

# NPDA Privacy Statement

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## What data are we collecting, and why?

The Healthcare Quality Improvement Partnership (HQIP) has commissioned RCPCH to carry out the National Paediatric Diabetes Audit (NPDA). The purpose of the audit is to monitor the number of different types of diabetes amongst children and young people on a national level and monitor and compare the quality of care received and outcomes achieved by children and young people receiving care from different paediatric diabetes units and regions. This will lead to an improvement in the care provided to children with diabetes, their outcomes and the experiences of patients and families.

To carry out this audit on behalf of HQIP and NHS England (the joint data controllers), RCPCH (the data processor) is collecting patient data submitted by paediatric diabetes units (PDUs) relating to completion of recommended health checks performed for the children and young people receiving care from their service, as well as the results of these health checks. The full dataset collected can be viewed [here](#). The data collected are held on secure servers which meets all data protection legislative requirements and are hosted within the EU.

Participation in this audit is mandatory for all hospitals in England as per the NHS standard contract and mandatory in Wales as per the NHS Wales National Clinical Audit and Outcome Review Plan 2015-2016. Your information is important as, without this data, we would not be able to conduct this audit which would make it more difficult to make national improvements in paediatric diabetes care.

The NPDA has also produced reports on hospital admissions related to diabetes in order to identify trends and inform strategies to reduce avoidable admissions. In order to produce these reports we obtained patient identifiable data from the Hospital Episode Statistics (HES) database supplied by NHS Digital, and from the Patient Episode Database for Wales (PEDW) managed by the NHS Wales Informatics Service. We linked these data to our own data in order to ensure a complete picture of diabetes-related admissions. Patient identifiable data received from the HES and PEDW databases is deleted from our servers once it has been used, in accordance with NHS good practice guidelines. As of June 2023, we have no further plans to use HES and PEDW data in this way, as we will rely on the data submitted by PDUs as the basis of our admissions reporting.

As well as collecting information from PDUs, we also invite children and young people with diabetes (and their parents/carers) to complete online surveys called Patient Reported Experience Measures (PREMs). These ask questions about the care given by your clinic. The answers we receive are anonymous, so they can't be traced back to individual patients. The feedback we receive from children and young people will be presented within a national report and reports for individual clinics to help them understand what they are doing well and what they could do better according to the children and young people (and their parents) using their services.

## Legal basis for processing

The NPDA has section 251 approval to collect patient identifiable data without explicit patient consent as its aims are in the public interest, as the audit will help improve standards of paediatric diabetes care. To find out more about section 251 approval, visit the [Health Research Authority website](#).

Processing is permitted under GDPR on the following legal bases:

- **Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.** This is justified through commissioning arrangements which link back to NHS England and the Welsh Government.
- **Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.** This is justified as the NPDA aims to drive improvements in the quality and safety of care and to improve outcomes for patients.

## Information we share

Data may be shared with third parties for the purposes of service evaluation or quality improvement by external academic researchers. Data will only ever be shared in a pseudonymised format (unless the requesting institution has its own legal basis for holding patient identifiable data) and only with the approval of HQIP. For HQIP to approve the request, the requestor must be able to demonstrate compliance with stringent data protection policies and arrangements and the aims of the research must be approved, as per HQIP's [guidance to applicants](#). Personal data shall not be transferred to a country or territory outside the EEA. Pseudonymised or summary data may be shared outside of the EEA as per HQIP guidance.

The NPDA also collaborates with the National Diabetes Audit managed by NHS Digital to produce audits of young adult care. This initiative, and the production of the admissions report using HES and PEDW data, involves the flow of patient identifiable data to trusted third party organisations (NHS Digital and NWIS) for linkage with their datasets. An annual audit report is published which is available publicly via our website and via [data.gov.uk](#). All data is reported at the level of individual paediatric diabetes units so that no patient identifiable data will ever be published. Privacy information relating to this audit is available from [NHS Digital](#).

The NPDA has also shared data with NHS England to investigate the role of COVID-19 infection and Type 1 Diabetes in children, adolescents and young adults under Regulation 3(4) of the Health Service Control of Patient Information Regulations 2002. More information about the legislation is available [here](#).

## **How long do you keep my data for?**

The NPDA team at the RCPCH acts as the data processor on behalf of HQIP, who are the data controllers for the NPDA data. The RCPCH will hold the NPDA data for as long as it is contracted to deliver the NPDA. All data will be deleted or transferred back to HQIP within two weeks of the end of our contract as per HQIP's instructions.

## **Can I opt out of the NPDA via the National Data Opt Out?**

In England, the [National Data Opt-Out service](#) allows patients aged 13 or over (or those with parental responsibility for patients under 13) to opt out of their information being used for purposes beyond their direct care. The Secretary of State for Health and Social Care, having considered the advice from the Health Research Authority Confidentiality Advisory Group, has decided that the National Data Opt-Out will not be applied to the NPDA.

This is because applying the National Opt-Out could introduce bias to the data and make it difficult to monitor care safety and quality at Trust level, leading to poor quality of care and health services and jeopardising patient safety. It could also reduce the impact of the data on improving care locally and nationally. However, you can still opt out of your personal information being used for this audit. Please let your paediatric diabetes team know and they will remove you from the submission so that we don't receive your data. Alternatively, you can contact the NPDA team directly at [NPDA@rcpch.ac.uk](mailto:NPDA@rcpch.ac.uk) and we will ensure that your personal identifiers are removed from our database.

## **Can I opt out of the NPDA via any other means?**

Yes. You can opt out by asking your paediatric diabetes team not to submit any data to the RCPCH for inclusion in the NPDA.

## **Accessing, deleting and updating your personal information**

If you have any queries or would like to make any rights requests in relation to your patient record, please contact your unit directly. In relation to the data we collect for the NPDA audit, you have the following rights:

- Right of Access: The personal data we hold about you is provided by your unit. We can let you know which categories of data we collect but you will need to contact your unit directly for a copy of your personal data as they are data controllers of your patient record.

- **Right to Erasure and Right to Object:** The right of erasure does not apply to this audit because your data is being processed for the purposes of performing a task in the public interest, which in this case is for ensuring high standards of quality and safety health care. However, if you want to opt out of future audit rounds, please let your unit know and they will remove you from the submission. Alternatively, you can contact the NPDA project team: [NPDA@rcph.ac.uk](mailto:NPDA@rcph.ac.uk) and we will ensure that your personal identifiers are removed from our database.
- **Right to Rectification:** Any requests to amend or update your personal data should be sent to your unit as we are not data controllers of your patient information. If we receive any requests, we will forward these to the unit.
- **Right to Restriction:** Any requests for restriction of processing should be sent to your Trust and they will inform us where applicable. Any requests we receive will be forwarded to your unit.

To find out more about your rights, visit the [ICO website](#). If you would like to make a request in relation to the data held by RCPCH, email the NPDA project team: [NPDA@rcph.ac.uk](mailto:NPDA@rcph.ac.uk). This only relates to the data processed by RCPCH for the purpose of the audit. If you would like to make a request in relation to your healthcare record, you will need to contact your trust/local health board directly as they are the data controller of this information and will be able to advise you about which rights apply.

## **Changes to our privacy policy**

This privacy policy was last updated in June 2023.

## **Further information and how to contact us**

If you would like more information about the NPDA, please contact [npda@rcpch.ac.uk](mailto:npda@rcpch.ac.uk) or call us on 020 7092 6167. If you have any questions or concerns about how your information being shared for the purposes of the audit, please first contact your diabetes team.

NHS England and HQIP are the joint data controllers of this audit. HQIP can also be contacted if you have any questions or concerns how your information is being used for the audit: [data.protection@hqip.org.uk](mailto:data.protection@hqip.org.uk). If you have any concerns about how your personal data is being processed by RCPCH, you can also contact RCPCH's Data Protection Officer: [information.governance@rcpch.ac.uk](mailto:information.governance@rcpch.ac.uk).

You do also have the right to lodge a complaint with the ICO if you have concerns about the way your/your child's personal data is being handled: [casework@ico.org.uk](mailto:casework@ico.org.uk).