

# Personal, Public Involvement (PPI) and Co-Production

2020 – 2021  
Annual Report



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# Foreword



Welcome to our Personal and Public Involvement (PPI) Annual Report for 2020/21. This Report outlines the work we are doing to promote personal and public involvement in the planning and delivery of services and details how we are taking forward the Department of Health's Co-production Guide. The COVID-19 pandemic resulted in us having to rapidly reconfigure services and provide care in new and different ways. Measures taken to limit the spread of the virus meant we all had to adapt quickly, and change the ways we work. This was also true of those undertaking and participating in personal and public involvement activities. Face-to-face engagement that would normally be expected, has been restricted by guidance on physical distancing and shielding but despite this we have remained strongly committed to engaging with service users, carers and the public in a meaningful way during these challenging and exceptional times.

I believe that engaging and involving the people who use services and their carers is as important as ever, but the complexity of the current environment for health and care services cannot be understated, with services facing many competing challenges and pressures. Many changes had to be made rapidly to respond to the pandemic but we also have to consider the future provision of services over the short, medium and long term. This should be informed by engagement with service users, carers and the public.

We must shape our services together and going forward we will need to consider who we engage with and what are the best methods of engagement. This year we are establishing an Engagement Advisory Group to help us with this. Its membership will reflect the communities we serve to make sure we reach out to all those who use our services. Service users and carers are experts in their own lives and we need to recognise this in all that we do.

**Jennifer Welsh**  
**Chief Executive**

# Foreword



I believe that involving people with lived experience in the delivery of services, strengthens working relationships and creates a level playing field, which validates the expertise of service users and carers. In the past we have been reliant on working face-to-face but as the COVID-19 crisis started to escalate during March 2020 we were forced to move to online events and meetings. Whilst this was a daunting task for many, there are clearly some advantages to engaging online.

I have been impressed with the energy and drive that the Trust has put into engaging with service users and carers and I have attended many of their online events where there was lots of different interaction, including the chance to use break out rooms, run polls, allow people to share their screens and to use 'chat' to comment and share responses. It is now vital that the impetus is maintained and that engagement continues - whatever your role you have an active part in making this happen.

We all know that change is required to make sure that our health and social care services can cope in the future and bringing about this change will require collaborative working relationships so I encourage as many service users and carers to join the Trust's Involvement Network.

**Thelma Dillon**  
**Chair of Older Peoples Panel**  
**and Trust PPI Representative**

# **Governance and Assurance**

# Governance and Assurance



**Wendy Magowan**  
Director of Operations is responsible for the implementation of PPI and co-production across the Trust and assuring our Trust Board that we are abiding to our statutory duty to fully engage our service users and carers.



**Glenn Houston**  
Non-Executive Director continues to be the Non-Executive PPI and co-production lead and plays a key role in embedding involvement into the culture and practice of the organisation.



**Alison Irwin**  
PPI Operational Lead and Head of Equality



**Lynda Elliott,**  
PPI Co-Ordinator



## Governance and Assurance

We continue to ensure partnership working is integral to all aspects of our business agenda and have a range of governance, management and reporting mechanisms to reflect this. Our Engagement, Experience, Equality and Employment Group (Quad EG), chaired by Wendy Magowan, seeks assurance that the Trust is compliant with PPI statutory requirements. Membership includes all divisional directors, non-executive directors and the Patient Client Council. The Quad EG reports directly to the Trust's Assurance and Improvement Group, then through to Trust Board.

Within each of our services we have a number of PPI champions who continue to provide support and promote personal and public involvement across the organisation. Opportunities for specialised training are provided and staff continue to be provided with the information and resources required to mainstream PPI and co-production activities.

The Trust continues to support a number of service user panels in partnership with service users, carers and the community and voluntary sector, with each panel being user led, chaired by a service user or carer. We also have our Involvement Network which continues to provide opportunities for members to be involved in the developing and planning of services. These partnerships ensure an effective network for on-going stakeholder involvement and co-production in our work. We continue to support and value the networks we have already established and work in partnership with them to ensure everyone has the opportunity to be involved. If you are interested in joining one of our user groups or would like more information please contact: [ppi.coordinator@northerntrust.hscni.net](mailto:ppi.coordinator@northerntrust.hscni.net) or phone (028) 2766 1453.

## 10,000 More Voices

10,000 More Voices encompasses the fundamental principles of PPI, promoting meaningful engagement with patients, clients, service users, carers and their families. The method used to gather views focuses on the person's personal story. This form of engagement values the voice of the respondent, providing the opportunity to express what mattered most to them throughout their journey.



In light of the ongoing COVID-19 pandemic in Northern Ireland the 10,000 More Voices work plan focused on capturing the most recent experience of patients, clients, relatives and staff engaging with our health and social care system during the pandemic – including the projects below.

- Experience of accessing mental health services during COVID-19. This focused upon the introduction of online therapies, telephone and video consultations and changes to face to face services
- Experience of residents, families and staff in care homes during COVID-19 pandemic
- Experience of wearing PPE during COVID-19 Pandemic
- Experience of working during COVID-19 Pandemic
- Experience of Patient Care Services in Northern Ireland Ambulance Service (NIAs)



## Service User Feedback

**The Trust encourages complaints, enquiries, comments/suggestions and compliments and views them as a positive opportunity for learning and improving services.** The total number of formal complaints received this year was 636 (including 88 follow on complaints). Services across the Trust receive many compliments; these can range from written letters and thank you cards, verbal feedback and donations to our Charitable Trust Funds in recognition of the service provided. This year the Chief Executive received a total of 2236 compliments.

Feedback from our service users, carers and members of the public/visitors using our services or facilities helps us to identify areas where high quality care is being provided, and where this is not the case we will make changes to improve service quality and safety.

Feedback can be given directly to the service involved either verbally or in writing or by sending your feedback directly to the Chief Executive. **Complaints, enquiries, comments/suggestions and compliments can be sent in writing, by email telephone or calling in person to Complaints/Service User Experience Office**, Northern Health and Social Care Trust, Bush House, 45 Bush Road, Antrim, Co Antrim, BT41 2QB , Tel: (028) 9442 4655      Email: [user.feedback@northerntrust.hscni.net](mailto:user.feedback@northerntrust.hscni.net)

# Care Opinion

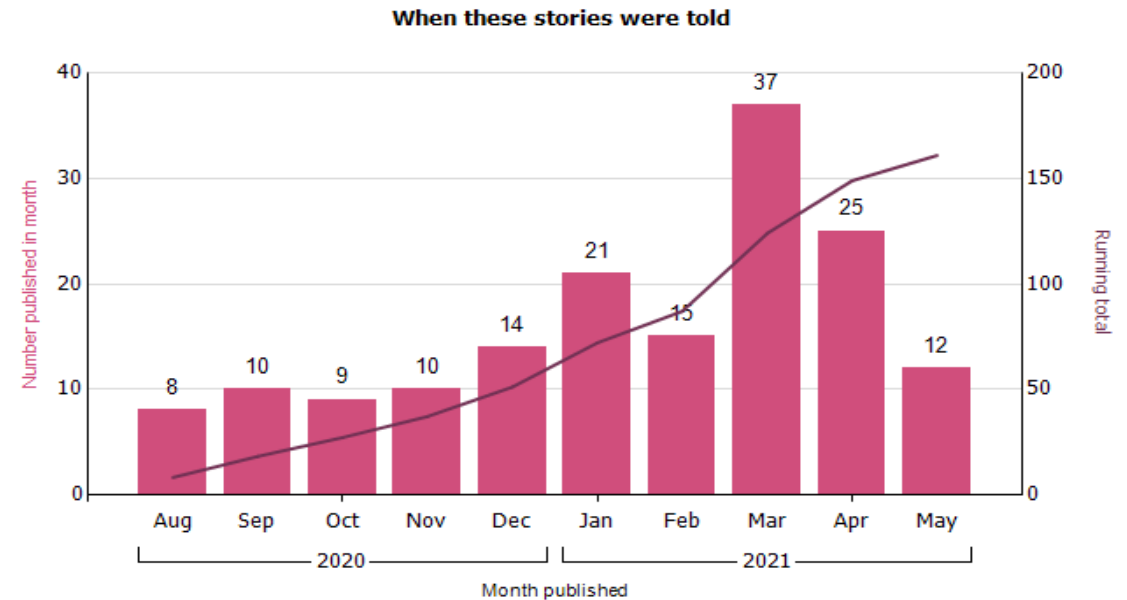


On the 3<sup>rd</sup> of August 2020 Care Opinion was launched in Northern Ireland by the Health Minister. This is a real-time, on line service user feedback platform that provides service users, families and carers with the opportunity to share their experience of health and social care in Northern Ireland.

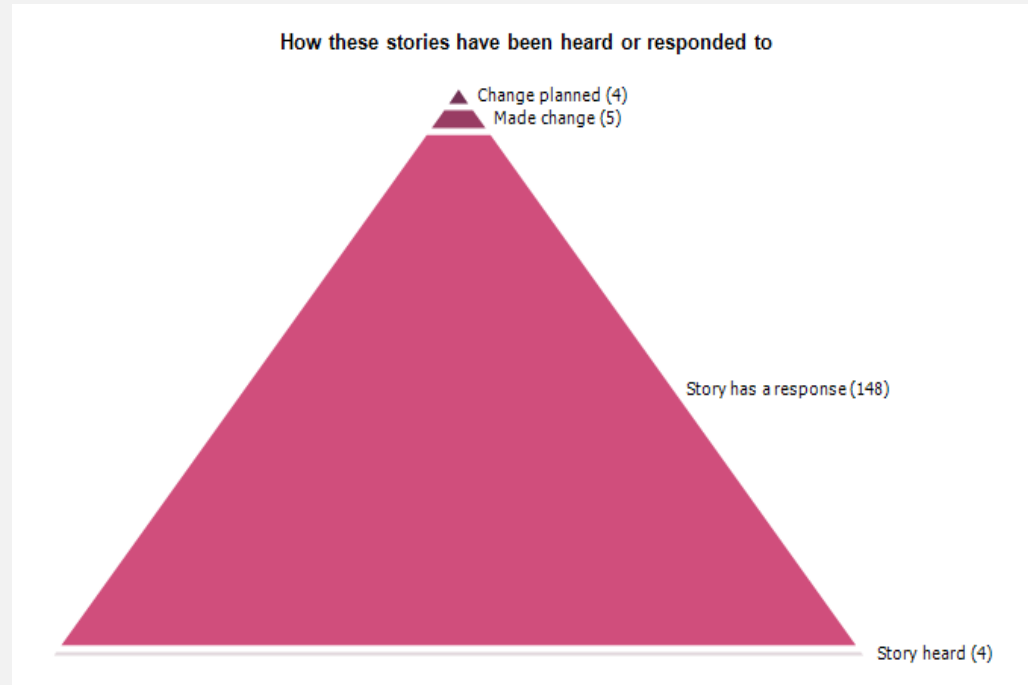
This platform allows the Trust to find out how service users and carers view the services they use and the standard of care that they have received. Stories posted also help the Trust to identify areas of good practice, and areas where change and improvements are required.

Each story, good or bad, will be responded to in an open and transparent manner by a member of Trust staff, to reinforce that the service user has been heard.

Since the launch in August, we have received 161 stories from service users, families and carers about their experience of care.



Following the stories received on Care Opinion, there have been 4 changes planned and 5 changes made.



One of our service users gave us their views on how it felt to leave feedback and be involved in co-producing a poster on Guide Dog Etiquette.

*"The Care Opinion platform was a fantastic and timely way for me to share my experience in a targeted way and it was fantastic to get some responses from people within the Trust thanking me and planning to actively address it. I was asked to review documents to improve visible information around correct guide dog etiquette which was an incredibly positive and empowering outcome."*

For more information on any of this work please contact Leigh Morgan, Patient Client Experience Facilitator [Leigh.morgan@northerntrust.hscni.net](mailto:Leigh.morgan@northerntrust.hscni.net) or phone (028) 9442 4000

# Opportunities and Support for Involvement



### Involvement Network

Our Involvement Network of service users and carers continues to grow. We have been working extensively with our Involvement Network over the last year engaging while rebuilding our services. We have provided our Network with 68 involvement opportunities, including the development of our new 'Phone First' service and the setting up of the regional Nightingale facility at Whiteabbey. They also helped us to think about how we can use virtual mechanisms for appointments going forward. If you would like more information or to become a member of our Involvement Network, please contact Lynda [ppi.coordinator@northerntrust.hscni.net](mailto:ppi.coordinator@northerntrust.hscni.net) or phone (028) 2766 1453.

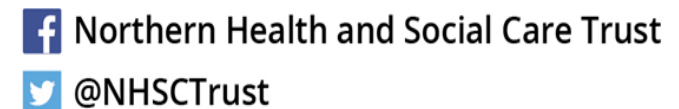
### Newsletter

The second edition of our Involvement Network Newsletter continued to keep our service users up to date with the latest support available during the COVID-10 lockdown. We also highlighted some of the involvement opportunities that they had been part of including input into the design of our new 'Phone First' service and our Regional Nightingale facility at Whiteabbey. A copy of the newsletter can be found [here](#).

### Social Media

We continue to use our Facebook page and Twitter account to circulate any opportunities for involvement to over 35,000 people. We continue to use YouTube as a platform to provide service users, carers and the public with a variety of information including videos and audio interviews.

You can follow us on Facebook and Twitter as follows:



# Knowledge and Skills



# Knowledge and Skills

We continue to provide support, advice and guidance to staff, service users, carers and the public as required.

## Engage

We continue to work in partnership with staff, service users and carers in the ongoing development of Engage to ensure there is a wide range of tools available to effectively involve service users and carers.

Engage is also accessible by the public to find out about involvement opportunities and training.

Check out Engage at <http://engage.hscni.net>

## Citizen Space

Citizen Space is a regional consultation tool which we use to develop questionnaires and surveys. It continues to be very popular with our staff especially useful during lockdown as a method of engagement. 165 staff now have accounts set up and have received training. It is the only tool of its kind which was designed in collaboration with government, specifically for public sector use. The consultations are hosted live on the NI Direct Website.

## PPI Training

This year 561 staff have completed our PPI training programme. We continue to raise awareness and promote PPI. It is incorporated into many of our other training programmes which we have had to adapt to virtual classrooms. We have a range of resources available on the Trust internal Staffnet site ranging from our PPI toolkit, Welcome Pack for Service Users and guides which have been developed regionally.

# Knowledge and Skills

## Zoom Webinar

In the midst of the Coronavirus pandemic we were all learning to communicate and deliver services in new ways. To help with this NHSCT purchased a number of ZOOM licences for video calling with colleagues and service users. Practical guides to ZOOM for staff and service users were made available. To ensure staff had the knowledge and confidence we held a webinar on using Zoom to help develop skills. The session included establishing virtual ground rules and check-ins, specific for virtual meetings, how to keep online meetings interactive for everyone but keep it on track and how to host and keep it effective and engaging.

The webinar was recorded and made available on staffnet as a resource for staff and we also developed an ebook on good Zoom etiquette which has been used regionally and made available as a staff resource.

## Online Guides

A range of involvement tools and resources are available to help staff effectively involve service users, carers and the public.

As government guidance during the last year was to stay at home where possible and socially distance we had to change how we involved our service users and carers. To ensure staff had the skills and knowledge to support online engagement we developed some new guides to help. These guides supported staff during the rebuild phases of COVID-19 providing them with more confidence in online engagement.

All guides and other resources are available on staffnet.



# PPI and Co- Production in practice across the Trust

The following pages highlight some of the service user and carer engagement that has been carried out over the last year

# PPI and Co-Production in practice across the Trust



## Phone First

Prior to Covid-19, there was evidence that our urgent and emergency care services were under increasing pressure. With the impact of the COVID pandemic and the focus on infection prevention and social distancing it is even more important that vulnerable patients who need emergency treatment aren't asked to wait in crowded waiting.

'Phone First' is a new telephone number for patients who are unwell and planning to travel to an Emergency Department (ED) with an injury or illness which requires urgent treatment but is not immediately life threatening. On 12 November 2020, an engagement event took place with over 30 service users, carers and representative groups. The session enabled an informed discussion about the "Phone First" service and an opportunity for participants to ask the Panel questions and provide valuable feedback.

## Phone First (No More Silos) Patient Experience Feedback

A patient experience survey has been launched on Citizen Space and promoted via Social Media to get feedback from service users, carers and members of the public who have used the Phone First Service prior to attending Antrim Area and Causeway Hospitals' Emergency Departments and Mid Ulster Minor Injuries Unit.

The first survey ran from 24/02/2021 to 31/03/2021 and returned a total of 47 patient experience responses. These responses were so valuable for helping the Trust to identify where the service is working well, and where further changes to improve the service are necessary. So much so, that it was agreed to run a further survey until end of May 2021 to continue to learn and shape the service with patient experience firmly at the forefront.

## PPI and Co-Production in practice across the Trust

### Care Home Support

During the Covid19 pandemic the Trust developed close supportive working relationships with Care Home staff. As a result of restrictions being placed on visiting a Family Liaison Officer (FLO) role was developed initially in the East Antrim Locality to facilitate meaningful contact between residents and their families alleviating anxiety of both residents and families.

The Care Home support received very positive feedback from all involved and attracted favourable media coverage. An approach was made by a local school wishing to support Care Home residents, the Trust facilitated links between the two and cards made by the school children were distributed to Care Home residents.

### Causeway Inflammatory Bowel Disease Patient Panel

In January 2019 an Inflammatory Bowel Disease (IBD) Patient Panel was established to help improve services. They have designed their own logo and since COVID have continued to communicate using the Telegram app. The Panel has responded to the new 10 year Mental Health Strategy 2021-2031 consultation and has also identified that a self-help 'IBD Buddy' scheme would be a useful support service for patients and their families throughout the IBD journey. Causeway is the first hospital in Northern Ireland to set up a successful IBD Patient Panel and we are collaboratively breaking down barriers by interdisciplinary working and involvement of many stakeholders. As a team we are so proud of the enthusiasm and commitment from our Patient Panel, which is ensuring we work towards creating a holistic service for our service users.



## PPI and Co-Production in practice across the Trust

### Co-Produced Acute Frailty Unit Patient Leaflet

A patient information leaflet for the Acute Frailty Unit was co-produced by a team of staff and service users. The purpose of the leaflet is to provide useful information to patients and carers in relation to their stay on the Unit.

The leaflet was drafted by the Ward Team and disseminated through the Service User Involvement Network for comments and feedback. Extensive feedback in relation to the content and design of the leaflet was received and utilised to develop the final draft. The leaflet is now provided to patients on admission to the Acute Frailty Unit.

### Ambulance Arrival and Handover Service User and Carer Engagement Event

A Service User and Carer Engagement Event was held on the 25<sup>th</sup> March 2021 to get feedback from stakeholders on the additional 5 bedded area being developing within the footprint of Antrim Area Hospital Emergency Department for ambulance arrival and handover.

The engagement event took place via Zoom and a number of service users, carers and Trust staff attended. Information about the proposal was discussed and we received valuable feedback that will enhance the patient journey.



## PPI and Co-Production in practice across the Trust

### Pilot of elastomeric pumps for 24 hour continuous intravenous (IV) antimicrobial infusions for consideration in Outpatient Parenteral Antimicrobial Therapy (OPAT)

The aim of the small pilot project was to determine if delivery of IV antibiotics via elastomeric devices is a feasible alternative to broader spectrum once daily antibiotics and avoid sub-optimal timing of antimicrobials that require dosing frequencies of three times daily or more. The project was carried out on ward B1 at Antrim Area Hospital and the multidisciplinary project team included staff from pharmacy, medicine and nursing. The team worked closely with and involved patients from the outset to ensure they understood how to manage the device and obtain feedback on its use. Feedback was good and has helped inform how the OPAT team could take this initiative forward.

“Instructions on how to manage device straight forward. Information leaflet very good.”

“Much better than being connected to infusion via drip-stand, more freedom to move whilst receiving antibiotic.”

“Can see how this would benefit patients receiving therapy at home”

# PPI and Co-Production in practice across the Trust

## Nightingale Facility at Whiteabbey

In September 2020 the Minister for Health announced that Whiteabbey Hospital would become a second Nightingale facility for Northern Ireland in preparation for the second wave of the coronavirus pandemic. This was a regional service operating as Enhanced Nursing and Therapies Rehabilitation and Step Down unit, providing extra bed capacity to aid the flow of patients from acute care.

An engagement event took place, using Zoom on 5th November 2020 with over 30 service users, carers and representative groups to hear about and have input into the plans for the Nightingale. There was then an opportunity for participants to ask the panel questions and give their feedback on what they had heard. The feedback from this engagement event is available [here](#).

We provided service users and carers with a number of updates and also held another engagement event in May 2021 which was used to talk about the options for the future use of the Nightingale facility following a decrease in COVID admissions.



## PPI and Co-Production in practice across the Trust

### Tocilizumab Patient Information Leaflet (PIL)

As new treatments for Covid-19 emerged so did the need for new information leaflets and counselling on these treatments. When Tocilizumab was approved for use outside of clinical trials, we recognised the need to provide written information to patients and carers when this is received. The pharmacy team developed a patient information leaflet that documented important information about Tocilizumab, but we wanted to make sure that this was as clear and accessible as possible. As such we enlisted the help of the Involvement Network to get service user and carer feedback on the leaflet. They provided feedback that vitally shaped the information leaflet. The leaflet was then approved for use by the pharmacy team, and is used to provide information to patients and carers about the care patients received during the course of their hospital admission.

### Delirium Care Pathway

An information leaflet 'Recognising Delirium' was co-produced by the Delirium Co-ordinator and service users via the Involvement Network. The leaflet provides useful information for relatives to help them recognise the signs and symptoms of delirium and advise staff of any changes to their relative's condition. The leaflet is included in a 'Delirium Information Pack' for patients and relatives in wards in Antrim and Causeway Hospitals.

Information for families and carers of patients who have been diagnosed with a delirium, has now been added to the A-Z Services on the Northern Trust website. A link has also been included to the 'Care Opinion' website, so that patients and families can leave feedback about the care and support they received.

## PPI and Co-Production in practice across the Trust

### Cardiology Ambulatory Pathway, Antrim Area Hospital

The Cardiology Ambulatory Pathway at Antrim Area Hospital is an ambulatory service that facilitates referrals from GPs, thereby enhancing patient access to Cardiology Services and reducing attendances to the Emergency Department. The Service offers same day urgent care to patients at the hospital, which allows patients to be assessed, diagnosed, treated and if possible, sent home the same day without being admitted overnight. A service user engagement event, hosted by Dr Lambros Petrou, Consultant Cardiologist and Stephanie Greenwood, Clinical Services Manager was held on Friday, 12<sup>th</sup> March 2021. The event was well attended and gave service users, carers and representatives from voluntary organisations the opportunity to learn more about the pathway and pose questions to members of the project team involved with the development of the pathway. Feedback during and following the engagement event has been very positive:

*“Fast tacked pathway and confidence to know you are on a track to be seen quickly – very reassuring”*

*“Provides confidence and reassurance”*

*“This pathway will give people the confidence in attending hospital and getting the treatment they need, the pathway sounds great”*

*“Speed is of the essence. The pathway increases the chance of getting the treatment so much quicker”*

*“Excellent pathway. People may be stressed about their symptoms/condition and will be delighted to see an expert quickly. It will be so reassuring.”*

These personal, individual experiences will assist greatly when considering expansion and continual development of the Service.

## Recruitment and Selection

Despite COVID restrictions, service users and carers continued to receive Recruitment and Selection training through e-learning. This year service users sat as panel members in interviews for services including the Regional Trauma Network and Brain Injury Service. Further training will be given to service users, carers, and recruiting staff across Psychology Services to increase representation on interview panels.



## Brain Injury Service

Our service users have been involved in reviewing and updating our “Information for Service Users, Families and Carers” leaflet. 14 service users were involved in this project and had input into reviewing, making suggestions around wording, layout and making sure it was accessible and a format easy to understand.

### Northern Trust Brain Injury Service

Information for Service Users,  
Families and Carers





# PPI and Co-Production in practice across the Trust

## Psychological Therapies Service (PTS)

Our Whiteabbey Arts Care Group worked remotely during COVID on artwork for the social services building in Whiteabbey Hospital including individual and collective pieces which explore what nature and nurture means to the group. It is remarkable such a large project was created given via Zoom, supported by our artist-in-residence Ciara who shared techniques to assist everyone. Service users said they want to be involved in future projects so co-production is valued and worthwhile.

*“I find it very socially engaging and look forward to the class each week. I have also learned quite a few things from yourselves as I take small notes throughout the class and can then reflect on them after it's finished. All in all, I've loved being part of the arts group”*

We have also received positive feedback from clients who are currently attending our service who have commented on how they value this new environment.





# PPI and Co-Production in practice across the Trust

## Clinical Health Psychology

A partnership project between the Causeway Inflammatory Bowel Disease (IBD) Patient Panel, the Northern Health and Social Care Trust's Inflammatory Bowel Disease Service and the Clinical Health Psychology Service led to a survey of those living with IBD identify the psychological need that IBD presents. The findings from this project have been shared locally and regionally..

A service review of Clinical Health Psychology input into Intensive Care Unit follow up clinics across the Trust includes service user feedback to evaluate and shape future service provision. Using the online platform, Citizen Space, feedback is being sought from service users following initial consultation and also at the point of discharge from the Clinical Health Psychology. Collating information about the accessibility and acceptability of the service helps to assess the extent to which service aims are being met.

A service user reference group made up of young adults living with Diabetes have continued to meet and has been working towards increasing visibility of the emotional wellbeing of young service user and accessibility to services. The Group is working on the design and branding of a logo for use on leaflets and posters to raise awareness among young people and healthcare staff of the importance of thinking about emotional well-being when living with Diabetes. They are also designing a tool to use when introducing conversations about mental health into Diabetes clinic review appointments. The Group has also designed workshops for young adults with Diabetes, aimed at normalising the impact on emotional well-being of living with diabetes, and reducing isolation by helping make connections with others in the same situation.

## Child and Adolescent Mental Health Service (CAMHS)

From March 2020 to June 2020 the Specialist Child and Adolescent Mental Health Service (CAMHS) and the Children's Early Intervention Service (CEIS) completed a telephone audit with 224 young people and their families to ascertain what their experience of remote appointments has been like and to obtain feedback about how the services could further adapt to best meet the needs of families during the pandemic. This feedback was used to directly shape on-going service delivery as services continue to adapt to the impact of COVID-19.

The Specialist Eating Disorder Service in CAMHS has an on-going monthly peer support forum where families can receive support from other families and professionals who have been involved with the service and also provide peer support and mentoring to other families within the service. This peer support forum is facilitated by a team member however the stakeholders and their families have a very active role in deciding function and focus of the meetings.

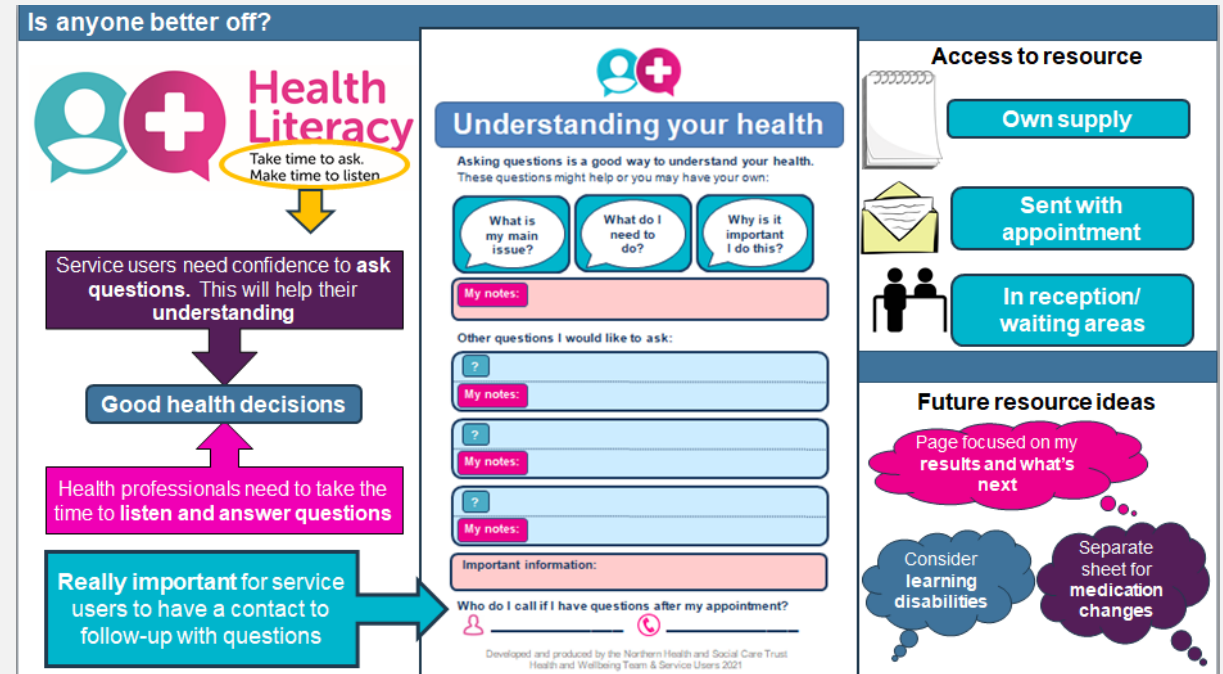
Children's services (which includes CEIS, Specialist CAMHS, Paediatric ASD team) facilitated an interactive workshop to promote involvement in our services which resulted in a number of involvement projects including;

- A joint project with the Arts Care and young people to design and decorate the waiting room in the Masserene base in order to make it more suitable for children and young people who attend appointments.
- The CEIS team facilitated a project with young people and their families to create an information video about the CEIS service and what young people can expect when they attend.
- The Paediatric ASD team are engaging with parents and carers about their experience of their teenage program to shape its content and delivery.

## Health Literacy

Three focus groups (18 service users) were held via zoom in February 2021 to pilot a resource to support service users in getting the best out of health or care consultations and conversations. Everyone's thoughts and opinions were taken on board to develop something which would allow service users to write down their questions and make notes.

This is continuing on from the co-development of the health literacy logo and strapline 'Take time to ask, make time to listen' which was developed by service users who wanted people, like them to feel more confident to ask questions so they can better understand their health condition.



**Is anyone better off?**

**Health Literacy**  
Take time to ask.  
Make time to listen

Service users need confidence to **ask questions**. This will help their understanding

**Good health decisions**

Health professionals need to take the time to **listen and answer questions**

**Really important for service users to have a contact to follow-up with questions**

**Understanding your health**

Asking questions is a good way to understand your health. These questions might help or you may have your own:

What is my main issue?    What do I need to do?    Why is it important I do this?

My notes: \_\_\_\_\_

Other questions I would like to ask:

? \_\_\_\_\_  
My notes: \_\_\_\_\_

? \_\_\_\_\_  
My notes: \_\_\_\_\_

? \_\_\_\_\_  
My notes: \_\_\_\_\_

Important information: \_\_\_\_\_

Who do I call if I have questions after my appointment?  
\_\_\_\_\_

**Access to resource**

Own supply

Sent with appointment

In reception/waiting areas

**Future resource ideas**

Page focused on my results and what's next

Consider learning disabilities

Separate sheet for medication changes

Developed and produced by the Northern Health and Social Care Trust Health and Wellbeing Team & Service Users 2021

# PPI and Co-Production in practice across the Trust

## The JAM Card

Supported by the Northern Area Autism Reference Group, in partnership with NOW Group (an organisation that supports people with autism and learning difficulties into employment) we have become a JAM Card friendly organisation. The JAM Card stands for **Just A Minute** and was developed because service users said they would like a discreet way of telling people that sometimes they need a little extra time and patience. Initially created as card and has recently been developed into an app for smartphones. There are currently approximately 70,000 JAM card users, and over 5,500 JAM Card App users.



To date JAM Card training has been completed by various Trust services who now display visual material highlighted the service is JAM Card friendly and thereby reducing anxiety for those attending. Co-design has always been at the heart of the JAM Card and as a result of feedback from Northern Area Autism Reference Group a new addition to the JAM Card Family has been formally introduced which states 'Please be patient, I am autistic'.

*Debbie a member of the Northern Area Autism Reference Group stated - "As an autistic adult carrying a JAM card helps to reduce my anxiety about going to JAM friendly spaces, as I know if I have any problems they will understand and give me the time I need. It means that I do not need to verbalise the problem, something I may not be able to do, but can simply show the card. I really like the new wording using identity first language, as autism is a fundamental part of who I am, not something I have and can be separated from me."*

*Elvin another member of the Northern Area Autism Reference group said – "For me, sometimes what people say to me sounds like a different language, and I need a moment to "translate it" - it's not about lack of understanding due to low intelligence, it's about my mind having a different way of processing information"*

# PPI and Co-Production in practice across the Trust

## Loneliness Networks

There are five locality loneliness Networks within the Northern area including the NHSCT Loneliness Network which launched in late 2018. Each of the locality networks comprise of members from the voluntary community and statutory sector who work together to raise awareness of loneliness, promote opportunities for socialisation and initiate actions which address loneliness. They have been instrumental in supporting those feeling lonely and isolated during the Coronavirus pandemic.

In March 2021 Networks members' completed a questionnaire 'Reflections and future plans' asking them about achievements of the past year, potential gaps and issues they wished to focus on in the year ahead.

Causeway Loneliness Network has also asked its members to feedback on the concept of 'Chatty Benches'.

## Recovery Pack

Service user groups in the Coleraine area created a Recovery Pack for therapists and clients to work on as part of discharge planning. The idea came from service users who had recently finished therapy and identified this as a way of further supporting clients after discharge. The pack has been shared for all PTS therapists to is used for training on Discharge Planning.



# PPI and Co-Production in practice across the Trust

## Independent Advocacy during Covid-19

To make sure that the Covid19 restrictions would not stop clients accessing the advocacy service a protocol was put in place to ensure continued uninterrupted advocacy delivery and equity of access. Advocates contacted wards on a daily basis and information posters and leaflets were distributed to wards and community facilities. Technology has supported the provision of advocacy – phone, email, Zoom, Skype, Teams and Whatsapp - and conferencing has been used both for individual consultations as well as in group meetings. Contact with the service has increased substantially since the onset of the Covid19 pandemic.

## CLEAR Dementia Care© App

CLEAR Dementia Care was co-produced by people with dementia, carers and healthcare professionals within the Northern area. Funded by the Department of Health (DoH), the NI Executive and Health and Social Care Board the app provides information about dementia and advice to help support a person with dementia. CLEAR Dementia Care © App - Northern Health and Social Care Trust.





## Transforming the 'Communication with Children' early language intervention programme

Re-design of the Speech and Language Therapy parent/carer programme, 'Communicating with Children', was imperative to ensure safe delivery of the programme and maintenance of the service given COVID 19 restrictions. A virtual 'Communicating with Children' pathway was developed.

Crucial to the development of the virtual pathway was feedback from parents about how they learn, their expectations and about what would work best for them in terms of accessing the programme. Parents told us that they would prefer the programme content to be shared with them in video format rather than 'live' virtual sessions; they told us that they would prefer the content in short bite-size videos; they told us that they would find it useful to have a written summary of the content alongside the videos. The virtual pathway takes a blended learning approach, providing parents/carers with access to a series of short engaging videos, detailing the 'Communicating with Children' language support strategies; an accompanying booklet - an accessible written summary of the strategies with activities to increase learner engagement; a partially booked telephone call with a therapist for a solution-focused coaching conversation, assisting parents/carers to implement the language support strategies; and follow-up assessment.

Parents have commented on the flexibility that the virtual delivery enables, allowing for self-paced learning and for families to fit in the content around their daily lives.

## 'Intro to RISE' - Virtual Groups

RISE NI NHSCT is a school based service supporting children with needs which impact on their ability to learn. Given the school closures imposed by COVID restrictions, we had to think of more innovative ways to work with our children so the 'Intro to RISE' virtual group was developed for those children newly referred to the service.

This consisted of 3 x 30 minute sessions aiming to support the child's overall health and wellbeing. The activities targeted attention and listening skills, listening to longer, more complex instructions, fine and gross motor activities and opportunities to explore relaxation and emotional language. Parents were provided with a summary of their child's participation in the group along with suggested activities to promote further development in areas of need.

At the end of the sessions, parents were asked for feedback – 100% rated the sessions as good or very good; 100% would be interested in further Zoom therapy sessions for their children; 100% would recommend group therapy via Zoom. The results speak for themselves!

'Intro to RISE' is now being embedded as part of a new 'blended' approach of service delivery for RISE NI NHSCT.



## RISE NI Page Tiger for Education Staff

A large component of the RISE NI NHSCT model of service comprises of training for education staff. Until last year, this had all been delivered via face to face sessions. Given COVID restrictions, we realised that this was not going to be feasible for the 2020-21 school year and that the training would have to be adapted to online sessions.

As a service, we had developed a Page Tiger for Parents in the first lock down, so it was decided that we should use a similar platform for education staff training. Presentations were adapted for online delivery, recorded and uploaded to the platform. A sample of education staff were involved in the development and review prior to the launch. Suggestions were taken on board and changes made.

The Page Tiger site was launched in March 2021. To date there have been 7944 views, 852 training requests from NHSCT schools and 352 post course evaluations completed. These will be analysed over the summer months to inform future developments for the 2021-22 school year.

Please feel free to view the site via <https://view.pagetiger.com/RISENI/educationstaff>

## Hard to Swallow Project



In 2020, MEAAP partnered with the Dysphagia Support Team, NHSCT, through the Community Foundations Northern Ireland (CFNI) Community Innovators Programme. The result of combined specialist professional knowledge of best practice dysphagia management and expertise in community partnership working was the **'Hard to Swallow'** project.

The two strands of this project involved co-production of an information booklet and a social media campaign with an overarching aim to:

- Increase community awareness of eating, drinking and swallowing difficulties (dysphagia)
- highlight the professional support available within the NHSCT for people with eating, drinking and swallowing difficulties and those involved in their care.

A co-production approach was adopted to ensure those with lived experience of eating, drinking and swallowing difficulties were involved in the steering group for the **Hard to Swallow** project. The project team sought wide community engagement from service users and carers, health charities, community groups, hospitality sector and Council stakeholders and invited them to join the project steering group. They shared their stories, insights and lived experiences of eating, drinking and swallowing difficulties to help plan, shape and develop the resources and ensure the information was presented in an accessible way.

# PPI and Co-Production in practice across the Trust

## Hard to Swallow Project cont....

5000 copies of the 'Hard to Swallow' information booklet have been printed and are now ready for distribution within the Mid and East Antrim locality

6 virtual swallow awareness education events for the general community and community groups were organised (March – June 21) and delivered by a Speech and Language Therapist and Dietitian from the Dysphagia Support Team alongside MEAAP. Feedback from one service user, in response to the Hard to Swallow information booklet highlights the very real need for enhanced community awareness of eating, drinking and swallowing difficulties:

**“If I had known this, my wife’s life may have had a very different outcome.”**

If you would like to receive a copy of the 'Hard to Swallow' booklet email: [admin@meaap.co.uk](mailto:admin@meaap.co.uk) or call 028 25658604.



*Members of the 'Hard to Swallow' team from MEAAP & NHSCT at the Community Innovators workshops in February 2020*

## PPI and Co-Production in practice across the Trust

### Comfort packs

Members of staff continue to work in collaboration with Mothers Union, Mid and East Antrim Agewell Partnership group, Randalstown Girl Guides and Macmillan to ensure the Comfort Pack initiative which has been running since December 2019 continues.

This initiative is only possible through the generous donations from local businesses, partner organisations, community and voluntary groups to support families/ carers whose loved ones have been suddenly taken into hospital, or who are currently very ill or dying in hospital. These packs contain essential toiletries especially during this past year, when visiting has been very limited. These have been very much appreciated by both patients and the staff looking after them. To date approx. 650 packs have been given to patients and families who have been in need of them.

### Cancer Service Health and Well Being Events

In recent years the Cancer Services team engaged with cancer patients and their families through face to face Health and Wellbeing events. These educational events enabled those with a cancer diagnosis to learn more about the support services available to them and to engage with the clinical and voluntary groups offering this support.

Due to COVID-19 restrictions and the need to safeguard patients, NHSCT Health & Wellbeing events had to be postponed. Where HWB events met a specific need of providing information and support following a patient's diagnosis and treatment, there became a significant gap.

With the pandemic reducing contact and support with family, clinical staff and support services, the Trust recognised patients increased need for these HWB events. In order to meet this need, we explored, developed and piloted a number of different formats to engage people virtually, e.g. high quality educational videos, Zoom Q&A's with health care professionals and Zoom Webinars. The feedback from patients after each event helped us to develop a robust, person-centred format that will meet the needs of our patients and their families. Live phone-in options were available for the live events with DVDs also available for those patients unable to utilise the virtual technology.



# PPI and Co-Production in practice across the Trust

## Teenage and Young Adults (TYA)

A Steering Group of 5 young adults informed the adaption of our planned group work and peer support programme to move to digital platforms. The focus remained supporting their needs relating to diagnosis, treatment and life after treatment whilst providing opportunities for peer support and connectivity. The Steering Group advised on; best virtual platforms, tools of engagement, roles and responsibilities with regards recruitment of young people and the development of Covid-19 Wellness Packs which were sent out to 70 young adults last year in response to the pandemic.

In consultation with young people we adapted aspects of our group work programme, in particular; we moved away from using Look Good Feel Better and instead have a 'peer led' make up session format that is delivered by a young person with an experience of cancer. This increased attendance from an average 6 TYAs per session to 12 TYAs. We also increased the frequency of these groups at the request of the young people. In response to Covid-19 we offer all our group work virtually with great attendance and contribution. Young adults took on roles of facilitating games night virtually with the TYA Cancer Service Team which evolved over a 20-week period through their continued feedback and suggestions.

In response to the mental health impact of lockdown, 2 young adults with a lived experience of cancer developed a regional exercise challenge- 'MOVE Forward through lockdown'. They encouraged over 40 young people and staff to 'move more' during lockdown and created a healthy competition. This was their idea and led by them whilst being supported by the TYA Cancer Service Team.



# PPI and Co-Production in practice across the Trust

## Community Stroke Service

During the COVID 19 pandemic, the Community Stroke Service was faced with the issue of continuing to deliver rehabilitation for services users following stroke while balancing the risk of COVID 19 transmission brought about by face-to face contact. The team swiftly developed a range of tools, assessments and treatment options which could be delivered remotely. Central to this change in service delivery was an ethos of positive risk taking and patient centred care. The range of interventions that were adapted for remote delivery included cognitive assessments, functional assessments, environmental checks, exercise programmes.

To evaluate the impact of this change, feedback from service users who had participated in this very new way of working was gathered using questionnaires and guided conversations. The feedback was generally very positive with service users commenting on how they valued the opportunity to continue to participate in programmes but feedback also highlighted that a number of service users struggled to use the technology on their own and required assistance from a family member. This insight has helped to shape and further develop the delivery of remote therapeutic interventions following stroke and their continued use as a treatment medium.

## District Nursing

In response to service user feedback that they did not want visits from district nurses during Covid19, the Service devised a structured telephone review process so they could continue to provide wound care and palliative care when appropriate.

The District Nursing Care Opinion campaign was launched on the 22 March 2021 with the caption “WE WANT TO HEAR YOUR STORY”. District Nursing services are keen to learn from the experiences of patients, families and carers. Share your story at [www.careopinion.org.uk](http://www.careopinion.org.uk) . This provides district nursing with a contemporary, real time analysis of the service from the patient and their carer.

## Launch of our new Accessibility Guides to Northern HSC Trust

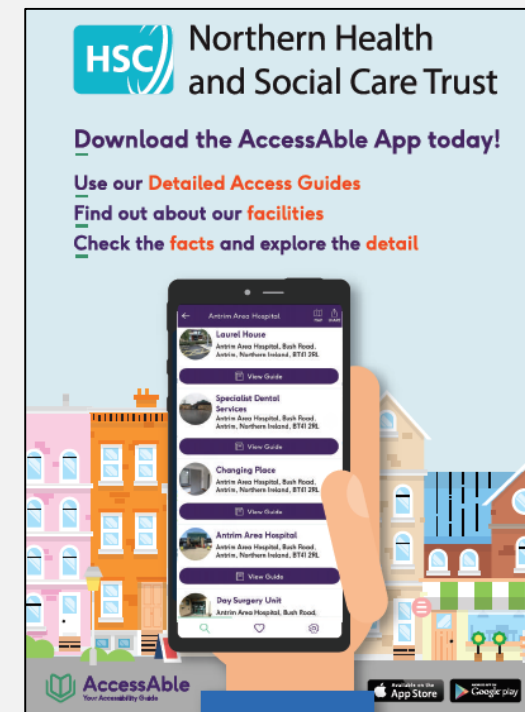
Northern Health and Social Care Trust became the first healthcare Trust in Northern Ireland to partner with AccessAble; the UK's leading provider of detailed disabled-access information. The Trust worked in partnership with AccessAble and a number of service users to create over 80 Detailed Access Guides to facilities, wards and departments at Antrim Area Hospital and Causeway Hospital, including the maternity services, intensive care units, occupational therapy, and outpatients.

The Guides include facts, figures and photographs to help patients, visitors and staff plan their journeys to and around the hospitals, covering everything from parking facilities and hearing loops, to walking distances and accessible toilets.

The Guides also include a newly developed section dedicated to giving updated information about COVID-19 measures.

We know everyone's accessibility needs are different, which is why having detailed, accurate information is so important. It's why all of the details you'll find in the Guides have been checked in person, on site, by trained surveyors.

You can view **Northern Health and Social Care Trust's** Accessibility Guide here: <https://www.accessable.co.uk/northern-health-and-social-care-trust>



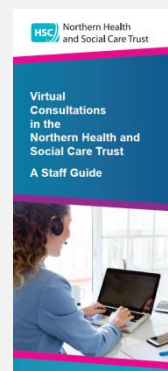
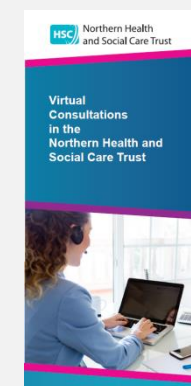
# PPI and Co-Production in practice across the Trust

## Virtual Consultation

The COVID-19 pandemic resulted in Trust staff, across most settings, considering alternative methods of service delivery where face to face consultations were high risk for both service users and staff. As a result, we changed how we communicated with our service users, making more telephone calls and appointments by video.

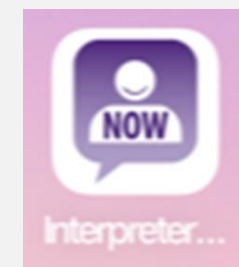
On 23 October 2020, the Trust held an engagement event with service users, carers and representative organisations to find out what their experiences and views were on the effectiveness and accessibility of these virtual consultations. Experiences were mainly positive and we came away with 4 main themes to keep in mind when planning a virtual consultation. These were Choice, Preparation, Accessibility and Communication. To read about the themes in detail you can view the full feedback report from the event [here](#).

One of the main outcomes from the engagement event was to work with our service users and carers to develop and information leaflet for service users on virtual consultations that could go out with all new appointment letters.



We also developed an easy access staff guide to help in preparation for virtual consultations.

We continue to work with the Health and Social Care Board to ensure a remote sign language interpreting service is available for health and social care staff to contact Deaf service users and vice versa by using the Interpreting Now app.



## Good Relations

During Good Relations Week (14 – 21 September 2020), the Northern Trust hosted a regional engagement event via Zoom to develop a coproduced visible, accessible and unequivocal Good Relations Statement for HSC organisations to promote positive relations between persons of different religious belief, political opinion or racial group. The event was well attended by individuals, representative groups and trade unions. The final co-produced statement is displaying in offices and waiting areas.



**Working together we will promote good relations between people of different race, religion or political opinion**

This means that we:

- Will actively address and challenge racism and sectarianism in all its forms
- Will treat each other fairly, with respect and dignity
- Will make sure our spaces are shared, welcoming and safe.

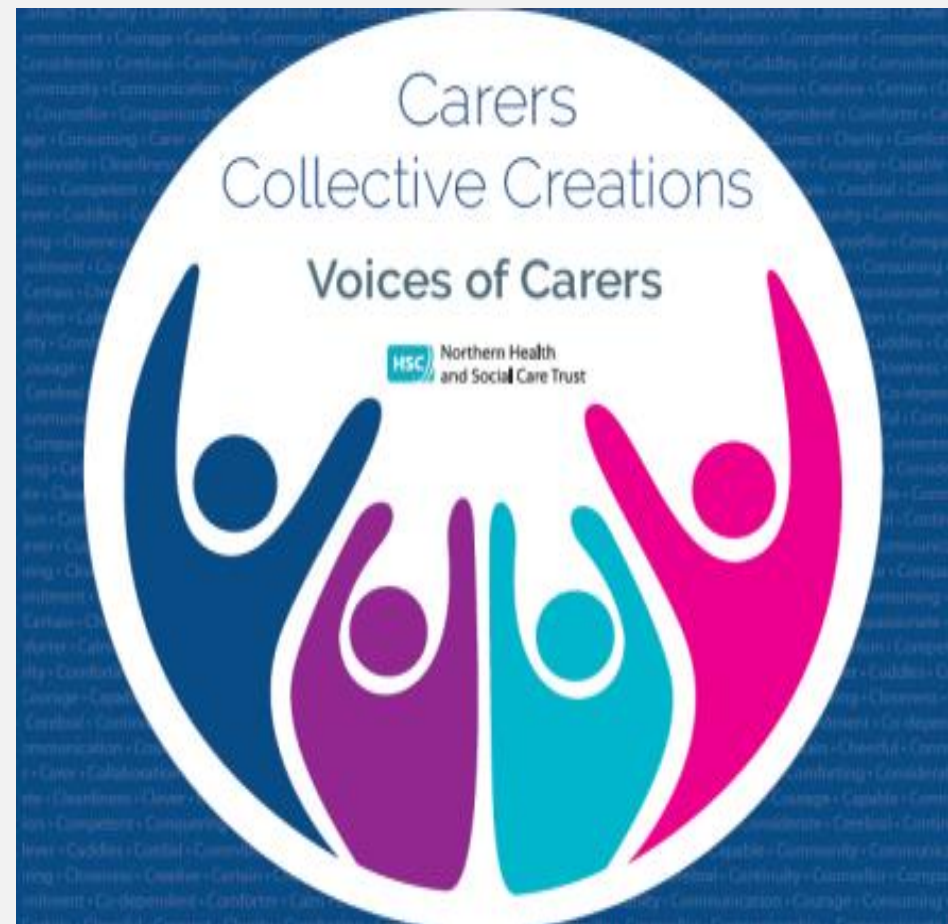


## Carers' Collective Creations

On 9 June during carers week the Health Minister Robin Swann launched a unique collection of creative stories produced by informal family carers.

The Carers' Collective Creations are the personal stories of seven carers told through illustrations and creative writing. The stories describe how their caring role has shaped their lives and the impact of caring during the COVID-19 pandemic.

The carers wrote the stories together, benefitting from new friendships, a sense of connection and community. This co-produced resource will not only offer other carers the chance to relate to and benefit from the stories, but will be of great value to a wider audience.





# PPI and Co-Production in practice across the Trust

## Assistance Dogs Etiquette

Through Care Opinion we received a story from a service user who described their poor experience whilst visiting hospital with their Guide Dog. In this case, staff did not adhere to the etiquette required when an assistance dog is in harness resulting in the dog becoming distracted. As a result, in partnership with a group of service users, including the service user who raised the complaint, a poster was co-designed for display in Trust areas. This has also been shared regionally to improve awareness of assistance dog etiquette.

The positive outcome from this feedback demonstrates how valuable service user feedback can be and how important it is for the Trust to listen and learn from the experiences our service users, families and carers.

 Northern Health  
and Social Care Trust







**Do you know your  
Assistance Dog Etiquette?**





Assistance Dogs need to concentrate on their job to keep their owner safe. If you break that concentration, you could be putting the dog and its owner in serious danger!

**Please respect Assistance Dogs and their owners  
by following this simple etiquette guide**

**DO** 

-  Speak to the owner first, not the dog.
-  Allow the dog to work without distraction.
-  Respect that the dog is working.
-  Allow the dog to rest undisturbed.
-  Let the dog owner know if the dog approaches you as this may be unwanted behaviour that needs correcting.

**DO NOT** 

-  Approach, touch or speak to the dog without the owner's permission as this can be a distraction.
-  Offer the dog food.
-  Allow other pets to interact with the dog.
-  Be offended if the owner does not want to answer questions or says no when you ask to pet the dog – they may be in a hurry to get somewhere.



**If you think a handler needs help,  
remember to ask before acting!**



## **Acknowledgement**

We would like to extend our sincere appreciation to everyone who continues to be a champion of PPI. Your commitment will help shape our future services.

Please contact the PPI Team for further information on our engagement work or if you wish to join our Involvement Network.

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