OPTIMUM PATIENT CARE
RESEARCH DATABASE – OPCRD

ANNUAL REPORT 2024

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ESTABLISHING ORGANISATION

Optimum Patient Care Limited (OPC)
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DATA CONTROLLER

Professor David Price
Managing Director | Optimum Patient Care Ltd (OPC)
Professor of Primary Care Respiratory Medicine

DATA CUSTODIAN

Mr Francis K. Appiagyei
Data Protection Officer | Optimum Patient Care Ltd (OPC)

DATABASE MANAGEMENT

Miss Nevaashni Eleangovan
Database & Data Quality Manager | Optimum Patient Care Ltd (OPC)

Mr Steven Cooper
Senior Database Administrator | Optimum Patient Care Ltd (OPC)

RESEARCH ETHICS COMMITTEE (REC) APPROVAL

REC: East Midlands – Derby REC
REC reference: 20/EM/0148
IRAS project ID: 356524

DATA ACCESS GOVERNANCE

Anonymised Data Ethics and Protocol Transparency committee (ADEPT)
https://www.regresearchnetwork.org/adept-committee/

DATA SECURITY ASSURANCE

- ICO Data Protection Registration: ZA197058
- NHS Data Security and Protection Toolkit, Ref: 8HR85
- Cyber Essentials, certificate: d8632649-8959-4fbc-8c68-4cf00770143f
- ISO 27001 and ISO 9001, certificate: 385342022

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ANNUAL DATABASE METRICS

METRIC	COUNT
Total number of Patients	28,288,253
Total number of Practices	1,179

DATA COLLECTION

OPC manages the collection of deidentified data from contributing and consented GP practices that use all major UK GP clinical systems including EMIS, SystmOne and Vision. Deidentified data is transferred from contributing GP practices to OPC Service Database (OPCSD) in an encrypted form via the secure Health and Social Care Network (HSCN). On receipt, the data is verified for integrity and completeness before further deidentification and transfer to OPCRD.

OPCRD collects the following deidentified data from consented contributing GP practices:
- Deidentified electronic health records (EHR) data of patients at a participating GP practice. This includes deidentified coded data, free text and documents/attachments.
- Deidentified questionnaire data of patients at a participating GP practice. GP practices may contribute any deidentified patient questionnaire data to OPCRD, provided that the GP practice is the Data Controller for the questionnaire data. This may include questionnaire data for any condition or disease.
- Deidentified OPCRD-linked data from other health-related datasets and registries for patients from consented contributing GP practices.

DATABASE SERVICES

OPCRD continues to offer a quality-assured resource of longitudinal, real-world patient health data that is generally representative of the UK population. OPCRD provides access to anonymised datasets to academic and commercial organisations for ethically approved scientific, medical and public health research. OPCRD also continues to support the conduct feasibility assessments, data insights and exploratory analyses, which are essential for development of research and clinical tools and services.

The types of research currently supported by OPCRD include the following:
- Epidemiology
- Pharmacoepidemiology, drug utilisation and drug safety
- Public health research
- Pragmatic trials in primary care including implantation and cluster-randomised trials
- Post authorisation safety studies
- Medical devices and technology
- Research of innovative diagnostic and therapeutic methodologies including algorithms.
- Health economics and resource utilisation
- Clinical audits and quality improvement

DATA ACCESS - APPROVED STUDIES

During the reporting year 01 January 2024 to 31 December 2024, ADEPT reviewed and approved 14 research applications for OPCRD anonymised data access. Please refer to "OPCRD DATA ACCESS FOR APPROVED STUDIES" at the end of this document or visit the OPCRD website for details of approved studies. https://opcrd.optimumpatientcare.org/approved-studies

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DATABASE GOVERNANCE

OPCRD continues to be regulated by an independent advisory and governance committee – the Anonymised Data Ethics and Protocols Transparency committee (ADEPT). ADEPT govern the approvals for research requests to access OPCRD anonymised data including OPCRD-linked data.

This year, the HMA-EMA Catalogues of real-world data sources and studies has now replaced the previous EU PAS Register® and ENCePP Resource Database. In addition to ADEPT approval, research studies are required to register their study on public registry such as HMA-EMA Catalogues or other public research registration for public transparency and knowledge sharing.

PUBLICATIONS

OPCRD data is provided for research conducted with intent to publish. Five (5) studies were published in 2024. To date, OPCRD has contributed to 113 peer reviewed publications on medical science, use of medicines, effectiveness of treatments, effectiveness of health care delivery and disease risk factors. https://opcrd.co.uk/publications/

DATABASE DEVELOPMENTS

OPC has further develop the quality of research data accessible from OPCRD by improving the types of data extracted from primary care electronic health records (EHR) of contributing GP practices i.e. enhanced primary care data collection. Our data processing technology has enabled OPC to improve and implement a robust and secure redaction and deidentification process for extraction of coded and redacted free text data in primary care EHR. This enables collection of valuable descriptive text data which has had the relevant patient identifiable information removed and/or redacted prior to the data being transferred to OPC and contributed to OPCRD.

The following improvements were made to the database during the reporting period of 2024:
- Addition of rural/urban classification to practice information available in OPCRD.
- Addition of indicators for drug regiments such as maintenance and reliever therapy (MART) and anti-inflammatory relievers (AIR).
- Addition of a patient summary table with pre-derived data from the last 5 years for key demographic and clinical characteristics for researchers.
- Addition of standardised dataset interrogation queries for researchers to use.

The following improvements to OPCRD data collection are planned and/or anticipated to be implemented over the coming year:
- Continue to improve extraction of SNOMED coded deidentified data from GP practice EHR including questionnaire data, referrals, immunisations, etc.
- Work is in progress to add estimated costs to therapy and drug information made available in OPCRD to facilitate more health economic and health utilisation research.
- Work is in progress to generate a synthetic dataset – which is "dummy dataset" based on OPCRD format but not actual patient data, to show potential benefits to prospective clients without need to access real OPCRD data.
- A new GP clinical system has been introduced in the UK called Medicus Health. OPC is working with Medicus to enable GP practices using this new EHR system to be able to contribute to OPCRD. https://www.medicus.health/
- OPC is currently working with NHS England to pilot and provided linked OPCRD primary care data and HES data in NHS Secure Data Environment (SDE). This will be the first of its kind for NHS England, and if successful the model will be used for other databases linkages.

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NOTABLE COLLABORATIONS

Asthma UK Centre for Applied Research (AUKCAR)

OPCRD continues to provide anonymised data to the Asthma UK Centre for Applied Research (AUKCAR) to support research into asthma and respiratory science and health. Access to OPCRD (at low cost) is made available to AUKCAR researchers from the network of academic institutions to conduct anonymised scientific and public health research in asthma. As part of this partnership OPC also provides extensive subsidised research data services to primary care cluster randomised and implementation studies being conducted under the AUKCAR collaborative network e.g. IMP2ART study.

Observational and Pragmatic Research Institute/International (OPRI)

OPC continues to collaborate with the Observational and Pragmatic Research Institute/International (OPRI). OPRI is an independent, research-driven organisation established to cultivate initiatives, provide evidence and drive quality standards within the growing field of real-life, pragmatic research. All research data requests from OPRI to utilise the OPCRD anonymised data require ADEPT review and approval.

Akrivia Health

Akrivia Health (Akrivia) are a health data research company committed to advancing research for discovery and development in mental health and dementia. To achieve this aim they collaborate with multiple mental health trusts across the UK to provide ethical and complaint access for researchers to mental health data. To this end OPC collaborates with Akrivia across three main domains; multi-modal registries, linked retrospective data for protocolised research and patient identification and recruitment for clinical trials and other study activities.

Mendelian Health

Mendelian is a UK-based health-tech company focused on accelerating the diagnosis of rare diseases by providing tools that assist healthcare providers in identifying undiagnosed patients earlier. Their platform utilises machine learning and data analysis to streamline the diagnostic process, aiming to reduce misdiagnoses and improve patient outcomes. Mendelian license OPCRD data to develop, validate and test their algorithms. Further OPC, supports in the deployment of these algorithms into UK primary care through quality improvement programmes to improve patient outcomes.

It is worth noting that OPC supports several companies and academic partners, beyond just Mendelian, in the development, testing and deployment of 'patient finder' algorithms.

University of Plymouth / L-Risk

OPC collaborate with researchers from the University of Plymouth on the 'L-Risk' initiative. This piece of work has used OPCRD data to develop, test and validated an algorithm to facilitate the categorisation of a patient's risk of developing liver disease to facilitate more timely clinical intervention, either as a screening activity for diagnostic screening (such as Fibroscan) or in the earlier management of the risk itself (such as promoting life style changes). OPC is actively exploring opportunities to test 'L-Risk' within clinical practice.

DECLARATION

Francis K. Appiagyei
OPCRD Data Custodian

Professor David B. Price
OPCRD Data Controller

10 January 2025

10 January 2025

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OPCRD DATA ACCESS FOR APPROVED STUDIES
01 JAN 2024 – 31 DEC 2024

Approval Date	Approval Reference	Study Title	Organisation
05/12/2024	ADEPT2024	Phenotyping Asthma Exacerbations in primary care: an electronic medical record study (PHASE).	University of Oxford
15/11/2024	ADEPT1824	Validity of using prescription records to identify patient comorbidities.	Queens University Belfast
15/11/2024	ADEPT1724	CompAIR: COMParative clinical effectiveness of FostAIR (extrafine beclomethasone/formoterol) as maintenance and reliever therapies in adult patients with asthma.	Observational and Pragmatic Research Institute (OPRI)
13/11/2024	ADEPT1624	Evaluation of patient histories completeness in linked primary and secondary care electronic health records (EHR) data – a proof of concept study between Akrivia Health and OPCRD.	Optimum Patient Care (OPC)
28/10/2024	ADEPT1524	The development and evaluation of prognostic models to predict biologic eligibility.	Queen's University Belfast
11/09/2024	ADEPT1324	Development of a prediction model to identify Neuroendocrine tumours (NET), based on UK electronic primary healthcare records.	Volv Global SA
09/09/2024	ADEPT1224	Disease trajectory and treatment escalation in severe asthma: A retrospective analysis of data from the Optimum Patient Care Research Database (OPCRD).	Welcome-Wolfson Institute for Experimental Medicine at Queen's University
24/07/2024	ADEPT0924	Repurposing Existing Pharmaceuticals for the Prevention and Treatment of Metabolic Dysfunction-Associated Steatotic Liver Disease (MASLD).	Shandong Provincial Hospital Affiliated to Shandong First Medical University
12/06/2024	ADEPT0824	Patient characteristics and treatment pathways in patients with asthma or asthma-COPD overlap treated with Medium-Strength ICS/LABA and switching to High-StrEngth ICS/LABA or Medium-Strength TRImbow (BETRI).	Observational and Pragmatic Research Institute (OPRI)
16/05/2024	ADEPT0724	Depicting real-life treatment journeys for patients affected with an immune-inflammatory condition and treated with methotrexate.	Scienta Lab, France
24/04/2024	ADEPT0624	Incidence, prevalence, and characterisation of medicines with suggested drug shortages in Europe (EHDEN MEGA Study).	Optimum Patient Care (OPC); European Health Data Evidence Network (EHDEN)
19/04/2024	ADEPT0524	Investigating the effectiveness of interventions that improve medication adherence in school-aged children with asthma.	University of Sheffield
26/01/2024	ADEPT0224	The Breathlessness Rapid Evaluation and Therapy Study - CDSS Development.	The George Institute for Global Health
10/01/2024	ADEPT0124	AI-powered stratification of autoimmune diseases for Precision Medicine.	Scienta Lab, France