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Ascertainment of Chronic Kidney Disease and Palliative Care using routine health administrative data consolidated in a Health Information Exchange, Western Cape South Africa

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The Provincial Health Data Centre (PHDC) integrates person-level clinical and administrative data in the public health systems, using clinically-informed phenotypic algorithms to infer health conditions (episodes), from laboratory, medication and service-use data. Identifying patients living with CKD and requiring palliative care is essential for effective health service delivery, as existing data sources, such as the national kidney replacement therapy registry and morphine monitoring, underestimate true prevalence. To develop and apply a phenotypic algorithm (ascertainment) to define CKD and palliative care episodes, and to integrate end-stage renal disease (ESRD) patients into the palliative care episode. Ascertainment used a rules-based inference engine processing data via phenotype algorithms. CKD clinical data points (evidences) included longitudinal laboratory data defining CKD by KDIGO eGFR

criteria, the South African Renal Registry, triangulated clinical data, and associated medications. Palliative care episodes were inferred using ICD-10 codes, morphine dispensing, referrals, and an ESRD disease-specific layer. Descriptive statistics characterised the epidemiology for both conditions in the public sector of the Western Cape. The PHDC enumerated 224 469 CKD patients (170 977 alive and 145 719 visited health facilities within the last 5 years) and 56 931 palliative care patients identified (26 397 alive and 18 561 last visited a facility within the last 5 years) from 2000 to 2024. The ascertainment algorithm and ESRD integration more effectively identified patients requiring palliative care than previously possible. These findings demonstrate effective use of routine, linked health data to identify CKD patients with palliative care requirements, supporting health service delivery and planning.

