

LeDer Programme Privacy Notice

Plain English Explanation

Learning from Lives and Deaths – People with a learning disability and autistic people, or LeDeR (formerly known as the Learning from Deaths Review Programme) started in April 2017.

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care people received.

The Integrated Care Board (ICB) holds and uses patient data for the purposes of the Learning from Lives and Deaths Programme (LeDer).

LeDeR needs to know the personal details of people with a learning disability who have died so that their deaths can be reviewed. We may have to gather information from a number of different services, so we need to make sure that we are collecting information about the right person. We cannot review deaths anonymously because people with a learning disability and autistic people are often in touch with several different services (primary and secondary healthcare, physiotherapy, speech and language therapy, community learning disabilities team, care providers etc.) and without identifying them carefully we could review the same person more than once, or mismatch information about people with similar profiles.

LeDeR requires information about the closest living relative, family member or close friend (name, contact details, relationship), in order to invite them to contribute their views to the review.

We collect and store information that has been received from other healthcare organisations and providers.

SEL ICB has commissioned an organisation, PBSC, to undertake the case reviews of deaths in South East London.

1) Controller contact details	South East London Integrated Care Board 160 Tooley Street London SE1 2TZ https://www.selondonics.org/icb/
2) Data Protection Officer contact details	ICBDPO@selondonics.nhs.uk
3) Purpose of processing personal data	The LeDer Programme at SEL ICB is commissioned by NHS England instructed to carry out the reviews of deaths of individuals with learning disabilities and autism. The data is processed as part to of the reviews which informs the improvement the quality and standard of care provided to individuals with learning disabilities and autism.
4) Lawfulness Conditions and Special Categories	The lawful justifications for the processing and possible sharing of this data are;- <i>Article 6(1)(c) “the processing is necessary for compliance with any legal obligation to which the controller is subject”</i> and

	<i>Article 9(2)(h) "processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services"</i>
5) Recipient or categories of recipients of the shared data	The data will be shared with GP Practices or other Healthcare Providers.
6) Your Individual Rights	<p>Right to Object</p> <p>You have the right under Article 21 of the UK GDPR to object to your personal information being processed. Please contact the ICB if you wish to object to the processing of your data. You should be aware that this is a right to raise an objection, but this does not mean that the ICB will oblige your wishes in every circumstance.</p> <p>Right to Access and Correct Information</p> <p>You have the right to access any personal identifiable data that is being shared and to have any inaccuracies in recorded data corrected.</p>
7) Retention period	The data will be retained for the period as specified in the Records management code of practice and records retention schedule. Records Management Code of Practice - NHS Transformation Directorate . For further information, please contact the Information Governance Team
8) Right to Complain	<p>NHS SEL ICB is committed to ensuring that your data is managed and processed lawfully and securely, however if you require an further support, please contact the organisation's Data Protection Officer at: ICBDPO@selondonics.nhs.uk</p> <p>If, however, you are not satisfied that your query has been resolved, you have the right to contact the Information Commissioner to lodge a complaint: You have the right to complain to the Information Commissioner's Office. You can contact them at this link: https://ico.org.uk/global/contact-us/ or by calling their helpline on 0303 123 1113 (local rate) or 01625 545 745 (national rate). There are National Offices for Scotland, Northern Ireland and Wales, (see ICO website).</p>