



Assuring Transformation data - guide on fair processing and managing individual objections

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Action Required	All commissioners are required to follow this guidance when processing patient objections to the collection of Assuring Transformation data
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The NHS Commissioning Board (NHS CB) was established on 1 October 2012 as an executive non-departmental public body. Since 1 April 2013, the NHS Commissioning Board has used the name NHS England for operational purposes.

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¹ Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:

- eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it;
- reduce inequalities between patients in access to, and outcomes from, healthcare services;
- ensure that services are provided in an integrated way where this could reduce health inequalities.

1 About this guide

Assuring Transformation (AT) data collects information about ²individuals with learning disabilities and/or autism, who may have a mental health condition or behaviour that challenges, in in-patient settings, and it gives commissioners broad oversight of their care.

This document outlines what NHS commissioners - CCGs and NHS England's specialist commissioning teams - that participate in the [AT data collection](#), are legally required to do:

- to inform those are receiving care, their families/carers, on what they should do, if they do not want their information to be included in the AT data;
- and, if an individual, their carer/advocate 'objects' to their information being included, the process for handling objections.

2. Background on the AT data collection

2.1 Why we collect the AT data

The decision to collect and track data for people with learning disabilities and/or autism was agreed as part of the [Winterbourne Review Concordat: Programme of Action](#), with the following requirements for commissioners and providers:

- commissioners should hold, manage and maintain a register of people with learning disabilities and/or autism for people in in-patient settings that covers their current care provision;
- providers should provide data to populate the registers to ensure that patients receive the right care and that their care is tracked and managed across providers and commissioners;
- individuals' care plans must be reviewed regularly to ensure they continue to meet their needs.

2.2 What the AT data covers

The AT data is collected by the Health and Social Care Information Centre (HSCIC) on NHS England's behalf and is collected from NHS commissioners. It covers all people with learning disabilities and/or autism that are being cared for in in-patient settings and includes: the number of people in in-patient settings; discharges and admissions; whether individuals have a care plan, a care co-ordinator, regular care reviews and access to independent advocacy; the age and gender of individuals; and the type of in-patient setting that is providing their care. The AT data is published monthly by the HSCIC.

3. Legal framework for collecting AT data

² Hereafter referred to as people with learning disabilities and/or autism

The Confidentiality Advisory Group (CAG) review applications made under Regulations enabled by Section 251 of the NHS Act 2006. The Secretary of State can approve an application and set out the conditions of that approval. The application and approval will state who can use the data, what they can use the data for and what data is involved.

The approved applications [reference CAG 8-02(a-c)/2014] provides the legal basis for the flows of AT data. This enables the flow of personal confidential data from organisations to commissioners, about the services that they provide for:

- people in in-patient beds with learning disabilities and/or autism of,
 - any age
 - any level of security (general / low / medium / high)
 - any status under the Mental Health Act (informal or detained)

However, the information cannot be shared if:

- the individual has objected to the use of their information as part of the AT data
- if the individual is unable to make their own decision (see appendix on assessing capacity) until a decision has been made – in these instances, the organisation would use their usual process for considering ‘capacity’ but this issue must be considered separately to the process described in this document.

More information on CAG and the application can be found at:

<http://www.hscic.gov.uk/assuringtransformation> and the list of applications approved by the Secretary of State can be found at <http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/>.

3.1 Legal requirements for commissioners and providers

The NHS constitution tells patients:

‘You have the right to be informed about how your information is used.’

It also states:

‘You have the right to request that your confidential information is not used beyond your own care and treatment, and to have your objections considered, and where your wishes cannot be followed, to be told the reasons including the legal basis.’

This means that:

- **providers** need to inform individuals in in-patient settings how any information that identifies them, and is collected about them as part of their care, is used for anything other than their direct care e.g. for research purposes. This is called ‘fair processing’ and is a legal requirement of the Data Protection Act 1998 and the requirement to notify patients is ‘patient notification’ that is a requirement of approval by the Secretary of State to use Section 251.
- **NHS commissioners** are required to have a process in place to handle individuals’ objections to their data being used for anything other than their care.

- **NHS commissioners** also need to ensure that providers are offering information to individuals/ their carers about the data collection and their option to 'object' to their information being included. Commissioners should seek assurance from providers that this is happening e.g. review examples of materials advising individuals about the use of their data. They can also use contractual levers e.g. the [NHS Standard Contract](#) requires providers to comply with the law.

3.2 Ensuring material is accessible for individuals

As part of this, healthcare providers need to ensure that any materials – to enable 'patient notification' - are accessible for people with learning disabilities and/or autism. Information should inform individuals whilst assuring them that any identifiable information is not shared externally.

Providers also need to ensure that the information includes details of:

- who is asking for their data i.e. the healthcare provider will be sending a summary of their care to the organisation that pays for their care
- why their data is being collected (see 2.1) and how it supports their care
- how they can find out more information about objecting to their information being included, with a contact point at their local commissioner.

To support providers/ commissioners, NHS England has produced an example of a patient notification leaflet in easy-read that enables commissioners to add local contact details for queries. This must be made available to patients and their families/advocates, and must include local contact details explaining who to contact if a patient wishes to raise an objection. This is available at <http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/atd/>.

4. Managing individual objections

As outlined above, an individual has the right to object to their information being used in the AT data collection and their objections considered. Personal and confidential information may be disclosed, only where the balance of public interest favours disclosure.

Under Section 251 CAG 8-02(a-c)/2014, if individuals object, the patient's data cannot be used as part of AT collection. However, commissioners need to consider whether there is another lawful basis for the processing the data, for example if the public interest in processing the data for the safety of patient(s) overrides the common law duty of confidence owed to an individual patient.

4.1 Understanding the implications of objecting

When a patient with 'capacity' objects to the use of their data, commissioners should explain the following:

- the AT data collection process has been developed with the views of people with learning disabilities and/or autism, families, advocacy groups and carers, and it helps to prevent instances of poor care;
- the impact of the individual's information being excluded - it will not be possible to track them across providers and have broad oversight of their care;
- the potential consequences to other individuals of the data being incomplete (for example, it could increase the risks to other patients of 'falling through the cracks' because it is an incomplete view of the whole patient cohort.)

4.2 Process for handling objections

If an objection is raised, the commissioner (CCG or NHS England's specialist commissioning teams) needs to consider the basis for any objection and advise the patient of the decision. Whilst the commissioner is making a decision, the patient's data can continue to be processed under the 'public interest override of the common law duty of confidentiality', but not CAG application CAG 8-02(a-c)/2014. This effectively over-rides the objection until it has been considered. This ensures that no harm comes to the patient, that their care is monitored and that the AT data continues to cover everyone in in-patient settings.

The commissioner will need to convene a panel to decide whether it is appropriate to continue processing the data and the panel should include:

- an appropriate learning and disability team professional;
- a case-manager from the commissioner;
- a relevant clinician;
- the Caldicott Guardian or an appropriately nominated deputy (such as the medical director) to advise the board about the decision and the rationale.

The panel needs to consider:

- the risks to the individual if their information is not included;
- whether the current provider of the service is a cause of concern or may have inappropriately influenced the decision of the patient;
- the risks to the total group of patients of an incomplete data set;
- the risk of harm or distress to the individual from their exclusion or inclusion.

The patient must be informed of the outcome and it should be recorded. If an objection is upheld, the Assuring Transformation team at NHS England should be informed and will provide additional advice if required.

Contact Details: All information and requests for advice should be sent to the secure mailbox at england.wvdata@nhs.net.

Appendix: Background information on capacity

The NHS Code of Confidentiality specifies that:

If a patient is ... unable... to give consent or to communicate a decision, the health professionals concerned must take decisions about the use of information. This needs to take into account the patient's best interests and any previously expressed wishes, and be informed by the views of relatives or carers as to the likely wishes of the patient. If a patient has made his or her preferences about information disclosures known in advance, this should be respected.

This appendix is for information only. Any issues of capacity must be managed separately to the 'objections' process, using the more detailed guides referenced below.

1. Assessing capacity

It should never be assumed that people are not able to make their own decisions, because they have a learning disability and/or autism. Adults are always presumed to be capable of taking health and social care decisions, unless there is evidence that this is not the case

Where any doubt exists, the capacity of the person to make the decision should be assessed, drawing on both the individual's carers and the assistance of specialists, such as learning disability teams and speech and language therapists as required. It is important to remember that capacity can change over time for some individuals.

Further detailed guidance is available from the British Medical Association (BMA) as part of their [mental capacity toolkit](#).

2. Individuals who lack capacity

Following confirmation that a patient lacks capacity, and could not provide consent, a decision can be made in the best interests of the patient. The BMA specifies that 'a best interests' decision is not an attempt to determine what the person would have wanted, although this must be taken into account. It is an objective test of what would be in the person's best interests, taking into consideration all the relevant factors.'

A further [toolkit card from the BMA](#) covers this aspect.