

# Chapter 1 - Introduction

## المقدمة

### National health information technologies to improve Iraqi renal care

Clinical management best practice is evidence driven. Evidence can be patient-based, sample-based, or population-based. The broader the base, the more solid the evidence, and the better it represents potential variations in disease manifestations and differences in clinical practice.

Disease registries generate broad scale population-based evidence and information, constituting the most powerful tool for a variety of applications: identify disease trends and demographic distribution, determine areas of strength and weakness in practice, help devise professional training and public disease education programs, develop practice guidelines, plan for future resource needs, inform prevention planning, and quantify performance measures that evaluate the country's long-term health plan for the disease.

Further, registries provide policymakers with evidence-based analysis to support long-term planning and development. The information provided by registry technologies are necessary to transition healthcare systems towards improved efficiency, effectiveness, and value. Recognizing the value of patient registries to the overall improvement of Iraq's healthcare system, Iraq's Ministry of Health and key physicians engaging in renal care, embarked on establishing the Iraqi Renal Transplant Registry (IRTR), which was officially contracted in October 2015.

The project was contracted to Partners in Wellness and Research (PWR), a research group based in Lebanon with extensive registry development experience. PWR coordinated the development and maintenance of the custom database software, field implementation, with grant funding from the pharmaceutical company Novartis.

In the first phase of the IRTR, the database provided key information describing prevalent kidney transplant patients and their corresponding profile in the 2018-19 incident cohort. The registry contained complete patient chart parameters, including patient demographics, health history, underlying disease parameters, organ matching, and operative and post-operative information.

Since its inaugural year, the IRTR has been an overwhelming success, achieving a key milestone of enrolling 72% of patients in Iraq (65% planned). PWR also placed high emphasis on presentations and publications based on the registry data. Presentations were given at 5 events for the Iraqi Nephrology community, and two international forums. Data from the registry was published in the International Chapter of the USRDS report – 2018, an article was published in the Iraqi Medical Journal, and a preliminary report was published in October 2018.

This Annual Report will discuss the registry's methodology and provide an in-depth reporting on the data collected from 2015-2019. The conclusion of this report will offer brief analysis of the data and make recommendations for relevant stakeholders involved in Iraqi renal care.

## PARTNERS

