

Chapter 7 - Future Topics

مواضيع مستقبلية

The establishment of the IRTR was accomplished over a four-year period. The emphasis in the project's first phase was to establish wide-scale adoption of electronic records to as many health centers caring for kidney transplant patients as possible while enrolling a minimum of 65% of patients in the country.

The electronic records that were accessible to participating institutions contain a comprehensive set of modules covering the entire spectrum of disease phases and characteristics, as well as services that correspond to each phase. Physicians can document the full disease course and management for every patient, even if services are acquired at multiple institutions by different doctors.

The first phase of the project focused on the geo-demographic and medical history components of the kidney transplant population in Iraq, obtaining reliable and comprehensive data on over 72% of patients Iraq-wide, and close to 97% outside the Kurdistan Region. A broad sampling of that information was presented in earlier chapters of this inaugural annual report.

Phase two of the project will have three primary objectives:

1. Complete incorporation of the Kurdistan region medical institutions
2. Expanding the use of registry documentation of clinical, diagnostic, and outcomes data
3. Ensure documentation of all incident transplants performed in the country.

Such an ambitious goal can only be achieved with a comprehensive and decisive regulatory role by the MOH, ensuring that registry data entry is a requirement physician engagement with MOH resources.

With the hope that phase two will succeed in accomplishing its objectives, future annual reports will gradually incorporate new chapters

and sections. The following table outlines these sections:

7.1	Pre-Transplant – Baseline	بدء المتابعة قبل الزرع
7.2	Organ Procurement & Matching	تقييم مطابقة العضو المزروع
7.3	Transplant Surgery	عملية الزرع
7.4	Post-Transplant	متابعة بعد الزرع
	a. Induction	التثبيت
	b. Acute Phase	الطور الحاد
	c. Maintenance Phase	المتابعة الطويلة الأمد
7.5	Rejection Monitoring & Emergent Comorbidity	مراقبة رفض الكلية المزروعة والمضاعفات المستجدة

7.1 Pre-Transplant – Baseline

The pre-transplant modules were formulated around two components:

1. General Medical: for patients who have advanced chronic kidney disease (CKD) but did not arrive into end stage renal disease (ESRD) yet. Unlimited number of doctor visits may be entered, including a summary of clinical management parameters and outcomes. Each visit constitutes a date-driven sub-record.
2. Dialysis: for patients who are already in ESRD and were started on dialysis while being evaluated for transplant eligibility. A monthly summary of dialysis parameters may be entered for any duration, along with any emergent comorbidities and outcomes.

These modules allow documentation and follow up of patients for the entire duration of their disease prior to being evaluated for transplant.

Prevalent patients who were enrolled in the registry after they were already transplanted will have that information reconstituted as much as possible from available patient records or the recollection of care providers.

7.2 Organ Procurement & Matching

This module becomes available for patients being evaluated for transplant. It provides entry screens for three aspects:

1. Donor(s) information
2. Diagnostics and clinical parameters serving as donor-recipient matching criteria
3. Generate matching tabulation and score for recipient with donor(s)

A byproduct of this module, we will produce a database of donors which can serve as a donor pool for consideration in future transplant surgeries.

7.3 Transplant Surgery

Once a specific donor is confirmed, the surgery module is made available. A summary of surgery parameters can be entered (i.e., side, surgical approach), as well as characteristics of the transplanted kidney.

In prevalent patients, the matching criteria and transplant surgery information was near impossible to obtain due to scarcity of records. Obtaining general patient information was prioritized during the first phase. In the next phase, a greater emphasis will be placed on obtaining more clinical information for incident patients who undergo transplant surgery.

7.4 Post-Transplant

Upon opening a record for prevalent patients completing the surgery, the module becomes available, allowing data entry of available information. To this point, the modules for organ matching, surgery, and clinical information have for the most part not been used.

- a. Induction: This section covers the immunosuppressive medications used for induction therapy and monitoring of patient clinical parameters during the first four weeks following surgery.
- b. Acute Phase: Modifications to immunosuppressive and other medications during first six months after surgery are captured along with clinical developments, especially adverse events, emergent comorbidities, and signs of organ rejection.

- c. Maintenance Phase: Captures clinical, diagnostic, and medications use from month seven onward, after the patient is assumed to have stabilized.

7.5 Rejection Monitoring & Emergent Comorbidity

This module places attention to specific signs and symptoms that accompany organ rejection, either as a prelude to it or associated with its occurrence in progress. The intent is to provide a clinical focus tool that helps in early identification of a potential rejection episode and hopefully initiate measure that help avoid its progression.

Conclusion

It is probably very ambitious to expect full documentation of the registry content for all patients. Special emphasis in the next phase of the registry evolution should focus on incident patients and attempt to have complete records for new patients who are being evaluated and assigned to undergo transplant surgery. If such effort was successful, a fully functional and mature registry could be achieved over the next 5-7 years.

Change in clinical practice of this magnitude, standardized across many health care centers on a national scale, is a monumental task requiring patience, perseverance, dedication, and collaboration of multiple stake holders. The goal is an incremental and progressive evolution of the registry. The utility and benefits of