

The logo for Picker, featuring a stylized blue and teal icon of three interconnected circles to the left of the word "Picker" in a bold, dark blue sans-serif font.

Picker



Involving Staff and Patients in Improvement Work

Housekeeping

This webinar will be approx 1 hour.

This session will be recorded and made available within 48 hrs

All attendees must remain muted

Please type your questions into the Q&A function

All questions and their answers will be made available as a PDF



The logo for Picker, featuring a stylized blue and teal icon of three interconnected circles to the left of the word "Picker" in a bold, dark blue sans-serif font.

Picker




Involving Staff and Patients in Improvement Work

NHS Kent and Medway

Co-producing a Long Covid assessment and support service for Kent and Medway


Rachel Parris, Deputy Director, Health Improvement and Transformation

Clare Delap, Engagement Lead

A purple speech bubble with a white background, containing text.

*The ability to talk to other patients
and doctors has been a lifeline...
We are all learning about this
new illness... we are all learning
from each other.*

Darren Winch, patient representative,
Long Covid Delivery Group

A blue speech bubble with a white background, containing text.

*They are not backward in
coming forward. They really do
tell us their opinions but equally
they help drive the work
forward.*

Rachel Parris, Deputy Director
Health Improvement &
Transformation

Our Long Covid co-production journey



Kent and Medway

- NHS Kent and Medway – who we are
- background: why it was important to work with people with Long Covid
- the story: how people got involved, how we listened, and what happened as a result
- views from patients and staff – why co-production made a difference
- What we learned



We plan and buy healthcare services to meet the needs of the 1.8 million people living in Kent and Medway.

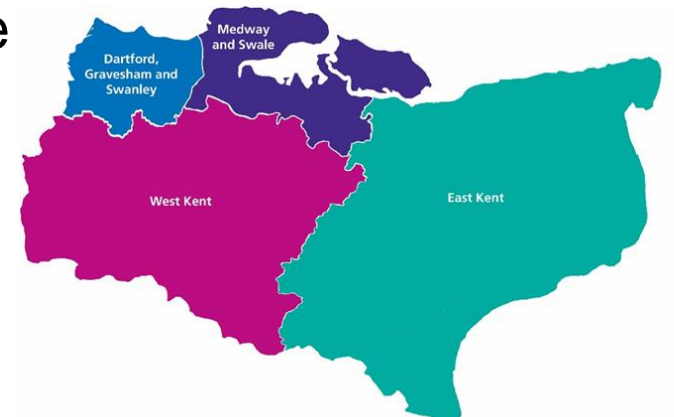


We have an annual budget of around £3.5 billion in 2022/23.

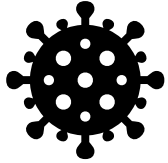


With our partners in the **integrated care system** we focus on:

- improving outcomes in population health and healthcare
- tackling inequalities
- enhancing productivity and value for money
- supporting broader social and economic development.



Long Covid – working together to tackle a new condition



10 to 13 per cent of people who get Covid will develop Long Covid. This could mean between 11,000 and 14,000 patients in Kent and Medway.



In 2020 very little was known about the condition, but it became clear that, for some, it was life-changing.



People suffering and their families felt ignored – they were calling for dedicated support.



We wanted to develop an assessment service. We knew we had to work with people with Long Covid from the start so that it would focus on what mattered to them.

When we started to listen, we realised much more was needed ...

Involving people at every stage

Step 1. Learning together: April – June 2021

To better understand people’s experiences, we carried out:

- surveys
- work with Healthwatch
- outreach focus groups with communities, and
- workshops

Heard from over 300 people

Engagement informed the post covid assessment service (PCAS) that opened in May 2021

Step 2. Driving delivery : July – September 2021

Set up a patient reference group

People with lived experience became part of a cross organisational delivery group monitoring and improving PCAS

Kent and Medway PCAS is now the largest in the country

Step 3. Listening for improvement: September 2021 - April 2022

The patient reference group told us more was needed

We ran further listening exercises, surveys and events with over 400 responses generated

This demonstrated the need for an enhanced service

Step 4. Co-design of new service: May 2022 onwards

Co-design of a new rehabilitation and support service

Patient reference group helped write the service specification

Further work being carried out with underrepresented communities

How we listened and acted

You said

- recognise our symptoms and start to assess them properly
- educate GPs, clinicians and employers so that they understand Long Covid
- help us help ourselves – speaking to others with Long Covid is essential
- provide us with rehabilitation and support – including ongoing management of our care


We did

- the Kent and Medway post covid assessment service (PCAS) has seen over 3,000 people since May 2021
- a film made by reference group members was widely circulated. Following education sessions over 90% of practices have referred to PCAS
- peer support groups are being set up by partners on the delivery group
- a new rehabilitation and support service is commissioned from April 2023 – co-designed with patients

NHS


Kent and Medway

Involving people and communities:
co-producing Long Covid services

A purple speech bubble with a white background, containing text and a name.

*There's a lot of work to do still
and if we work together as a team
and involve patients along the
journey then we will hopefully
improve patient care.*

Sophie Burns, patient representative,
Long Covid Delivery Group

A blue speech bubble with a white background, containing text and a name.

*It has bought me back to a core
value of the NHS: to create
services that respond to
patients experience rather than
what we the "professionals"
think people need.*

Abigail Kitt, Deputy Director Health
Improvement & Transformation

Lessons learned



Kent and Medway

Long Covid is a new condition – this was an opportunity to learn together and build a service from the beginning in partnership

How to keep involving people over the longer term – what is the role of patients in monitoring health and care services?

Some communities have not been as engaged as they should have been – we need to get better at involving people from diverse communities

People with lived experience should be involved across *all* commissioning and decision making in Integrated Care Systems

Working in partnership with patients/families requires **understanding** (expertise), **capacity** (time) and **courage** – it is a challenge to make this part of the day job across all teams.



NHS

Kent and Medway

Thank you patients and families with Long Covid!

clare.delap@nhs.net

rachel.parris2@nhs.net

www.kentandmedway.icb.nhs.uk

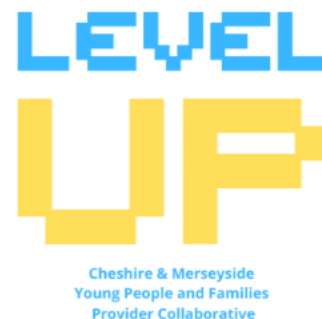
Thank you!





ADULT EATING DISORDERS
PROVIDER COLLABORATIVE
NORTH WEST

In partnership with:
Cheshire and Wirral Partnership NHS Foundation Trust
Priory Healthcare
Greater Manchester Mental Health NHS Foundation Trust
Lancashire & South Cumbria NHS Foundation Trust
Mersey Care NHS Foundation Trust



In partnership with:
Cheshire and Wirral Partnership NHS Foundation Trust
Priory Healthcare
Alder Hey Children's NHS Foundation Trust
Cygnet Health Care
Mersey Care NHS Foundation Trust

Jenny Scott and Fiona Jenkins
Cheshire and Wirral Partnership
NHS FT – Commissioning Team
February 2023



Our Provider Collaborative Commissioning Focus



ADULT EATING DISORDERS
PROVIDER COLLABORATIVE
NORTH WEST

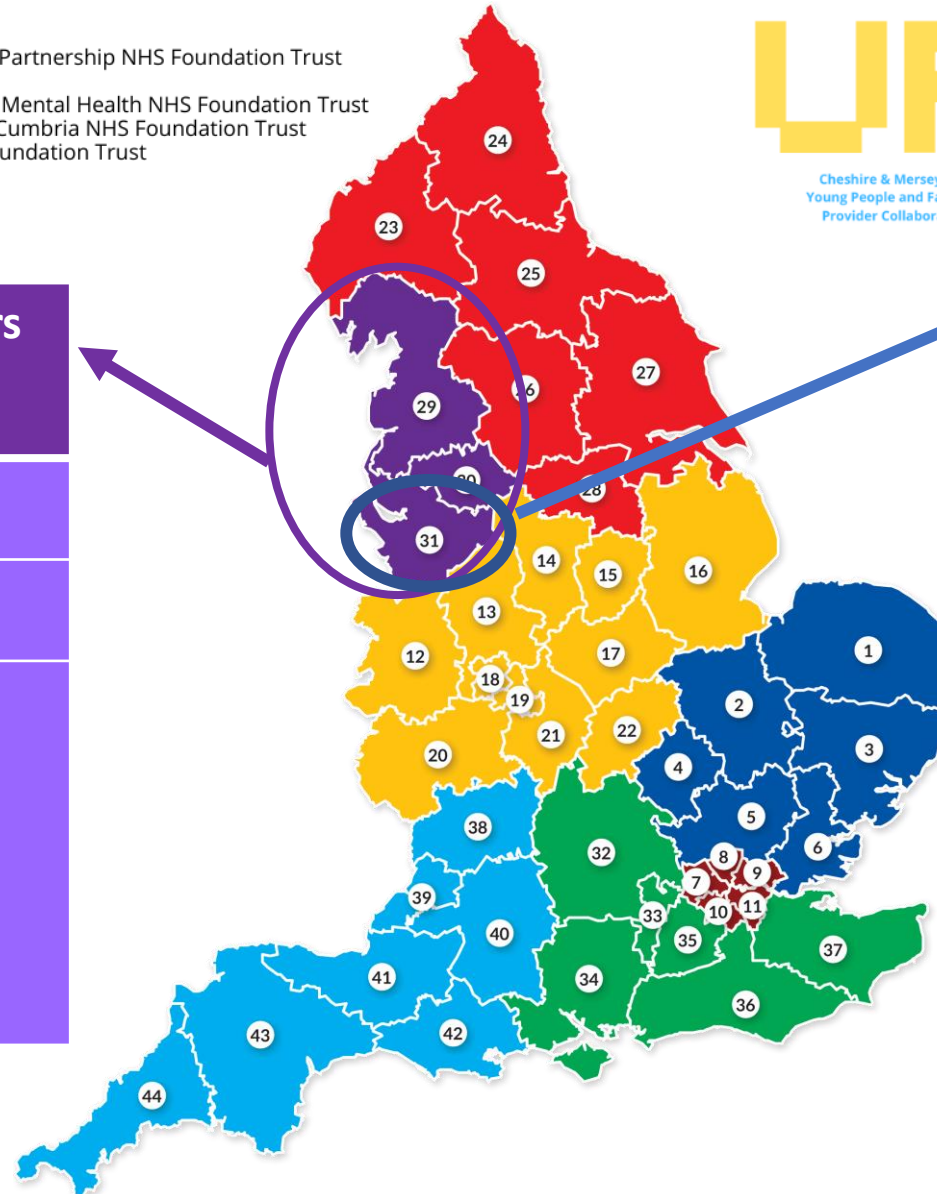
In partnership with:
Cheshire and Wirral Partnership NHS Foundation Trust
Priority Healthcare
Greater Manchester Mental Health NHS Foundation Trust
Lancashire & South Cumbria NHS Foundation Trust
Mersey Care NHS Foundation Trust

LEVEL



Cheshire & Merseyside
Young People and Families
Provider Collaborative

In partnership with:
Cheshire and Wirral Partnership NHS Foundation Trust
Priority Healthcare
Alder Hey Children's NHS Foundation Trust
Cygnets Health Care
Mersey Care NHS Foundation Trust



Empowered Adult Eating Disorders PC (North West)

Serving a population of circa 6 mill

NHS and IS Provision

- Challenges:
- increasing referrals post pandemic
 - community eating disorder gatekeeping,
 - Consistency in admission criteria
 - gaps in service provision,
 - Inpatient capacity across NW

Level Up Young People and Families PC (Cheshire and Merseyside)

Serving a population of circa 3 mill

NHS and IS Provision

- Challenges:
- increase in referrals, young people with highly complex needs
 - young people with eating disorders strengthening Local Authority partnerships
 - inappropriate use of acute paediatrics as safe places.
 - Delayed transfers of care
 - Harm from inappropriate admission

Our ambition for change

Specialised Mental Health Provider Collaboratives were established by NHSE/I with a mandate for creativity and innovation driven through delegated commissioning.

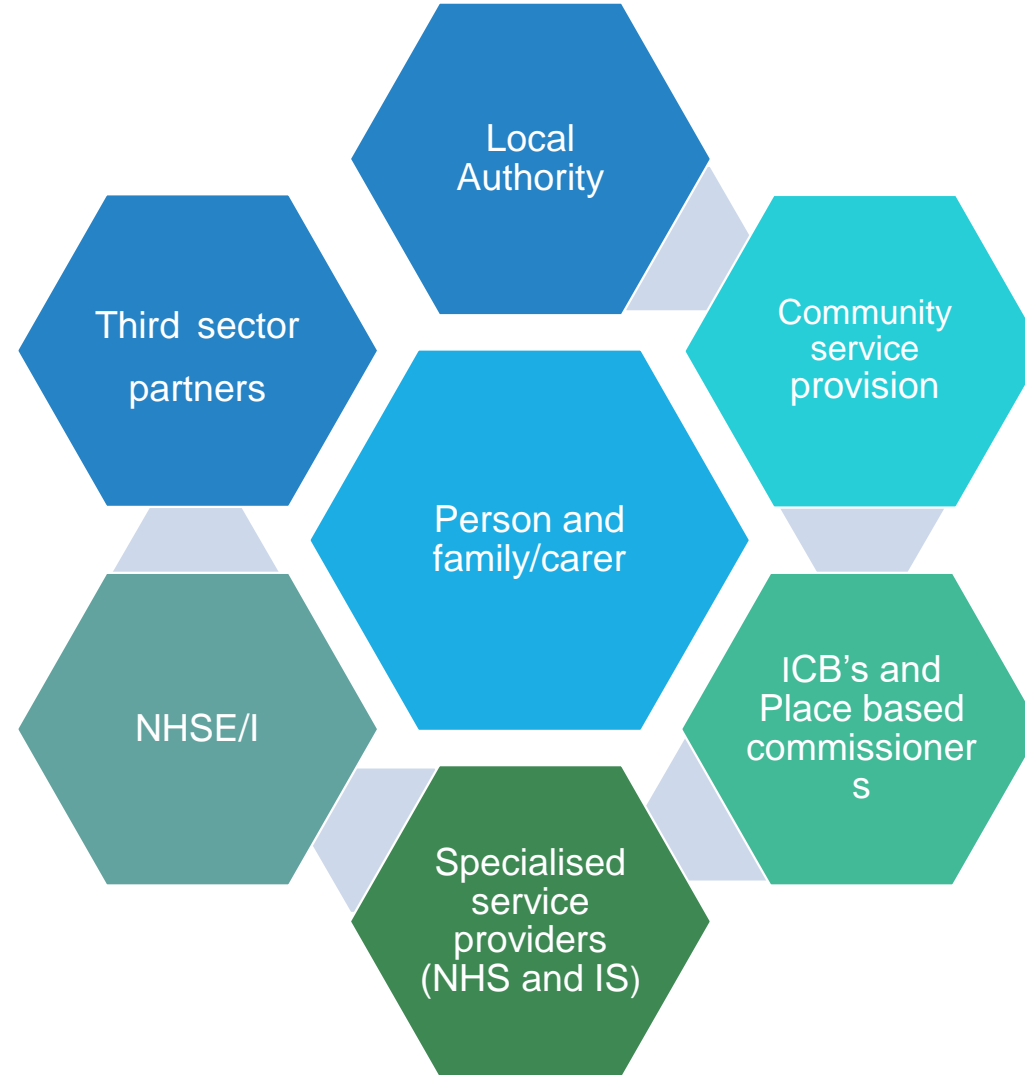
Collaborative partnerships spanning health and social care pathways are fundamental to achieving truly person centered care.

We want our young people, their families and adults with experience of eating disorders to work alongside us as equal partners in driving service change.

Our postcards from the future will describe a shared vision of possibilities and unite us in our determination for service improvement.

Not a soft option but a relentless focus on commissioning for quality, clinical outcomes and most importantly, patient experience through integration and continuity of care.

A person centred approach is the key in a complex and changing landscape



Impact on commissioning

Unique perspective – people with lived experience of services (either as service users or families / carers) tell us how services feel in reality.

Collective action - by being honest and open about key challenges, we can move forward together in partnership to seek solutions.

Organisational consensus - a reality based focus on person centred care unites disparate organisations in the important issues.

Evidence based discussions – we reference best practice evidence alongside the views of our experts by experience.

Resilience – we can face future uncertainties and challenges more robustly through our strengthened partnerships.

Early actions – our name and logos, our website, reflective and sharing event

Our Approach

Transparency and honesty – we are open about the challenges we collectively must address in our services.

Governance – we have hard wired our commitment to integration and partnership working through both our PC structures and decision making. This encompasses both provider and commissioning perspectives.

Pathways of care – patients move between different levels of care but they ‘belong’ to their place and must stay connected there.

A cultural focus – our work with experts by experience is cultural and is constant in all our planning and development not just at certain points in time. people with lived experience are trained and empowered to play a full and active role in PC groups and decision making.

Third sector partner expertise – commissioning support from Beat, Young Minds and Inspire Motivate Overcome (IMO) – formal recruitment, training and community connections.

Community engagement – harnessing the energy and enthusiasm of different communities in raising awareness of mental health.

Forum Recruitment



EmpowerED

ADULT EATING DISORDERS
PROVIDER COLLABORATIVE

NORTH WEST

LEVEL
UP

Cheshire & Merseyside
Young People and Families
Provider Collaborative

Adult with an
Eating Disorder

Experience of
Community
Care

Inpatient Care

Carers

Representation
from the LGBTQ
community

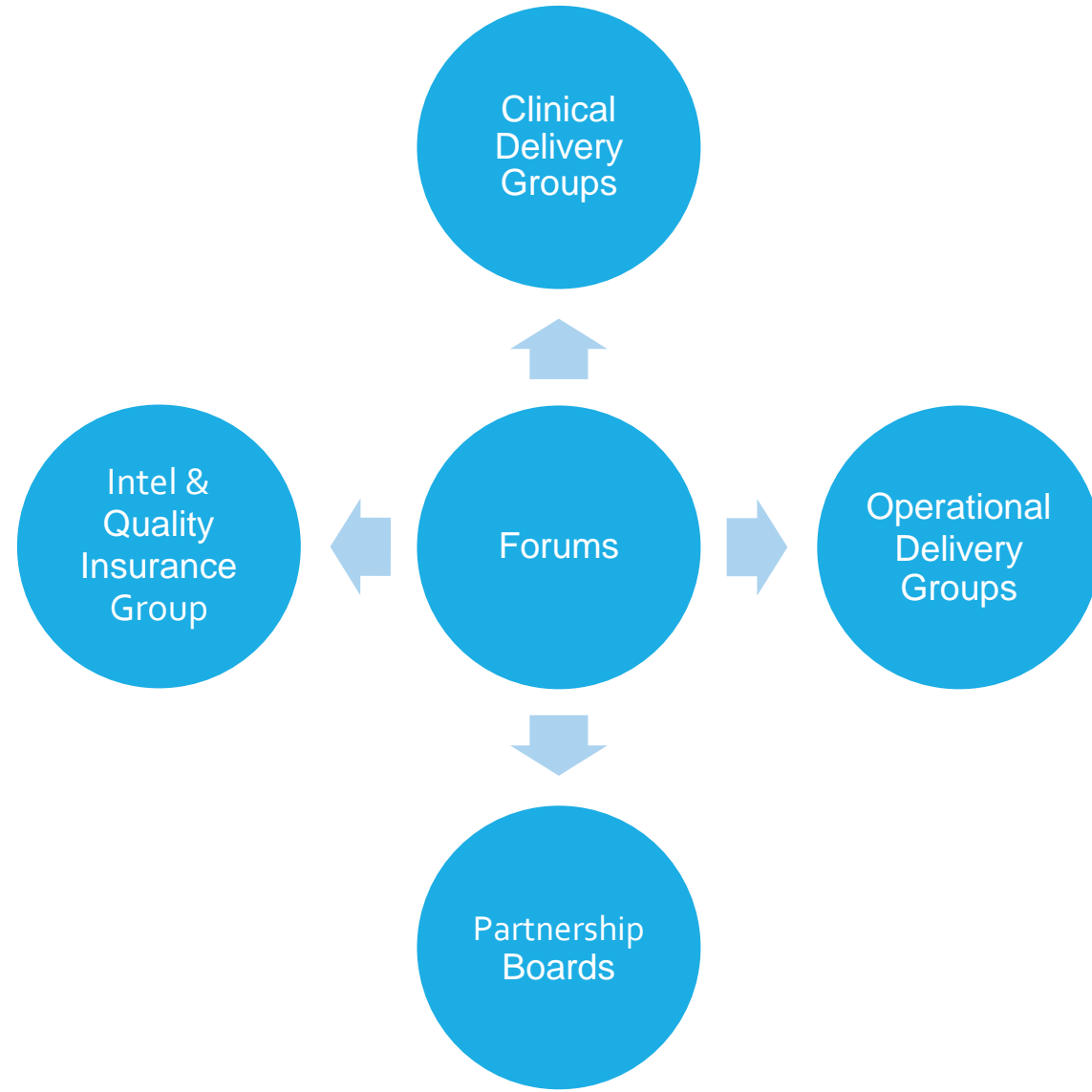
13-18 year olds

Tier4 inpatient
care

Tier 3 CAMHS

Care Leavers
aged 21-22
years

EmpowerED and Level Up Pathway to enable change





ADULT EATING DISORDERS
PROVIDER COLLABORATIVE

NORTH WEST

Topics



what good and bad community treatment looks like



What good and bad inpatient treatment looks like



Virtual support



Short term goals

Creating a nurturing environment that encourages recovery as best possible (implementing regular activities etc so patients are not bored)

Given choice over types of treatment/therapy. What groups you do/join

Knowing what the plan is

Support/gradual leave

Providing a holistic approach to care/treatment

Stay connected to outside world

Directed - clear and agreed goals, ambitions

Family involved (if needed)

Outpatient care in place as a follow up when discharged

Communication! - with family, patient, doctor, ...

Empathy from entire team

An understanding consultant

Balances the structure and rules necessary on a ward with opportunities to be/discover an individual

Clarity around "why" is this a rule/happening/the plan/helpful

Staff who listen and understand

Well staffed units not over reliant on agency staff

What does good in-patient treatment look like?

Care close to home

Openness - informed when something you're doing is potentially seen as 'wrong' or incorrect

Keeping relatives involved and up to date

Experienced staff

Taking into consideration an individual's wishes where possible (this should apply to all aspects of care)

Regular visits from loved ones + friends

Getting to choose who is involved or informed about you

Close to home - accents that are familiar, family to visit, staff and patients discussing places familiar with

Includes regular therapy and no delays to start therapy

Regular feedback on progress

Regular sessions with therapists, OT, dietician...

Multidisciplinary

Lack of options/choice

Lack of awareness/understanding from staff in regard to eating disorders

Inappropriate comments by staff

talking about patients, not with patients

Lack of activities at the weekend

Nobody communicating with you especially at the start. Not seeing professionals etc.

No actual help or therapy

Poor communication

Forced treatment used when there are other options

Removal from reality to the point that motivations disappear

patronising - no intellectual engagement but 'come and pet this pony'

No clear communication/information about rights

Professional paternalism; where professionals make decisions because THEY think it is right, even if it goes against a patients wishes

Poor internet connection so feeling cut off from the rest of the world

What does bad in-patient treatment look like?

Lack of activities

The mere mention of food in chats being banned or adverts on the radio coming on + the station being changed so good isn't mentioned in the dining room - ironic - and not real life

Staff not being cautious about triggering conversations initiated by them

Patients beliefs and culture not taken into account

Being patronised

Using restrictive methods of practice, before exhausting other less restrictive avenues first

Felt very restricted and changes made to help make things easier for staff rather than thinking about why more effort to do something might be worth while.

Being forced to eat foods you categorically do not like - only allowed 2 'dislike' foods. Made recovery so much harder

Other patients being extremely disruptive and then taking all staff time and attention

Being treated like a "trouble maker" or a problem

understanding that e.g. porridge is not just porridge to someone with an ED

Extremely long admissions where you end up a bit too comfortable there and reality is unmanageable

Referral processes
(school to CAMHS)

Transition into and
out of Tier 4
services

People who can't
access CAMHS

Communications –
around diagnosis
and how to access
support

Training
professionals –
when a YP asks a
curious question

Early services –GP
and what other
support is available

Information -
deeper meanings
around Anxiety and
types of therapy

What support is
there in between
young person and
adult services,

Reassurance and
support when faced
with waiting times

Topics

Engaging with our communities



What do our Experts by Experience think?



Thank you!





Liverpool University Hospitals
NHS Foundation Trust



St Helens and Knowsley
Teaching Hospitals
NHS Trust

The Development of a Regional Carer Passport: An Example of Best Practice in Co-production.

Picker Webinar
09.02.2023



Aim of the Project

- We will demonstrate our commitment to working together with carers as expert partners in care by including them in the creation of an information and support document for carers that is consistent across hospital Trusts in the Cheshire and Merseyside regional Network.
- We will implement the carer passport in clear recognition of the vital role and contribution carers make to their families and enable that role to continue (if wanted) through a clear partnership agreement.

How it all began...

- Harmonisation of LUHFT documentation following Trust merger in October 2019
- STHK reviewing their carers passport, which was due for an update

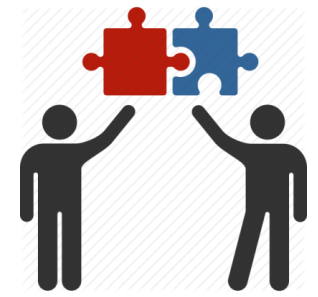
- The Patient Experience Team were reviewing the Trusts two Carers Passports, developed on each site
- Agreed to work collaboratively to create a version that could be used across both Trusts

- Engaged with both carers and carers associations across the North West area
- Facilitated engagement events to understand what carers needed to help support them

- Project presented to colleagues in the Merseyside & Cheshire Hope network
- Work began to co-produce a regional resource



Regional Collaboration



- It was agreed that from both the patient and carer perspective, it was essential to coproduce a passport that was recognised at all Trusts across the area.
- This would ensure that patients and carers could visit different Trusts for a range of treatments and specialties but have a consistent level of support.

“I think a key point is that carers are treated as partners and the co-production of the passport acknowledges this”

Regional Engagement

“We need to be part of the discussions before discharge.....only we know whether it can work”

Carer at Engagement Event

“We are the ones who know and understand them better than anyone. So we need to be there, and we need to be included”

Carer

“If I wasn't there....I think he would die”

Carer talking about adult son

Regional Engagement

“I got involved with the Carer Passport as I wanted the carers to have a voice that was listened to. It was also important to get some uniformity across different hospitals and be involved with some decisions about the person we cared for.”

Doreen (carer)

“As a long term carer for my husband I needed to be involved in his care in hospital. Particularly information sharing. I was interested in the idea of a Carer Passport from the beginning. Information sharing is the pivotal advantage of the passport”

Muriel (carer)

Some of the carers who took part in the engagement, requested that their photographs be used in the final document rather than stock pictures initially used

Launch Event



The Passport was successfully launched across the region, in all participating Trusts across Merseyside and Cheshire Regional Network in November 2021 to coincide with National Carers' rights day.

Passport Benefits for patients and carers

- + Ensuring patient's individual needs and preferences are understood
- + Ensures carers can be present with their loved one to provide emotional support and reassurance when they are frightened and anxious
- + Supporting communication, helping the patient to understand and make sense of what is happening
- + Encouraging compliance with treatment regimes
- + Ensuring the carer can support and encouragement with eating and drinking
- + Including the carer in discussions around care and discharge plans
- + Making the offer from the Hospital explicit

Passport Benefits for staff

- + Having carers present will reduce patient agitation and distress
- + Carers know the patient better than anyone can alert staff of any changes
- + Carers can support mealtimes
- + Carers can encourage compliance with treatment regimes
- + Carers can be involved in discussions to support discharge and ongoing plans of care

Carers Partnership Agreement

Carer Partnership Agreement

As the relative and/or carer of:

It has been agreed that:

Primary carer (name)

Additional carer (name)

(delete as appropriate)

- Can visit outside of normal visiting times.
- Can provide assistance in washing and dressing.
- Can provide assistance in feeding.
- Can be actively involved in team meeting discussions, and planning the discharge where appropriate, about the person they care for.
- Provide support to the person they care for when having procedures / treatments in the hospital.
- Can stay with the person they care for during the day and / or night as required.

You will need to discuss any additional requests or requirements with the Ward Manager or Nurse in Charge.

leaving the ward outside of normal visiting hours and I understand that, at times, I may be asked to leave the ward or bay if there is a clinical necessity.

- ♦ I agree that, if I am assisting with feeding, washing or mobilising that staff may work alongside me to fulfil their clinical responsibility.

** This agreement is only valid for this hospital episode.*

- ♦ This agreement will be for the duration of the patient stay and will be monitored/ reviewed accordingly. There may be circumstances when the carers agreement is adjusted or suspended and this would be discussed with all relevant parties.
- ♦ Please understand this agreement may be revoked in the light of any NHS Guidance or National Policy
- ♦ Is there a Lasting Power of Attorney (LPA) agreement for Health in place and has it been seen? Yes No

Signed (carer)

Authorised by

Ward Manager

Nurse in Charge

Ward

Date

Once completed a copy of the agreement should be provided to the carer/s together with the carers card.

A copy of the agreement should be retained at the Trust.

- The agreement is part of the passport
- Staff simply complete the patient and carer/s names
- Sign and complete their designated role
- Retain a copy
- Give a copy of the agreement and a Carer passport card with the ward contact details to the Carer

Passport Feedback

The passport gives a carer a voice and gives us some respect from the hospitals. It enables us to carry on being involved with the person we are caring for even when they are in hospital. This can sometimes take pressure off the nursing staff and make a real difference when arranging discharges.

Having a passport that is used at all the hospitals also helps the carer and staff know what is expected from both sides”.

Doreen (carer)

“The Carers Passport will make a vital difference to both carers and NHS staff by the medium of relevant information sharing.”

Muriel (carer)

What's Next.....

Feedback from all areas regarding this passport has been positive including:

- + Improved individualised care
- + Increased recognition of carers as equal partners in care
- + Greater carer involvement in discharge discussions
- + The passport has been shared with Carer organisations, GP surgeries and Nursing/Care homes across the area
- + It has been promoted by the Alzheimer's Society, Dementia Support Groups and Barnado's Young Carers
- + The National Heads of Patient Experience (HOPE) Network have endorsed the passport and have expressed interest in introducing the passport as a nationally recognised document

Introducing Wendy & Jake



Introducing Wendy & Jake

- Jake is 22 years old
- Jake has Down's Syndrome and was born with two holes in his heart and chronic lung disease.
- He was dependent on oxygen until he was 4 years old
- Jake lives at home with his Mum ,Wendy and has a close relationship with his sister Natalie who is 34.
- Wendy is Jake's main carer
- Jake and Wendy are passionate about sharing their experience and working closely with us to be involved in improving care

Wendy & Jake



“ Alone we can do
so little; together we
can do so much”

Helen Keller



Thank you!



Question Time

