Collecting information to improve the quality of care for people with learning disabilities and/or autism
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We have produced this leaflet for people with learning disabilities and/or autism who are being cared for in a hospital, and their families or carers.

The leaflet is about information that the NHS collects to help us improve the NHS care for people with learning disabilities.

About NHS England

NHS England is a national organisation that helps people in England to have better health. We do this by putting patients and the public at the centre of everything we do.

NHS England works with other health and care organisations to look after the running of the NHS, including NHS services for people with learning disabilities and/or autism.
We also help NHS clinical leaders, including doctors, to make good decisions and provide high quality services for everyone.

**What is Assuring Transformation data?**

NHS England looks after the collection of information about the care for people with learning disabilities and/or autism in a hospital.

This is called ‘Assuring Transformation data’ and it helps us check that people are getting the right care, in the right place.

The Health and Social Care Information Centre (HSCIC) collects and publishes this information for NHS England, every month.
The HSCIC collects the information from organisations - who are called commissioners - that buy health services, including hospital care.

The information includes the number of people that are being cared for in a hospital and the type of hospital they are in,

how often their care and treatment is checked,

and how many people have moved from a hospital to the community.
How is the data used?

The data helps national and local health and care organisations to improve the care for people with learning disabilities and/or autism.

For example, they can check that high quality care is being made available in the right place.

This should, if possible, be in the community and close to a person’s home.

The HSCIC puts out the important information on a national and local level, on its website but it does not put in people’s names or other personal information.
It is important that the data includes information about everyone that is in a hospital if possible, so the NHS can be sure that all patients are getting high quality care.

Can people say no to sharing information about their care?

Yes. The person who is getting the care, or a family member or carer can say ‘no’ to sharing information about their care with anyone else, unless it is being used to improve their care.

People who do not want details about their care to be put in the HSCIC information, should contact the organisation that buys their care (see ‘who to contact’ below).

The organisation will then contact the person or their family member about this.
If you would like help doing this speak to your carer or a family member, or your advocate.

Who to contact

The information in the box below tells you who you should contact if you do not want HSCIC to collect information about you or someone you care for.

Please contact:

Records Department
Kingsway House
Kingsway Site
Derby, DE22 3LZ
Tel: 01332 623700 ext 31525