Lisa will be looking after all of our major campaigns including MIND the Gap, FIND the Gap and Bridging the Gap. We are very excited to have her on board!



Maria Page - Cancer Support Coordinator

Maria originally became an NCUK ambassador and has now joined our helpline team as a Cancer Support Coordinator, as well as supporting the team with various campaigns. Thanks Maria!



Famida Bishop - (returning from maternity leave) Administrative Assistant

Famida will be working from home and making sure all of our online orders are being processed and everybody who signs up to our mailing list is subscribed! Welcome back!



WELCOME!!

NEW TO OUR TEAM

Kate Quirk - Cancer Support Coordinator

Kate will be continuing to support the NCUK Natters and will be working on our helpline offering support, as well as managing our Twitter and LinkedIn account and building relationships with HCPs. Good work Kate!



Clare Gerrard - (returning from maternity leave) Marketing & Communications Officer

Clare will be producing monthly newsletters and e-bulletins, as well as supporting marketing and fundraising campaigns. Welcome back!



Jackie Clews Administration Assistant

Jackie will be providing administration support to the team, which will include dispatching all our of information and shop orders. Welcome to the team Jackie!





2022

NCUK Virtual Series

NOT JUST NE CANCER:

This year we launched our 'NeuroEndocrine Cancer is not just NE Cancer' virtual series, with the aim to educate, inform and support our online community by taking viewers on a virtual journey.

Each month the virtual series will focus on a specific topic right from initial Neuroendocrine Cancer symptoms through to treatments, follow up, looking after your emotional wellbeing.

This is showcased through informative, educational and supportive online content, including real-life patient experience videos, podcasts and educational videos from the experts.

[You can find out more about the virtual series here.](#)

BEING DIAGNOSED WITH
CANCER CAN BE A LONELY
VENTURE.

ESPECIALLY IF YOU HAVE
BEEN DIAGNOSED WITH A
RARE OR UNCOMMON
CANCER

PEOPLE AROUND YOU MAY
NOT UNDERSTAND, BUT
IT'S OKAY BECAUSE WE DO.

JUNE 11 WILL MARK OUR FIRST
**NATIONAL NEUROENDOCRINE
CANCER UK DAY**

SPOTLIGHT SERIES
RECTAL PRIMARY WITH METASTASES
TO LIVER AND ABDOMEN
CRAIG SPEIRS



My Name is Craig Speirs, I'm 41 years old, married to my beautiful wife Angela and I have two children, Adam aged five and Rhianne aged thirteen. I've been living with Neuroendocrine Cancer for over eight years now and to say it's been a bumpy road would be an understatement.

I was diagnosed with a primary in my rectum with Metastasis to my liver and abdomen, I also have severe Carcinoid Syndrome and Hedinger Syndrome (Carcinoid Heart Disease).

Three years ago I needed open heart surgery to replace my Pulmonary and Tricuspid valves But the 7th of December 2021 is not a day I'm going to forget anytime soon.

I had an appointment at The Golden Jubilee Hospital for an Echocardiogram and ECG as I had recently been struggling with my mobility and my team at the Beatson had concerns about the amount of flushing I was experiencing and chest pains.

When my ECG and echocardiogram was complete, I sat with the nurses waiting for my results when the curtain drew back and there stood a doctor I hadn't seen before. This doctor then invited me into her office, and I could tell by the tone of her voice that something was up.



[Read Craig's latest blog here](#)



"I think I'm a mentally strong person. I've been through so much in the last eight years and always came through it with a positive attitude. I know this is difficult, and our minds can be our biggest enemies at times, always making us think the worst in those difficult moments. I had to focus, so I began asking questions and the doctor was great at explaining everything in a way that I could understand."



NCUK BRAVEHEART
CRAIG SPEIRS

[Watch Craig's story here](#)

Not only is Craig an amazing father, husband, and wonderful NCUK

Ambassador, but he is also one of our most dedicated supporters and top fundraisers!

It takes a special kind of person to convince 30 people to jump out of an aeroplane for money but that's exactly what Craig did when he organised a skydive to raise money for NCUK. Craig was unfortunately unable to do the jump himself but that didn't deter him from rallying the troops!

He also gathered a group to take on this year's Glasgow [Kiltwalk](#) to raise funds for NCUK.

Families, friends, children and even a big dog (Marshall) from Paw Patrol were called up to take part in this 14.5 mile 'stroll' and well, they smashed it!

Over £9000 was raised by the challengers which will be matched by 50% by Sir Tom Hunter and The Hunter Foundation.

Thank you so much Craig!

YOU'RE AMAZING!!!



A huge THANK YOU to Pete Blomley who cycled 72 miles over 2 days from Instow on the north Devon coast, mainly on cycle tracks through the beautiful Devon countryside back home to Cornwood on the southern edge of Dartmoor.

You may already be aware of this incredible fundraiser, as Pete has featured in many newspapers, raising awareness of Neuroendocrine Cancer.

Not only has Pete almost raised over £6000 for NCUK but he has also partnered with us to work on a project, which we will launch in June this year!

**PETE RAISED A
WHOPPING £6,276.20!!**

Pete has kindly shared his Neuroendocrine Cancer story with us and once you've read it, I'm sure you'll agree that Pete is truly an inspiration.

[Read Pete's Story](#)



Well, my bike ride to raise awareness and funds for NCUK felt fantastic - two of the best days of my life! It was nearly a year ago to the day that my consultant told me that PRRT would get me back on my bike - but I was really struggling with my 'hypo' symptoms and medication and felt desperately low then - and I did not think that would ever happen. But it has! Thanks to PRRT, and the support I had from NCUK, I can now lead a more normal life again. This feels like a miracle, I am profoundly grateful and loving making the most of each day for however long this lasts.

FUNDRAISE FOR US!

Fundraising is an opportunity to set yourself a challenge, go on an adventure or just do something silly for money! Whatever your idea, make sure it's something you'll enjoy doing. There are so many ways to raise funds for NCUK and whether you run a marathon, shave off your eyebrows, skydive or organise a coffee morning!

Sign Up



NCUK FUNDRAISERS

Barefoot astronauts stun Snowdon walkers by stripping naked at summit for NCUK!

Gordon and Nick climbed Snowdon barefoot – before stripping off at the summit! They took on the challenge to raise money NCUK and their friend, Huw, who was diagnosed with NC in 2009.

Only two weeks prior to this, Gordon participated in a 200 mile ultra marathon, which he completed in 98 hours.

With another 8 ultra marathons planned until September, Gordon has already raised over £1600!

You can read more about the naked summit climb and Gordon's fundraising [here](#).



THANK YOU

**YOU ARE
AMAZING!**

£872.31 RAISED



WWW.NEUROENDOCRINECANCER.ORG.UK

A huge Thank you to Lee who recently ran the Manchester Marathon to raise funds for NCUK!

Here's why Lee chose to fundraise for us:

“ I ran the Manchester Marathon and chose this charity as it's one that has recently touched my family... my beautiful Mum, my best friend. Myself and my family are so proud how brave she is, always staying positive and taking treatment head on. We know she will get through this as we will always be right by her side.

We love you SO VERY MUCH. ”

THANK YOU!!!



SCAN ME



ALE'S ADVENTURES



SUMMITING
Mount Kilimanjaro

21st October 2022

On the 20th October 2022, NCUK's Operations Manager and Digital Lead, Leanne Talbot, along with her three friends (Aisling, Erin and Laura) will be landing on African soil ready to take on not only the highest peak in Africa but the highest free-standing mountain in the world - Mount Kilimanjaro!

Leanne has chosen to raise funds for NCUK and is asking for the NCUK community to support her and sponsor this venture:

"I am so excited and absolutely terrified about our Kilimanjaro challenge! I went on my first ever hike back in 2020, when I climbed Ben Nevis with no training - I mean what else was there to do during lockdown, other than walk?!"

Fast forward to 2022 and after a number of hikes around the UK, we've decided to up the game and set the challenge of a lifetime. I of course have chosen to raise money for NCUK. I am so passionate about the charity, the work we do and have the upmost respect for the Neuroendocrine Cancer community, most of whom I now call friends.

Any money raised will go towards our FIND the Gap campaign, to support Neuroendocrine Cancer research. I cannot wait to stand at the top of that mountain, wearing my NCUK shirt with pride! If you would like to support my venture, I would appreciate any donations, big or small!"

You can support Leanne's challenge [here](#)





GP E-LEARNING COURSE



Neuroendocrine Neoplasms

Over the course of these two modules we will discuss the types of NENs, common presenting symptoms, the challenge their diagnosis presents, and the importance of primary care input following diagnosis.



 **ACCESS COURSE**



NCUK are delighted to have collaborated with the Royal College of General Practitioners (RCGP) to fund an online learning course about Neuroendocrine Neoplasms (NENs). This activity is part of our vital [Bridging the Gap](#) campaign.

"BRIDGING the Gap is about change: changing attitudes towards and assumptions made about Neuroendocrine cancer, challenging delays, misdiagnoses, and restricted access to care and support to ensure all affected by this group of rare cancers have a clear, effective and holistic diagnostic/treatment pathway."

In an average practice of 10,000 patients, approximately 5 patients will be living with and beyond a diagnosis of neuroendocrine neoplasm (NEN). This course aims to increase the primary care clinician's knowledge of neuroendocrine neoplasms, and thereby improve the time to diagnosis and management of patients with NENs.

Suspicion of NENs is imperative to improve outcomes for all our community. Our Barriers to Diagnosis survey highlighted these issues and we need to change the facts.

The two course modules will discuss the types of NENs, common presenting symptoms, the challenge of a NEN diagnosis, and the importance of primary care input following diagnosis. 'Neuroendocrine Neoplasms' eLearning course is now live and is available to ALL healthcare professionals for one year.

You can access the course here: <https://elearning.rcgp.org.uk/neuroendocrine>

NCUK NURSE ACADEMY COURSE



Endorsed by:



Neuroendocrine Cancer UK is thrilled to announce that we have now launched the competency-based, CPD accredited NCUK Academy Nurse Course.

The NCUK Academy is independent and free-to-access any time. It was designed for nurses (and allied healthcare professionals), working across a range of healthcare settings, to provide a free online resource regarding Neuroendocrine Cancer – what it is, how it may present and how it is diagnosed, treated and managed.

Developed by our specialist nurse, AHP and expert patient faculty and endorsed by UKINETs, the Academy includes a combination of evidence-based, resources, clinical practitioner and patient video presentations and is divided into 4 key inter-related E-learning components:

- Part 1: An introduction and overview of Neuroendocrine Cancer
- Part 2: Site Specific Neuroendocrine Cancers
- Part 3: Related Syndromes
- Part 4: Holistic Care Considerations

The Academy is a competency-based modular programme that aims to work from promoting awareness to encouraging a deeper understanding of Neuroendocrine Cancers – enhancing knowledge, problem-solving and the critical thinking skills of those completing it.

NCUK ACADEMY MODULES

Developed by our specialist nurse faculty and including a combination of evidence-based, consensus guideline informed resources, clinical practitioner and patient presentations and videos, the NCUK Academy is divided into 4 key inter-related E-learning components:



Part 1

An introduction and overview of Neuroendocrine Cancer.



Part 2

Site Specific Neuroendocrine Cancers. (CPD accredited)



Part 3

Related Syndromes (CPD accredited)



Part 4

Holistic Care Considerations

NCUK NATTERS

NEW FOR 2022

- *National & Regional Natters - NEW All Wales Natter and an All Scotland Natter to be added alongside our All Northern Ireland and our England Regional Natters (Northern England, Midlands, East of England & Southern England).*



Please check our Natter Calendar for all dates and self-registration links.

- To self-register - visit the [Natter Calendar page](#) and find the Natter you would like to join - click "View Details" and follow the given link to self-register.
- Once registered you will receive an email with the link for that group's meetings.
- You should only need to register once for each group - rather than for each of the group's individual meetings.

- Tumour Site Specific National Natters - NEW MCC (Merkel Cell Carcinoma) Natter and High- grade (Grade 3 Neuroendocrine Cancers) Natter to be added alongside our National Lung Natter.
- New NCUK Carers-only Natter - for those living with and/or supporting those with Neuroendocrine Cancer.

- Due to ongoing COVID restrictions our Local Natters will continue on Zoom until further notice : we will review local arrangements for resuming face-to-face meetings as soon as government advice, across all 4 Nations, and local venue governance allows.
- Our Regional and National Natters will remain, as planned, online.



JOINING A NATTER

[LEARN MORE](#)



FIND A NATTER NEAR YOU

[VIEW MAP](#)



CALENDAR

[VIEW CALENDAR](#)

Join our Facebook Support Groups



Our Facebook groups are private groups and have been established to provide a safe place for those affected by Neuroendocrine Cancer to chat, talk and help each other by sharing experiences and knowledge, to both give and receive advice, support and friendship.



(NEW GROUP) - NCUK Merkel Cell (MCC) Support Group

- This group is for those, living in the UK and/or under the care of the NHS, affected by NC of the skin.



(NEW GROUP) - High Grade Neuroendocrine Cancer Support UK

- This group is for those, living in the UK and/or under the care of the NHS, affected by High Grade NC.



Neuroendocrine Cancer UK Support

- This group is an online support group that runs alongside our face to face Natter support groups within the UK.



Neuroendocrine Cancer UK - Family & Friends Support

- This is an online community group ONLY for family, friends, supporters of patients with Neuroendocrine Cancer.



Friends of Neuroendocrine Cancer UK

- Open to the whole NC community - UK & Global - patients, family, friends, patient advocates & healthcare professionals.



Click to join



**Neuroendocrine
Cancer UK**



NCUK SERVICES SURVEY

Thank you so much to everyone that has completed our [NCUK Services Survey](#) so far!

Your opinion is so important to us and with your answers we can endeavour to make any changes needed and improve our services for the NCUK community.

There's still time to get involved and have your say before we close the survey and share the results, so please click below and have your say!

