

What was said at The London Forum



On 6th July 2023



Robert and Pat co chaired the meeting

Who else was at the meeting

People came from:



Greenwich

Waltham Forest

Bexley

Hackney

Bromley

Hillingdon

Lambeth

Harrow

Barking and Dagenham

We had apologies from:

Richmond

We looked at what was said at the London Forum in April



<https://advocacyingreenwich.org.uk/wp-content/uploads/2023/06/LF-April-2023-Minutes.pdf>

We told you what was said at the last London Learning Disability and Autism Partnership Board



Robert said:



I attended the London Learning Disability and Autism Strategic Partnership Board on Teams on 15th June 2023.



It was also attended by health and social care bosses from across London.

Robert said:



I told everyone what you said at the last London Forum. I told them what you said about Employment Support. I told them what you said about Care Scandals.



The Big Bosses will share what you said in their area of London.

Robert said:



We heard a lived experience story about someone with complex needs who was biologically female but presented as male and they needed the right service for them to be discharged from hospital.



Services worked together find the right placement for this person and they are now very happy living in the community.



Robert said:

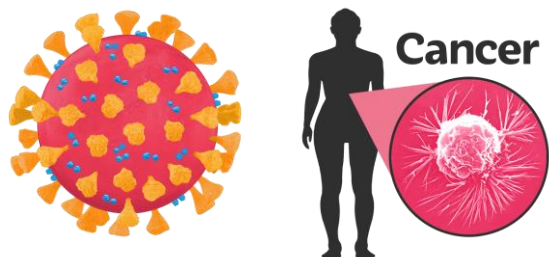
Jane Kachika gave an update on the LeDeR programme. This looks at the lives and deaths of people with a learning disability.



We heard that 326 deaths were reported in London in 2021.

The average age of death was 59.

48% of deaths were classed as avoidable.



Covid and Cancer were the top 2 causes of death.

Robert said:



We heard about a serious case review.

A serious case review is when something goes very wrong. Services have to look at what happened, why it happened and make sure it doesn't happen again.



We heard lots of work is being done supporting young people through transition.

Robert said:



The next London Partnership Board is **14th September 2023** and I will be going to tell them what you say today.

Jemma Sharples did a talk about the new Universal Care Plan





England

Universal Care Plan

<https://ucp.onelondon.online/>

Presented by:
Jemma Sharples



What is the Universal Care Plan?

The Universal Care Plans is an NHS service. It is also known as UCP

The Universal Care Plan is a digital care plan that is accessible to health and care professionals across London.

The care plan can be seen by doctors, nurses, the ambulance service, and NHS 111 telephone service in London..



What is the Universal Care Plan?

You need to give your consent to have a UCP care plan.

The Universal Care Plan can tell people about the care you would like in an urgent or medical emergency.

Having a Universal Care Plan helps you to decide what kind of care you want and where you want.

It makes sure that everyone caring for you knows about what you want.



Why is it important to have a Universal Care Plan

The Universal Care Plan can tell health and care staff what is important to you in your day-to-day life.

Your communication needs, likes, wishes and dislikes about your care

What support you need and who helps you and information about others who may be involved your care, such as family

A care plan that is visible to everyone who cares for you means that you will not have to retell your story.

Your care plan should always reflect what is important to you



What happens if you want a Universal Care Plan

You, your doctor, nurse, family member, support worker can help you write your Universal Care Plan.

The Universal Care Plan will always have to be completed by a healthcare worker.

A message will be sent to health professionals, ambulance services and out of hours doctors to tell them that you have a Universal Care Plan



How can you see the information in your Universal Care Plan

When your UCP plan is made, you will be offered a paper copy. You can ask for a copy at any time.



The Universal Care Plan will also be available in the NHS app on your mobile phone.



Thank You



@nhsengland



company/nhsengland



england.nhs.uk

You got into groups and we asked



1. What do people **need** to know about you if they are helping with your health?
2. Look at the list of questions that are asked about communication and reasonable adjustments. Are these good questions? Tick yes or no.
3. What else should have been on the list?
4. Are any of the words too hard to understand?

You said

1. What do people need to know about you if they are helping with your health?



- Allergies – food nuts.
- Medicine allergy
- If you have family or other support that is close by
- Food you like (culture)
- Dietary requirements
- If you use sign language
- Medication – times and name of medication
- That you have a learning disability
- If you cant walk
- Things you do not like
- If you need a quiet space

You said



- Background – medical history, family history
- Who are important to me – Emergency contacts, carers, advocates, other medical professionals
- My preferred terminologies eg. Learning disability / difficulty, pronouns
- Share I am involved in an advocacy project
- Communication preferences – verbal, communication aids, easy read.
- Any preferred names like nicknames if they are what I am more comfortable with. SPELL MY NAME RIGHT.
- Conditions I have – diabetes, shakes, mobility
- Mental Health and Physical health – triggers, how to help me, challenging behaviour
- Reasonable adjustments – what helps me

You said



- How you take your medication – tablets or injections
- If you have any special adjustments
 - Large print
 - Pictures
 - Easy read
 - Symbols
 - Ramps/lifts
 - Sign language or Makaton
 - The choice to have your carer with you or to be independent
 - Hospital staff trained to support you
- If you have a learning disability
- If you have a health passport or black book
- How I show my feelings

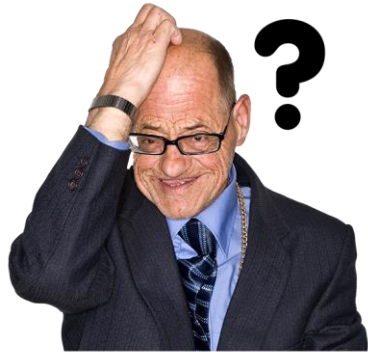
You said



- If you use a communication device - talking board, or if you sign
- What other disabilities you have
- What is going to happen, explain everything as you go along
- Speak slowly, simple words, might have to repeat things
- people might act differently if they are stressed or in pain
- If you need a support worker/ carer/ parent/ friend/ family
- If you need something to help you move around wheelchair, walker, crutches
- Who to call for you
- What things help you
- What do you like to be called
- What your disability is - invisible disability

You said

2. Feedback about the Communication and Reasonable Adjustments questions



easy read

Please fill in this easy read form

Your name

Address

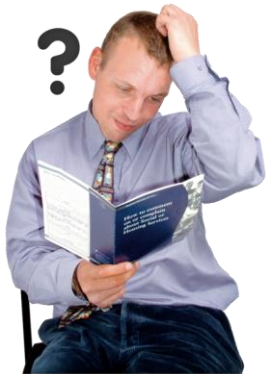
Phone

- “Reasonable adjustments” might be hard to understand
- Add “what reasonable adjustment do you want / need”
- “How can we help you have a say in your healthcare”
- “Sensory” is hard to understand
- “What are your reasonable adjustments”
- They should have pictures and easy read information to go with the questions.
- Needs pictures, easy to read words
- Communicate - need to give examples, communicate is a hard word for some people

You said



- Too hard - How would you find it easier to talk about your feelings?
- Too hard - how can we help you.....
- Reasonable adjustments- big words - better small changes, give an example - if things are too noisy, we could find a quiet space for you
- Health services - give an example like Doctors
- Sensory support needs - too hard to answer - if you need help with things you find tricky around you?



You said



- Question too hard - How can we help you?
- Better to use the words small changes - give examples tick list
- Do you need a routine? Would having a plan help you about what is happening next
- Do you need any help with eating and drinking?
- Do you need help with your medication
- Would it help if you could choose a male or female nurse
- Do you wear glasses, hearing aids, hearing implant, pacemaker
- Any phobias, anything that really scares you
- Need the question "Do you have a hospital passport"
- The question "If you are unwell, stressed or anxious how might this affect your communication?" needs re-wording.

You said



- Have “How do you prefer to speak with a doctor – face to face, online, phone, letter.
- What would make communication difficult?

General Feedback



- What about people with visual impairment?
- Talk button – Computer read it out
- Need a flag to know person has a learning disability
- Like the faces (and words) for yes/no questions
- Have multiple choice questions.
- Needs pictures, more easy read questions

We had Open Mic



- **Advocacy for All** told us about:
 - Their new Housing Advocacy project.
 - Their new Cost of Living Project – Money Matters.
- **Barking and Dagenham** told us about:
 - Learning Disability Awareness Week events.
 - A new computer project they are working on
 - Getting a medal and star for all their volunteering work.



We had Open Mic



- Kweku told us **Waltham Forest People First** is back up and running. Also Save the date - Weds 9th August – Free learning disability festival.



- **Greenwich** told us about the MP elections they had for their Peoples Parliament.



- Alison said they have done Housing Forum in **Harrow** to make housing more accessible and more relevant to the people who are receiving the care.

**We said goodbye and thank you for
coming to the meeting**



The next meeting will be
October 2023