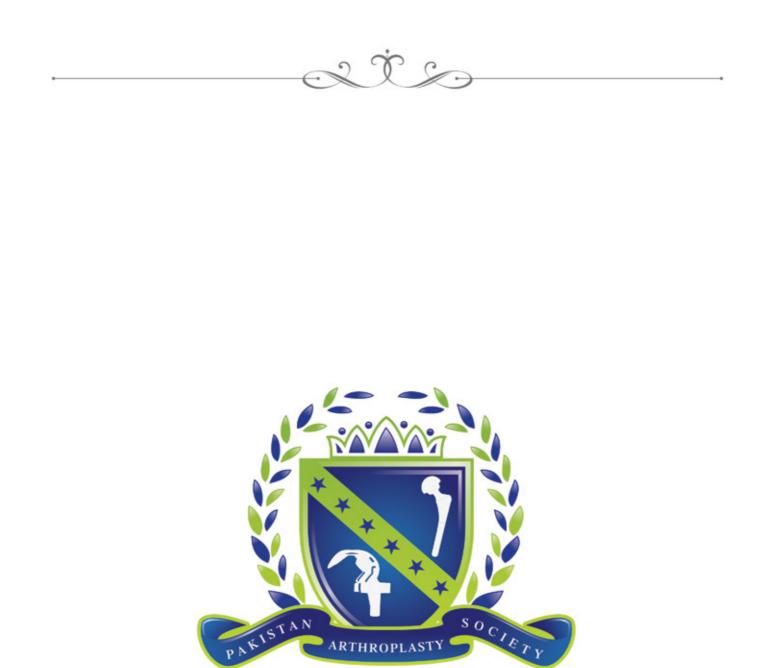


## PAKISTAN NATIONAL JOINT REGISTRY FIRST ANNUAL REPORT



2014-2015





## Theme Challenges in Establishing National Joint Registry in a Developing Country

Annual Report of Pakistan National Joint Registry

Pakistan Arthroplasty Society (PAS) Pakistan National Joint Registry (PNJR) www.arthroplasty.org.pk www.pasnjr.org





## Foreword



It is a great pleasure to be asked to introduce the first report of the Pakistan National Joint Registry. This project was conceived and Implemented in a very short time and the speed of implementation is a tribute to the hard work of the members of the steering committee, the network coordinators and the principal investigators.

Joint registries have become a very important tool in the management of patients with disabling joint disease and the information provided by the long established registries such as the Swedish and Norwegian ones, have provided a lot of information about the survivorship of implants and the success rates in patients. The newer registries such as the National Joint Registry in the United Kingdom are now supplying data on huge numbers of procedures which can only help in driving up standards of patient care.

The Pakistan National Joint Registry has been designed as an ambitious project, which will look at all aspects of the care of patients including survivorship of implants, pre operative health status and outcome measures. It is a particular challenge in a developing country but will become a very important registry over time. Joint replacement surgery in the Western world has been developed over 50 years and is a very well established discipline with very high success rates. The results obtained in large centres in Europe and the USA are not necessarily transferable to developing countries such as Pakistan where patients are required to perform activities such as kneeling to pray, squatting and sitting for long periods on the floor. The Pakistan registry should enable the effect of these activities on implant success and survival to be studied.

Of course there are challenges ahead for the registry and its principal investigators. Data collection is critical and a lot of work is needed to keep data accurate and validated. The quality of the reports from the registry are only as good as the quality of data.

I look forward to further annual reports from the Pakistan National Joint Registry.

#### **Mr. Philip Hirst (FRCS)**

Consultant Orthopaedic Surgeon Cheshire, United Kingdom

Fellow of Arthroplasty, Boston, USA Member, International Advisory Board Pakistan Arthroplasty Society



**Muhammad Ali Jinnah:** 25 December 1876 – 11 September 1948 was a lawyer, politician, and the founder of Pakistan. Jinnah served as leader of the All-India Muslim League from 1913 until Pakistan's independence on 14 August 1947, and as Pakistan's firstGovernor-General from independence until his death. He is revered in Pakistan as Quaid-i-Azam

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**Sir Muhammad Iqbal:** 9 November 1877 – 21 April 1938, widely known as Allama Iqbal was an academic, poet, barrister, philosopher, and politician in British India who is widely regarded as having inspired the Pakistan Movement. He is considered one of the most important figures in Urdu literature, with literary work in both the Urdu and Persian. Though Iqbal is best known as an eminent poet, he is also a highly acclaimed "Muslim philosophical thinker of modern times".

## **List of Authors**

#### 1 Prof. Syed Shahid Noor

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#### **2** Prof. Muhammad Amin Chinoy

MBBS, FRCS Treasurer, Pakistan Arthroplasty Society National Coordinator, PNJR Head, Department of Orthopaedics, Indus Hospital, Karachi

#### **3** Dr. Muhammad Ather Siddiqi

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#### 4 Dr. Imran Shabir Mughal

MBBS, FCPS (Orth) National Fellow, Pakistan Arthroplasty Society Senior Registrar Department of Orthopaedics, Lahore General Hospital, Lahore.

#### 5 Dr. M. Kazim Rahim Najjad

MBBS, MD, FCPS (Orth) Senior Registrar, Department of Orthopaedics, Liaquat National Hospital and Medical College, Karachi



Nawabzada Liaquat Ali Khan: October 1895 – 16 October 1951 often simply referred as Liaquat, was one of the leading Founding Fathers of modern Pakistan, statesman, lawyer, and political theorist who became and served as the first Prime Minister of Pakistan.

## **Executive Summary**

The Pakistan National Joint Registry (PNJR) is a voluntary project of the Pakistan Arthroplasty Society (PAS). It was established in 2014 and has successfully completed its first year of operations. There have been multiple challenges faced in the development of the registry in a resource limited country. The PNJR is designed to contribute to quality care and safety of patients in the country undergoing arthroplasty surgery. Through this registry implant companies and hospitals shall be able to retrieve national data for research to form guidelines on implant use based on national consensus.

#### **Challenges Faced in Establishing a National Joint Registry:**

A number of challenges were faced including financial, social and logistics. It was a mammoth task to form a consensus group of joint replacement surgeons to put their best foot forward to make this project a success. Second came the data development tools, questions on confidentiality of data and awarding the software development work. Currently we have one of the most detailed CRFs as compared to other national registry systems. We have both a paper CRF and an eCRF that is available in both online and offline versions for bulk upload of data. With only endogenous earnings of the Pakistan Arthroplasty Society through it's workshops and academic events, financing the registery had to be extremely cost efficient. There are currently no direct sponsors of the registry in itself.

#### **Data Quality:**

A complete register is an important component in any registry. We have however in our first year achieved 70 % accuracy in getting completed CRFs. The total numbers are small but on a rough estimate they comprise of about 60 to 70 percent of total joint replacements being done in the country. Since ours is not a government based registry, it is difficult to get 100 percent compliance. However, we hope that in due course of time, we shall improve the accuracy of data collection and strengthen our catchment to include all joint replacement surgeries in the country.

#### **Future Directions:**

In the years to come our first and foremost task is to improve the quality of data that we are currently getting with respect to completeness of CRFs. In the mean time we would like to keep expanding involving more PIs and hospitals to start to contribute their data to the registry. Since there is hardly any international data that comes from our region, we do not know the long term performance of joints in asian Muslim population where a lot of people insist on kneeling in prayers and performing other activities that are unusual for the western culture. We will also be modifying our CRFs to include patient reported outcome measures (PROMs) and quality of life indicators like patient satisfaction scores.



# INTRODUCING THE PNJR



## Section I



**Fairy Meadows:** named by German climbers locally known as Joot is a grassland near one of the base camp sites of the Mt. Nanga Parbat, located in Diamer District, Gilgit-Baltistan, Pakistan. At an altitude of about 3,300 metres (10,800 ft) above sea level, it serves as the launching point for trekkers summiting on the Rakhiot face of the Nanga Parbat. In 1995, the Government of Pakistan declared Fairy Meadows a National Park.

## **Section I**

### **Introduction to PAS and PNJR**

The Pakistan Arthroplasty Society is an independent society representing arthroplasty surgeons in the country. It was long felt by surgeons practicing joint replacement surgery that there was a need to form a body that represented and catered for the needs of thid surgeons community. the aim is to develop consensus on treatment protocols and to advance education and training in the field of arthroplasty in Pakistan. For decades, joint replacement surgery has only existed in the larger cities performed at only a few centers.

With humble beginnings as Pakistan Arthroplasty Forum under the umbrella of the parent body Pakistan Orthopaedic Association (POA) in 2012, the society has progressed in leaps and bounds. In a very short span of time, it has established itself as a leading force in promoting education and training for young orthopaedic surgeons. The main achievements of the society are the indigenously developed courses on primary and revision lower limb arthroplasty, lower limb arthroplasty national fellowship program and international fellowship programs. We have established partnerships and collaborations with international arthroplasty societies and institutes of repute to expand training opportunities for surgeons.

Pakistan National Joint Registry (PNJR) is a revolutionary project of the society that was conceived at its inception. It is a voluntary national joint registry, the first of its kind in a developing country. It was decided by the executive board of the PAS to establish this project mainly to serve the following purpose.

1. To help collect local joint replacement data in order to facilitate research and analyze outcomes after joint replacement surgery in the local population.

2. To guide local implant suppliers on provision of adequate inventory based on current demand of arthroplasty surgeons consensus group.

The registry was conceived, designed and implemented totally indigenously within Pakistan in collaboration with PAS research partner METRICS Research. A number of challanges were encountered during planning and designing of registry that are discussed in section 6 of this report.

The PNJR is now an established entity and is recognized overseas. Even before the publication of the first annual report, the registry has become an official member of EFORT-EAR (European Arthroplasty Registries) as well as ISAR (International Society of Arthroplasty Registries). Recently abstract titled "Challenges in establishing a National Joint Registry in a developing Country" was accepted for podium presentation at ISAR general meeting during the AAOS in Las Vegas, USA. The PNJR was the only national registry from Asia that was included in this meeting. The next presentation by PNJR is at the 4th International Congress of Arthroplasty Registries at Gothenburg, Sweden in May, 2015.

We are extremely committed to continue to improve and expand the coverage of the registry and to contribute to international data on joint replacement surgery.

## Section II



Lahore Fort: locally referred to as Shahi Qila is a citadel in the city of Lahore, Punjab, Pakistan. The trapezoidal composition is spread over 20 hectares. Origins of the fort extend far into antiquity but the existing base structure was built during the reign of Mughal Emperor Akbar in between 1556–1605 and was regularly upgraded by subsequent Mughal, Sikh and British rulers. The fort manifests the rich traditions of Mughal architecture. Some of the famous sites inside the fort include Sheesh Mahal, Alamgiri Gate, Naulakha Pavilion, and Moti Masjid. In 1981, the fort was inscribed as a UNESCO World Heritage Site along with the Shalimar Gardens.

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## **Section II**

### **Introduction to Registries**

A registry is an important research tool for any clinician. Registries can help practice in a number of ways. Following are some FAQ's that help describe what registries are.

#### Why are registries needed?

Registries can provide health care professionals and researchers with first-hand information about people with certain conditions, both individually and as a group, and over time, to increase our understanding of that condition. Some registries collect information that can be used to track trends about the number of people with diseases, treatments, and more. Other registries invite people to sign up to be contacted about participating in clinical research. These ask very basic questions about health history that would help determine whether someone is possibly eligible to join a research study.

It sounds like these registries collect personal health information. Is there a risk that such information could be disclosed?

Government agencies have strict privacy requirements set by law such as the Federal Information Security Management Act (FISMA), and the Health Insurance Portability and Accountability Act (HIPAA). If registries have followed all of these rules, the likelihood of identifiable personal information being shared is very small.

## What benefits will someone receive from participating in a registry?

Participation in a registry is likely to increase what we know about a specific condition, help health care professionals improve treatment, and allow researchers to design better studies on a particular condition, including development and testing of new treatments. Being part of a clinical trials registry can help people interested in participating in research connect with clinical investigators? However, individuals (and their families) who choose to participate in a registry should understand that participation will not guarantee a treatment or cure for their condition or that they will be eligible to join a study.

## Who has access to the information in a registry?

Usually, a federally-funded registry has a very limited

list of individuals (registry coordinator) who may have access to participants' personal, identifying information. ;Those individuals must be specially trained and certified regarding information security requirements.

## Who owns the data from a registry? Who makes decisions about how these data will be used?

The data collected in a disease registry is stripped of personal information. It belongs to the sponsor of the registry, and depending on how the registry is set up, may be shared with the participants and their families, and approved health care professionals and researchers. However, personal, identifying information is kept private. Usually, a registry has a governing committee that makes decisions about how the data can be used or shared.

## Can a participant withdraw from the registry?

Yes. Registries are free and voluntary; there is no penalty for choosing to withdraw at any point.

## Who should the participant contact with additional questions or concerns?

For any questions about participation or any issues that may arise, registries provide a contact, usually the registry coordinator.

## How is a registry different from a clinical trial?

Registries focused on specific diseases or conditions collect information voluntarily from people with those conditions. Clinical trials registries collect basic health information from people who agree to be contacted about participating in future clinical trials or studies. A clinical trial is the study of new ways to prevent, detect or treat diseases or conditions. Volunteering for a registry does not mean a person has signed up for a clinical trial. Participation in a disease registry can sometimes become a first step toward participation in a clinical trial, but registries and specific trials are not directly linked.

### **Introduction to Registries**

#### What are the standards for Data Registries

- 1. Develop a formal study protocol
- 2. Measure outcomes that people in the population of interest notice and care about
- 3. Describe data linkage plans, if applicable
- 4. Plan follow-up based on registry objective(s)
- 5. Describe data safety and security
- 6. Take appropriate steps to ensure data quality
- 7. Document and explain any modifications to the protocol
- 8. Collect data consistently
- 9. Enroll and follow patients systematically
- 10. Monitor and take actions to keep loss to follow-up to an acceptable minimum
- 11. Use appropriate statistical techniques to address confounding.

#### What are the types of national registries?

- 1. Patient organization registries
- 2. Medical registries
- 3. Health Ministry registries
- 4. Mixed systems

## What are the steps in establishing a national patient registry?

- Step 1: Organize a registry committee
- Step 2: Establish goals of the registry
- Step 3: Prepare your action plan
- Step 4: Select the system of data collection
- Step 5: Determine the data content
- Step 6: Design the data collection form
- Step 7: Collect the data
- Step 8: Analyze the data
- Step 9: Review the registry system
- Maintaining and using a national registry

## Section III



**Lake Saif-ul-Mulook:** is a mountainous lake located at the northern end of the Kaghan Valley near the town of Naran. At an elevation of 3,224 m (10,578 feet) above sea level, it is one of the highest lakes in Pakistan. **Section III** 

### **PNJR Steering Committee**

#### **Professor Syed Shahid Noor**

Director & Coordinating PI, PNJR Email: ssnoor@yahoo.com

#### **Professor Muhammad Amin Chinoy**

National Coordinator PNJR Email: chinoy786@gmail.com

#### **Professor Anisuddin Bhatti**

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Regional Coordinator PNJR (Punjab) Email: colsohail@hotmail.com

#### **Professor Muhammed Arif Khan**

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#### **Professor Mansoor Ali Khan**

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#### **Dr Saleh Tareen**

Regional Coordinator PNJR (Baluchistan) Email: drsaleh\_tareen@yahoo.com

#### **Research Partner**

**Metrics Research** 















## **Section IV**



**Jehangir Kothari Parade:** Jehangir Kothari Parade: is a promenade built on land bequeathed by Seth Jehangir Hormusji Kothari to the coastal city of Karachi, gateway to Pakistan. It is situated in the Clifton area of the city famous for its SeaView Beach which was built in 1919. There are two structures; 1) The Promenade Pavilion, 2) The Pier of the complex which is named after Lady Lloyd, Governor of Bombay Sir George Lloyd's wife. The pavilion structure was inaugurated by Lady Lloyd on 5 January 1920 while the pier was inaugurated on 21 March 1921. Pakistan's largest park was constructed on 130 acres of land around the pier and the newly formed park was named as Bagh Ibne Qasim in memory of the 8th century Muslim conqueror Muhammad Bin Qasim. **Section IV** 

### **PNJR Regional Coordinator Network**

#### **Director Coordinator**

Syed Munawar Ali, Metrics Research

#### **Lead Monitor**

Dr Sadia Altaf, Metrics Research

#### **Research Coordinator South**

Tariq Mubarik, Metrics Research

#### **Research Coordinator North**

Dr. Muhammad Asif Mahmood, Metrics Research

#### **Supporting Team**

Dr Kamlesh Permanand Mr Ali Hyder Qureshi

## Section V



**Natural Sphinx:** is a natural rock erosion formation located in the hingol national park region of Balochistan on the makran coastal highway. The whole region is lined with numerous rock formations, caves and mud volcanoes that continue to form awe striking natural architecture. The other famous formation from this region is the "Princess of hope" named by Hollywood film star Angelina Jolie. It resembles a lady in a hat and dress overlooking the coastline.

## **Section V**

### **PNJR Stakeholders Network**

Pakistan National Joint Registry could not have been formed without the commitments of its valuable stake holders. Each stake holder support and cooperation has enabled us to achieve our 1st year targets. There are number of stake holders but the following few are most significant:

#### I. Pakistan Arthroplasty Society

The board and members of Pakistan Arthroplasty Society take full ownership of PNJR project and have extended their extensive human and financial resources for the realization of this project. All financial funding for PNJR is exclusively supported by PAS.

#### **II. Patients**

Patients are at the center of all we do. Without the contribution of our patients, we would not have achieved this 1st annual report. We believe that their contribution will take us to newer heights in scientific research to benefit the masses in general. PNJR steering committee extends their thanks to all those patients who have contributed to this first annual report.

#### III. Research/Registry development partners

#### **Metrics Research Pvt. Ltd**

Metrics Research took this project as a challenge and devotedly provided its services in designing of protocol, CRF, ICF, data entry and data analysis. The experienced trained team members assisted PNJR in every step of development and publication.

#### **Collage Solutions**

Collage Solutions with an extensive knowledge and experience in data management, EDC, eCRF, CTMS design and development provided the expertise to develop PNJR registry database. These provide services from data management, data tracking, data backup and cleaning to complete audit trails, reports/graph generation, dataset building for SAS/SPSS analysis. They also help in resolving technical site issues and provide training and support to maintain "Data Quality".

#### **IV. Affiliated Institutions / Clinical Sites**

Institutes are the back bone of any clinical research activity. All our registered hospitals are supporting us in providing: access to patient data, logistics for data entry, utilities and use of their valuable and reputable name.

#### SINDH

- 1. Abbasi Shaheed Hospital, Karachi.
- 2. Darul Sehat Hospital, Karachi
- Dow International Medical College, DUHS, Karachi.
- 4. Institute of Orthopaedic & Surgery Pvt. Ltd.
- 5. Jinnah Postgraduate Medical Center, Karachi.
- 6. KPT Hospital, Karachi.
- 7. Liaquat National Hospital, Karachi.
- 8. MediCare Cardiac and General Hospital, Karachi.
- 9. National Medical Center, Karachi.
- 10. NMI Hospital, Karachi.
- 11. Orthopaedic & Medical Institute, Karachi
- 12. Patel Hospital, Karachi
- 13. Royal Institute of Medical Sciences, Karachi.
- 14. South City Hospital, Pvt. Ltd, Karachi.
- 15. Seven day Hospital, Karachi.
- 16. The Aga Khan University and Hospital, Karachi.
- 17. The Indus Hospital, Karachi.
- 18. TO Clinic, Karachi.
- 19. Ziauddin University and Hospital, Clifton, Karachi.

### **PNJR Stakeholders Network**

#### **PUNJAB**

- Aman Hospital, Civil quarters, Lahore.
  Allama Iqbal Medical College/Jinnah Hospital.
  Benazir Bhutto Hospital, Islamabad.
- 23. Combine Military Hospital, Rawalpindi
- 24. Combine Military Hospital, Lahore.
- 25. Doctors Hospital, Johar Town, Lahore.
- 26. Family Hospital, Lahore.
- 27. Ghurki Trust Teaching Hospital, Lahore.
- 28. King Edward Medical University, Mayo Hospital, Lahore.
- 29. Lahore General Hospital, Lahore.
- 30. Mid City Hospital, Jail Road, Lahore.
- 31. National Hospital, Defence, Lahore.
- 32. Quaid-e-Azam International Hospital, Islamabad.
- 33. SIMS/ Services Hospital, Lahore.
- 34. Sheikh Zayed Hospital, Lahore.
- 35. Sir Ganga Ram Hospital, Queen's Road, Lahore.
- 36. Surgimed Hospital, Lahore.

#### **KHYBER PAKHTUNKHWAH**

- 37. Hayatabad Medical Complex, Peshawar.
- 38. Khyber Teaching Hospital, Peshawar.
- North West General Hospital, Hayatabad, Peshawar.

#### **BALUCHISTAN**

- 40. Bolan Medical Complex hospital
- 41. Doctors hospital ,Quetta
- 42. Saleem Complex Hospital

#### V. Principal Investigators

Surgeons who strive hard to enter the data and keep the registry ticking are what keeps this registry alive. Following is the list of our registered investigators.

#### SINDH

- 1. Prof. Anisuddin Bhatti
- 2. Prof. Asif Qureshi
- 3. Dr. Aslam Pervez
- 4. Dr. Intikhab Taufeeq
- 5. Dr. Idrees Shah
- 6. Dr. Imtiaz Ahmed Hashmi
- 7. Dr. Iqbal Malik
- 8. Prof. Kamran Ahmad
- 9. Prof. Mansoor Ali Khan
- 10. Prof. Dr. Maratb Ali
- 11. Dr. Masood Umer
- 12. Prof. Muhammad Amin Chinoy
- 13. Prof. Muhammad Umar
- 14. Dr. Nasir Ahmad
- 15. Prof. Pervez Anjum
- 16. Dr. Riaz Hussain Lakdawala
- 17. Dr. S. Sajid hussain
- 18. Dr. Sohail Rafi
- 19. Prof. Syed Shahid Noor
- 20. Dr. Zaki Idrees

#### **PUNJAB**

- 20. Dr. Abdullah Shah
- 21. Prof. Abu Bakar Siddiq
- 22. Prof. Amer Aziz
- 23. Dr. Ijaz Ahmad
- 24. Dr. Muhammad Akhtar Malik
- 25. Prof. Ali Raza Hashmi
- 26. Dr. Atiq-uz-Zaman
- 27. Dr. Faisal Masood
- 28. Prof. Ghazanfar Ali Shah
- 29. Prof. Irfan Mehboob
- 30. Dr. Khalid Saleem Aslam
- 31. Dr. Mian Muhammad Hanif

### **PNJR Stakeholders Network**

- 32. Prof. Naeem Ahmed
- 33. Prof. Rana Dilawaiz Nadeem
- 34. Dr. Rana M. Arshad
- 35. Dr. Rizwan Akram
- 36. Prof. Shafique Ahmed Shafaq
- 37. Dr. Shahzad Javed
- 38. Prof. Maj. General Sohail Hafeez
- 39. Prof. Col. Suhail Amin
- 40. Dr. Tahseen Riaz
- 41. Prof. Yawar Anis

#### **KHYBER PAKHTUNKHWA**

- 42. Dr. Awal Hakeem
- 43. Dr. Israr Ahmad
- 44. Dr. Khushnood Ali Baz
- 45. Prof. M. Arif Khan
- 46. Dr. Malik Javed Iqbal
- 47. Prof. Muhammad Salim
- 48. Dr. Obaid-ur-Rehman
- 49. Prof. Raja Irfan Qadir
- 50. Dr. Syed Imran Bukhari
- 51. Prof. Zahid Askar

#### **BALUCHISTAN**

- 52. Dr. Amanullah Kakar
- 53. Dr. Khawand Bakhsh Umbrani
- 54. Dr. Saleh Tareen

#### VI. List of partner implant suppliers

- 1. Zimmer, Inc.
- 2. DePuy, Johnson and Johnson.
- 3. United Orthopadics.
- 4. Surgival
- 5. Biomet
- 6. Irene
- 7. Miscellaneous

## **Section VI**



**Faisal Mosque:** is the 2nd largest mosque in Pakistan, located in the national capital city of Islamabad. Completed in 1986, it was designed by Turkish architect Vedat Dalokay, shaped like a desert Bedouin's tent, is an iconic symbol of Islamabad throughout the world. The Faisal Mosque was conceived as the National Mosque of Pakistan and named after the late King Faisal bin Abdul-Aziz of Saudi Arabia, who supported and financed the project. Faisal Mosque was the largest mosque in the world from 1986 until 1993, when it was overtaken in size by the newly completed Hassan II Mosque in Casablanca, Morocco. Subsequent expansions of the Masjid al-Haram (Grand Mosque) of Mecca and the Al-Masjid al-Nabawi (Prophet's Mosque) in Medina, Saudi Arabia, during the 1990s relegated Faisal Mosque to fourth place in terms of size.

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#### **Section VI**

#### **Registry development and data collection tools**

This section will introduce key features of data recording system that consist of case report form (CRF) for both primary and revision hip and knee arthroplasty in manual and electronic version (eCRF).

It was a great challenge to develop a comprehensive data recording system, covering all the required fields to benefit the patient and the principal investigator. The clinical research forms and data recording systems of all the existing international registries were obtained and analyzed in detail in a meeting of the steering committee of Pakistan Arthroplasty Society (PAS) held at Liaguat National Hospital and Medical College (LNH&MC), Karachi on 2<sup>nd</sup> of December, 2013 and a basic structure of Case Report Form (CRF) of Pakistan National Joint Registry was designed. This basic CRF was then assessed by the National and international faculty of PAS and they were requested for comments and suggestions for further improvement. This trial version of CRF was then made available for the members to check that how efficiently information can be obtained. In a second meeting of the steering committee of PAS, the suggestions by the national, international faculty and members were discussed and necessary modifications were made in the CRF to make it final. A detailed informed consent form (ICF) was designed and translated in both Urdu and English for better understanding of the patient in obtaining informed consent. Collecting the data to improve patient care is certainly a noble goal. But we know that anything that can be used for good purposes can also be used in ways that may cause harm. Whenever data is collected, it is important to consider whether the project is asking useful and appropriate study questions, whether the information being gathered will be useful in answering the study questions, and whether more information, less information, or other information should be gathered. It is also important to consider whether the data is being analyzed by an informed, competent, and unbiased team. For that the research protocols, informed consent form and CRF were all submitted to institutional review

board (IRB) at Indus Hospital Karachi for approval and IRB approval for the PNJR was obtained.

The PNJR was launched at an inauguration ceremony held in Karachi on 15th of February, 2014 at College of Physicians and Surgeons, Karachi with live telecast with all CPSP centers in Pakistan. All the principal investigators were invited in that ceremony and hard copies of PNJR-CRF were distributed among them. In the same session they were trained to use the online version of PNJR. Online accounts of all principal investigators were made for the easy and quick access to their own data by specific login and password after signing a MoU between principle investigator and PAS.

The offline version and smart phone application of PNJR is under process and will be available soon.

Different components of CRF are demographic details of the patient, surgeon and institution/s detail, preoperative deformity and range of movement of the affected joint, co-morbidities and preoperative ambulatory status of the patient, anesthesia ASA grading. Scoring systems use for hip joint is Harris Hip score and for the knee joint are knee functional score. Other components include diagnosis and procedure details, whether the surgery is primary or revision, thromboprophylaxis, antibiotics and postoperative pain management. Details of each prosthetic joint component, design and company are also noted. Preoperative and postoperative pictures can also be recorded in online software version. A separate form is designed for the follow up visit recording of the patient at 2 weeks, 6 weeks, 3 months, 6 months, 01 year, 5 years, 10 years, 15 years and 20 years.

The data is being kept and monitored by the Metrics Research Pvt. limited who are the official research partner of PAS.

### **Section VII**



**Deosai Plateau:** The Deosai National Park is located in Skardu Gilgit-Baltistan province, in northern Pakistan. Deosai is accessible from Skardu District in the north and the Astore District in the west. The plateau is located at the boundary of the Karakorum and the western Himalayas. Deosai is a tourist attraction and lot of tourists who visit Baltistan go to Deosai as well. Deosai Plateau which is the second highest plateau in the world after the Chang Tang in Tibet.

#### **Section VII**

#### Challenges in Establishing a Joint Registry.

There were multiple challenges in establishing the PNJR. Starting from campaigning, it was a daunting task to gather a group of like minded surgeons to think on the same lines and be committed enough to achieve a sustainable registry. We knew in our minds that many smaller and more developed countries have tried to establish national joint registries but have failed due to non-cooperation from Pl's. Therefore we started by campaigning to convince surgeons and hospitals to participate actively to make this project a success. Similarly, we encouraged implant vendors and suppliers to support the registry so that we could communicate to surgeons across the country through their already established sales network.

The next challenge was securing a registry software. Multiple options were looked into. Imported software was both expensive and did not necessarily meet our entire requirements. For this our research partner Metrics Research took an initiative and we embarked on developing local registry software. This saved the society a lot of revenue that could then be utilized on other areas such as printing costs for case report forms (CRF's), transportation, mails and communication. In all we had to plan to make this a financially sustainable project. Had capital been invested in purchasing an expensive software, we would have spent unnecessary money.

Thirdly we had to conform to Good Clinical Practice (ICH-GCP) guidelines for institutional research involving human subjects. We also had local institutional policies regarding confidentiality of data and data sharing to comply to. We sought Institutional Review Board approval and the registry was granted approval by Indus Hospital IRB.

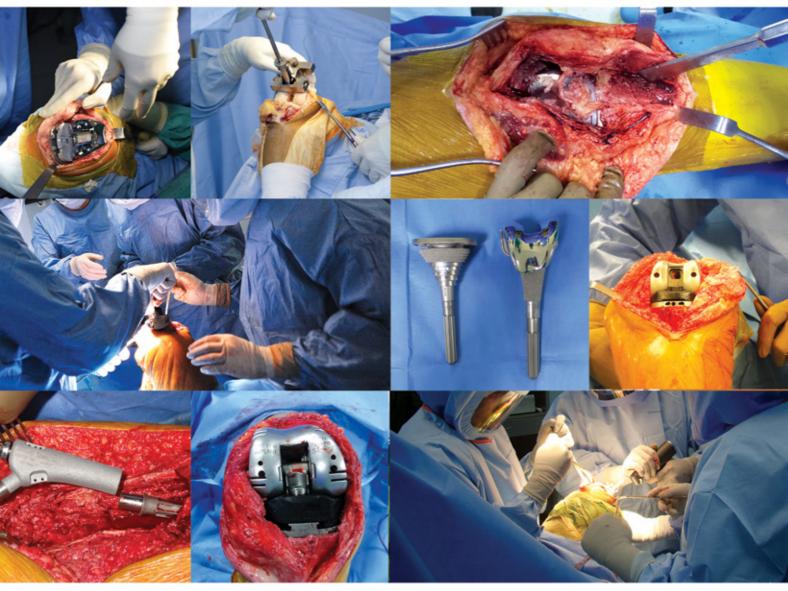
We also had to develop research tools such as Informed Consent Forms (ICF's) that were both simple and sensitive to linguistics. Therefore the national language Urdu was used as first translation. The PAS secretariat is further committed to develop forms in local languages if requested by any PI. The development of the CRF's took a lot of doing. Many samples were reviewed by the steering committee before deciding on the variables that need to be included in the final version. We were faced with the challenge of keeping the form simple yet comprehensive. We now have a very effective form that engages ample number of variables without making it labor intensive.

Finally the training of PI's and hospital staff has taken priority in the first year of operation of the PNJR. We provided training via video conferencing to PI's participating in the registry especially those who are using the online version of the eCRF.

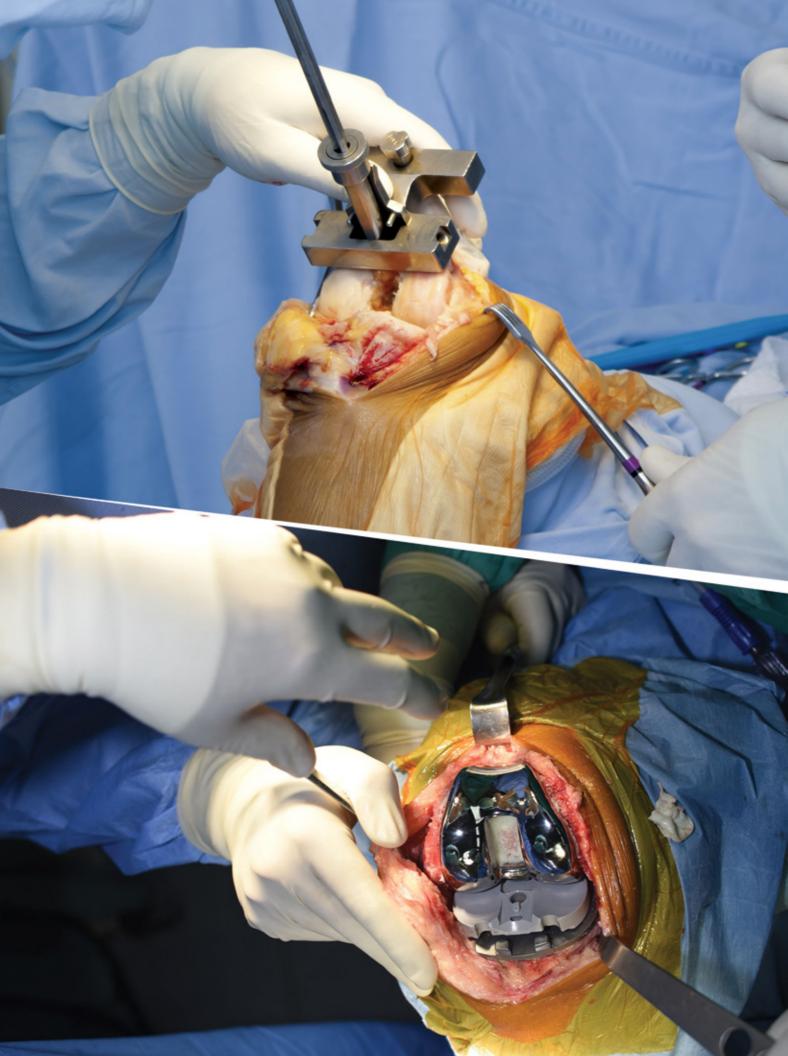
We feel that a grand project like the PNJR requires support from the whole orthopaedic community and from arthroplasty surgeons specifically to meet the current and upcoming challenges and to make this a symbol of national pride.



# DATA ANALYSIS AND INTERPRETATION

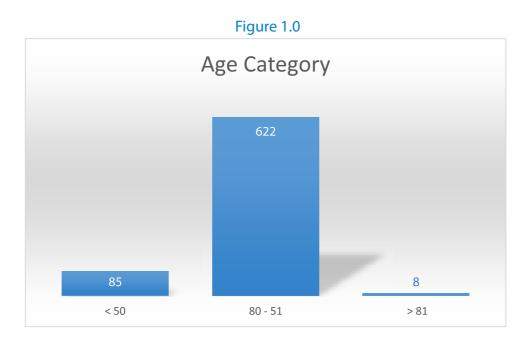


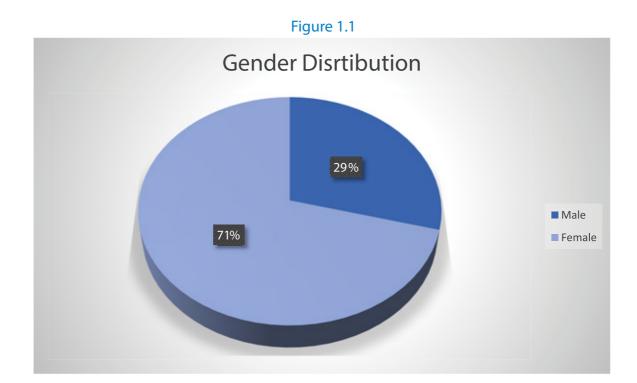
### Section I

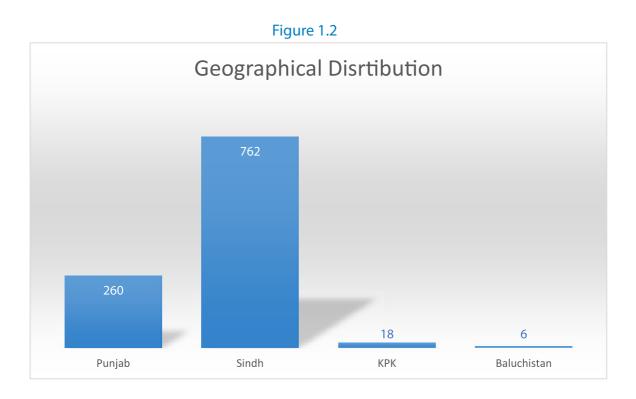


Section I

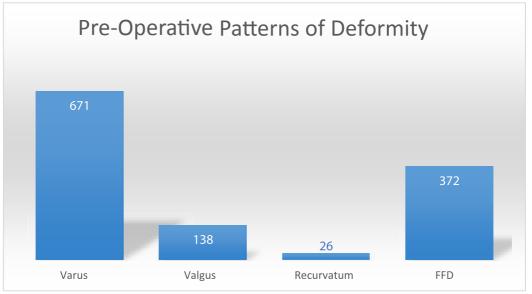
### **Primary Total Knee Arthroplasty**

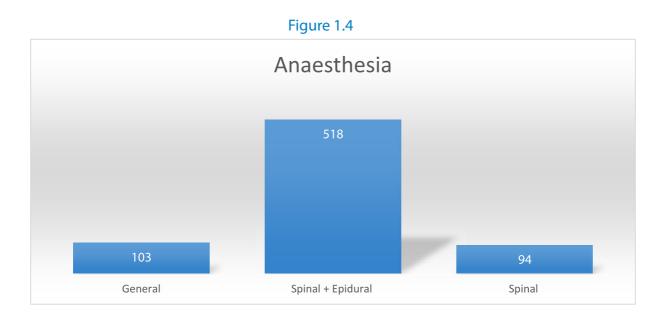


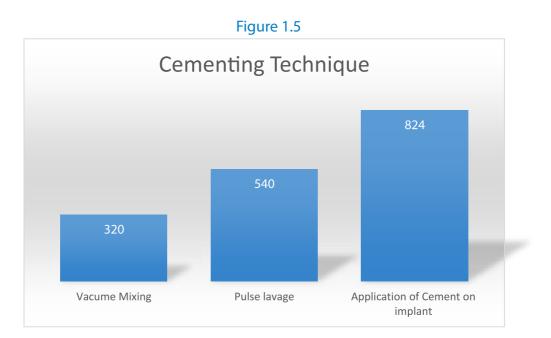




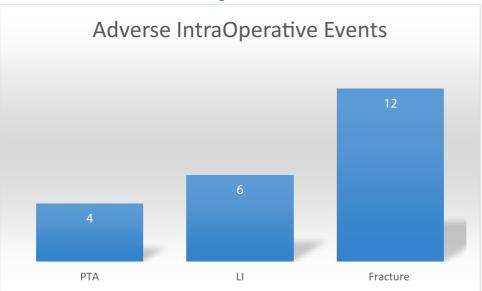
#### Figure 1.3



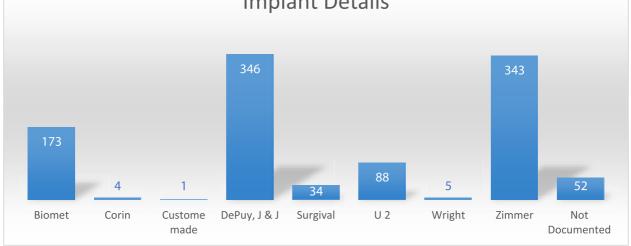




#### Figure 1.6



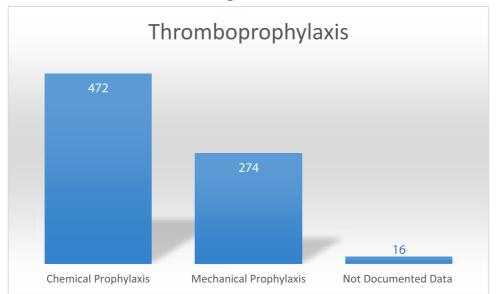




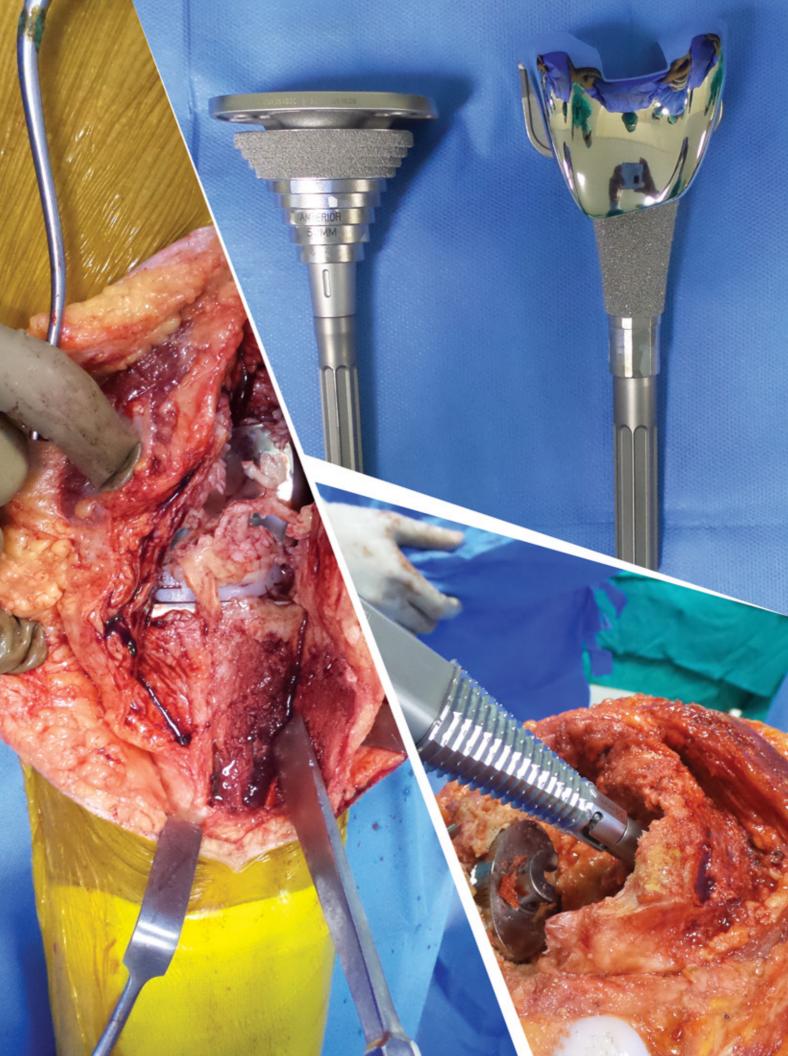




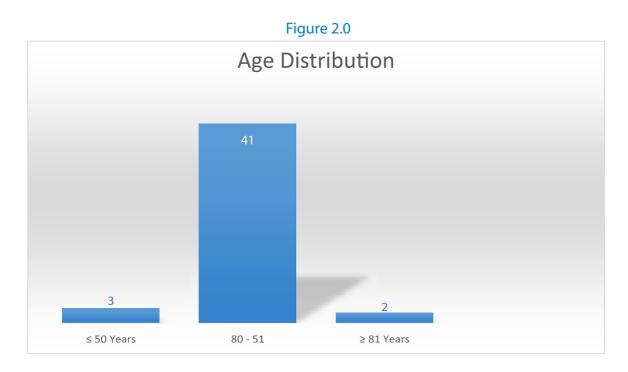
#### Figure 1.9



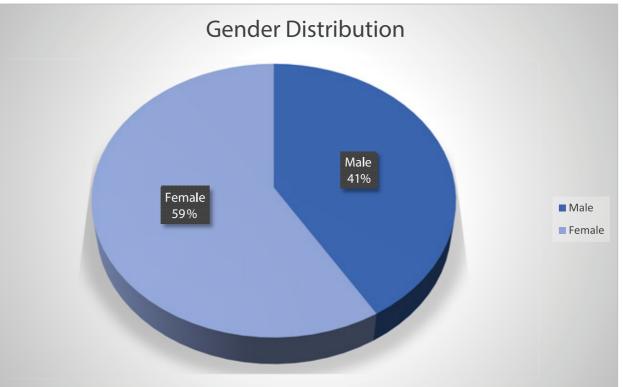
### Section II



#### **Revision Total Knee Arthroplasty**

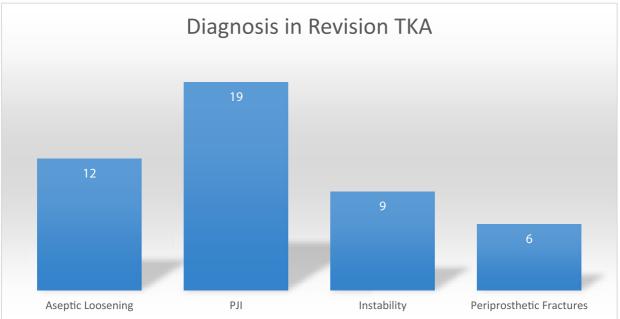


#### Figure 2.1

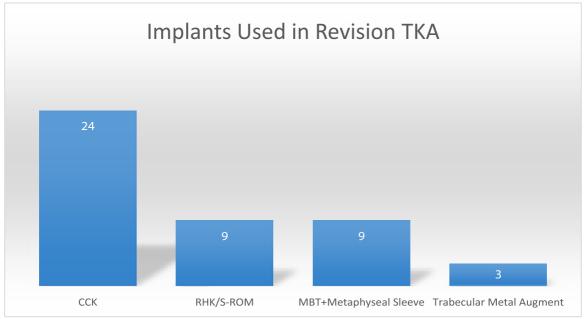


Revision Total Knee Arthroplasty continue to grow as arthroplasty surgeries have been taking place in the country for over two decades. Currently infection and aseptic lossening form the two main reasons for failure of primary total knee arthroplasties.

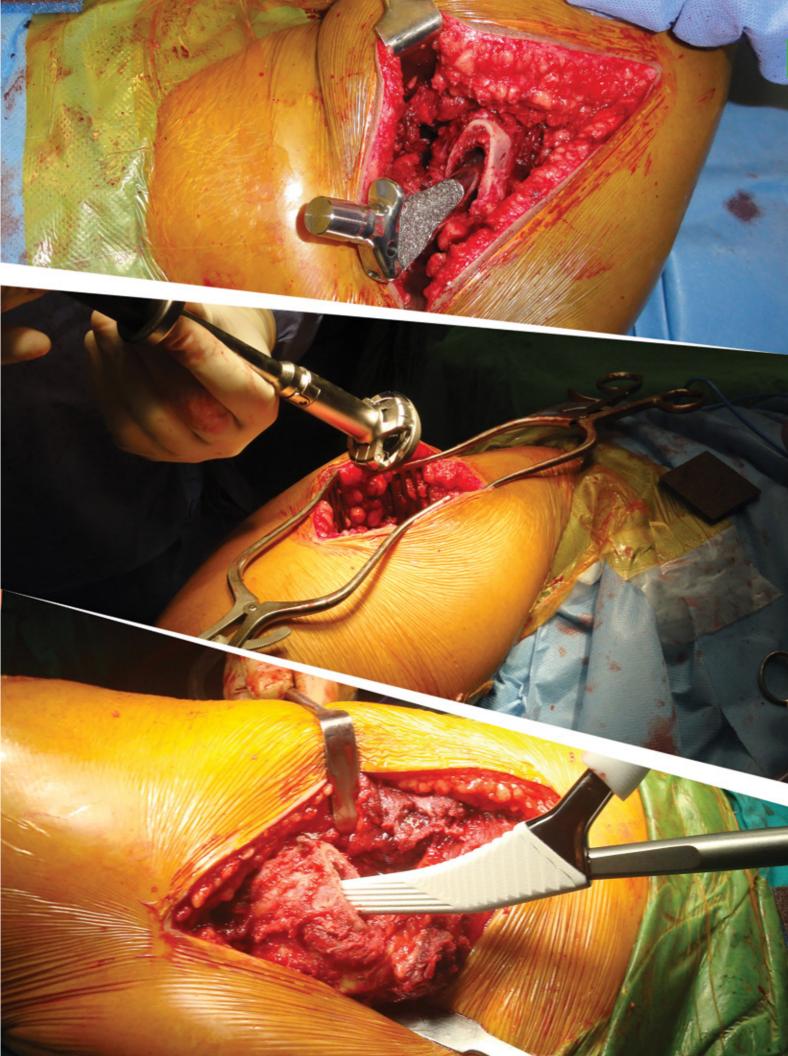






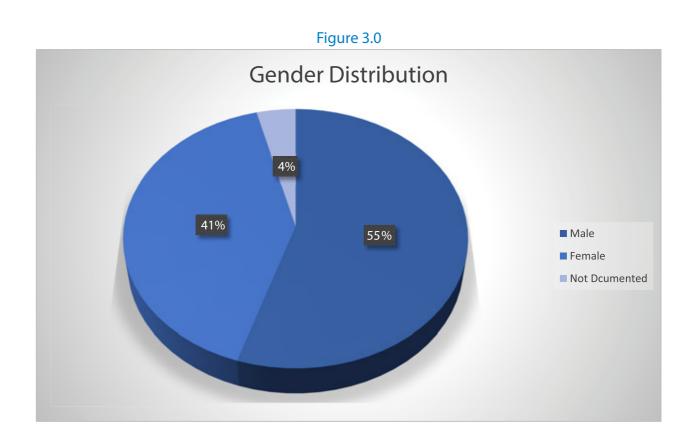


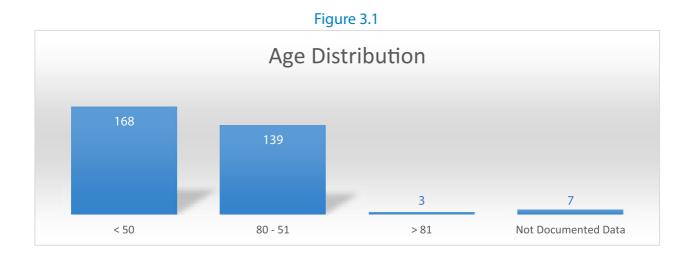
### Section III



### Section III

### **Primary Total Hip Arthroplasty**





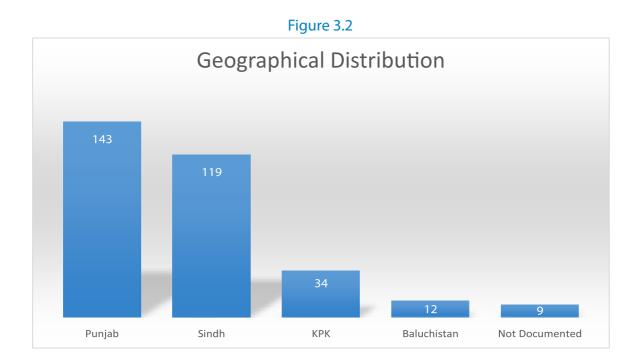
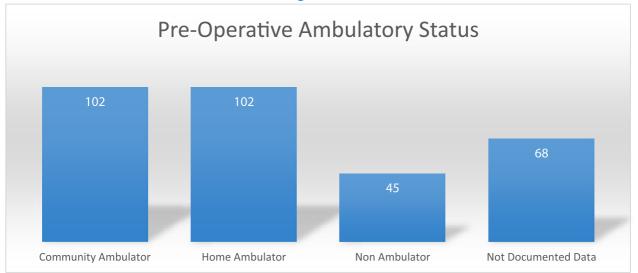
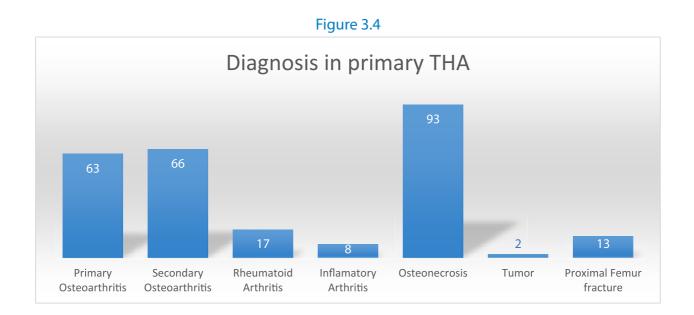
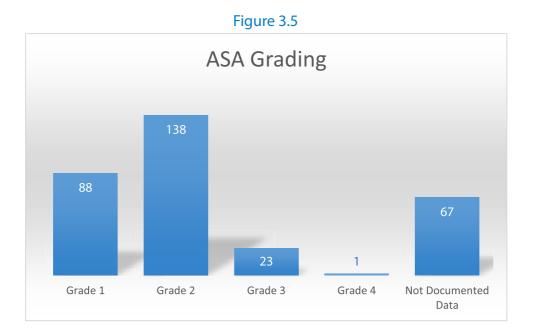
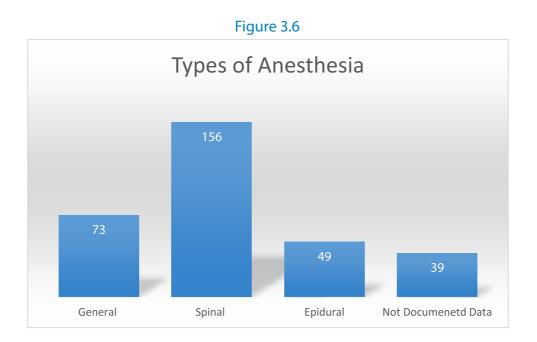


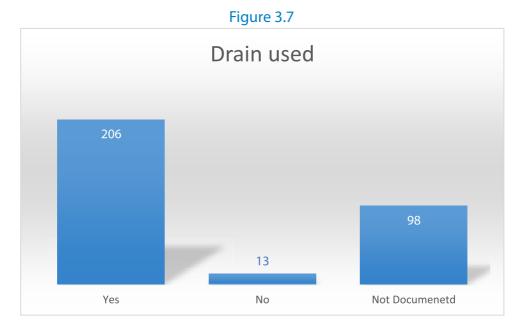
Figure 3.3

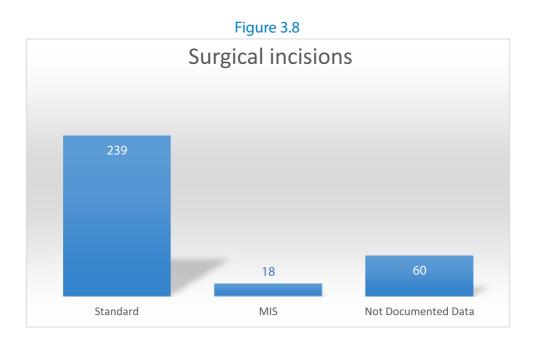


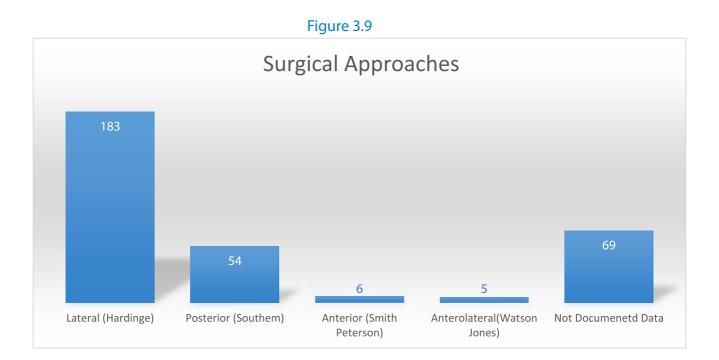


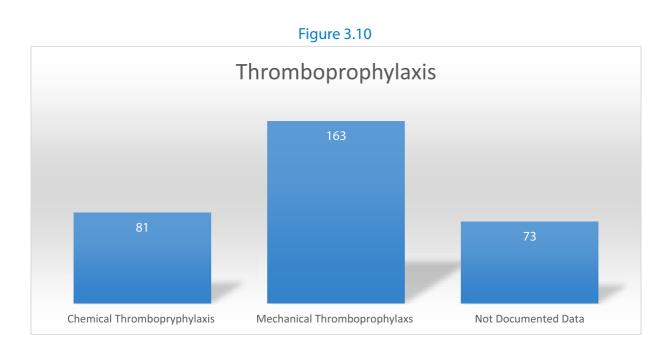




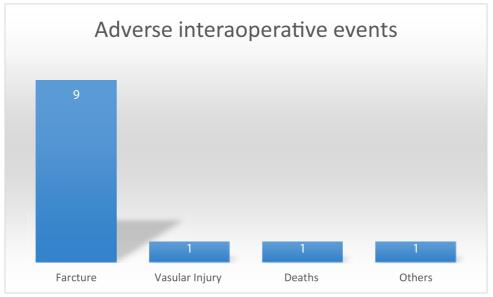


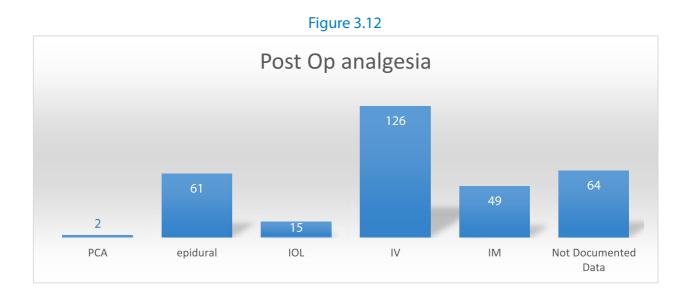


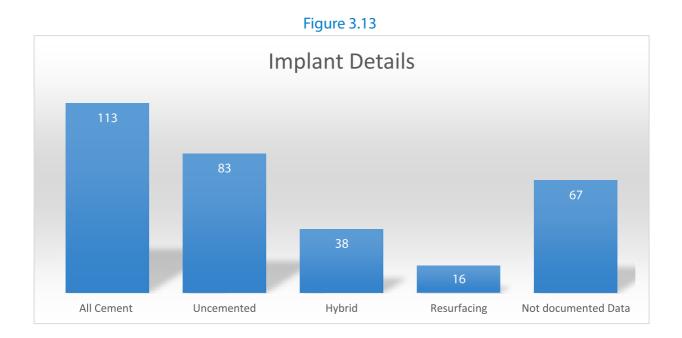


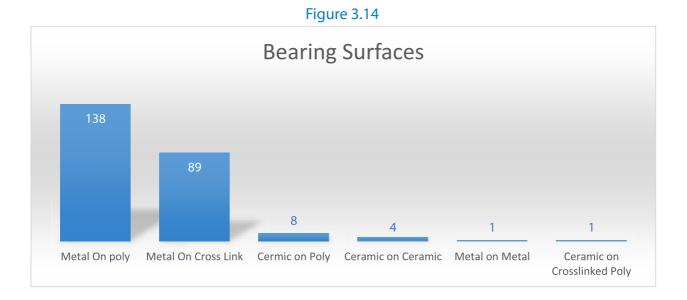


#### Figure 3.11

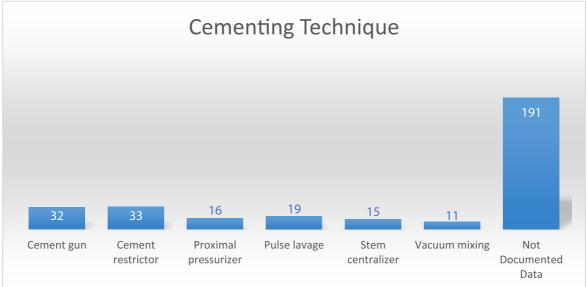


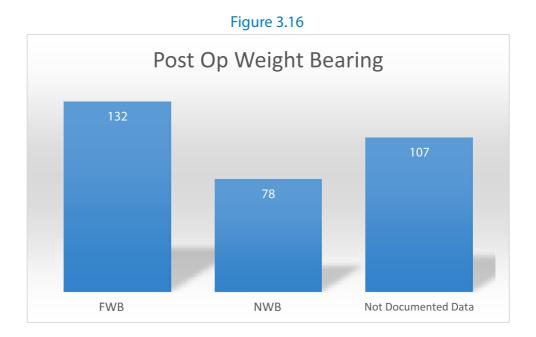




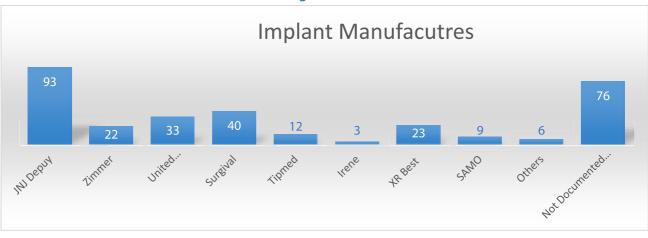




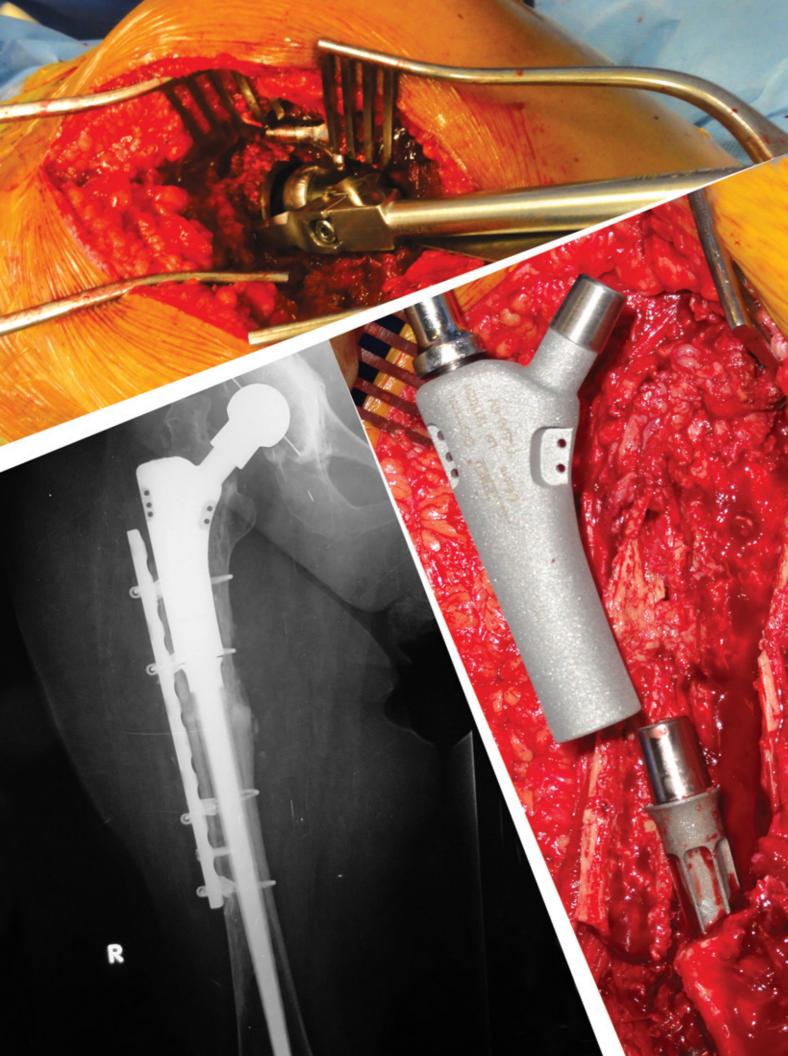




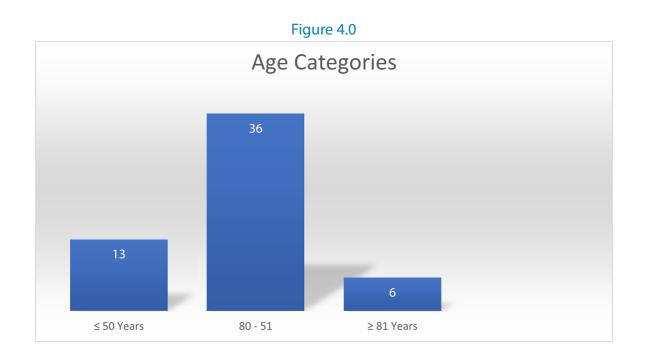
#### Figure 3.17



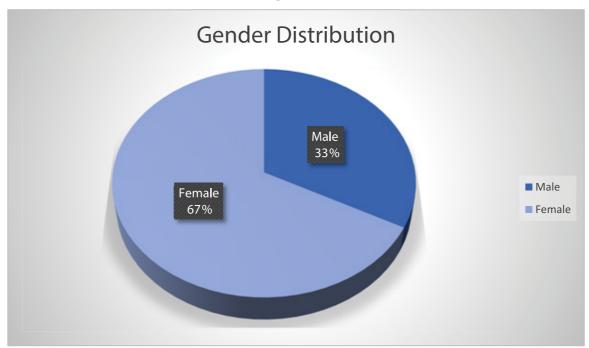
### **Section IV**



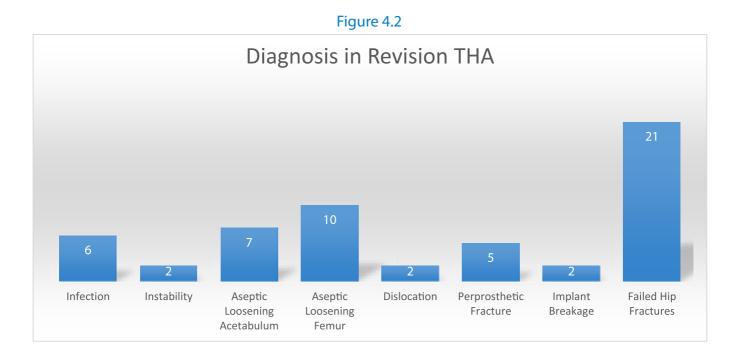
### **Revision Total Hip Arthroplasty**

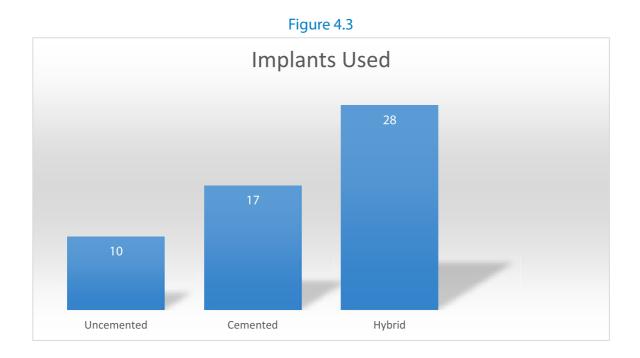


#### Figure 4.1



Revision hip surgeries are becoming more and more common. Most common form of revision is after a failed prosthetic replacement for a femoral neck fracture. There is a large number of patients who require revision for aseptic loosening. Infection however is less of a problem when it comes to hip replacement.





## **List of Abbreviations**

PJI	Peri Prosthetic Infection
FFD	Fixed Flexion Deformity
РТА	Patellar Tendon Avulsion
LI	Ligament Injury
PCA	Patient Controlled Analgesia
IOL	Intra Operative Local Anesthesia
IV	Intravenous
IM	Intramuscular
ССК	Condylar Constraint Knee
RHK	Rotating Hinged Knee
MBT	Mobile Bearing Tibia
MIS	Minimally Invasive Surgery
CRF	Case Report Form
eCRF	Electronic Case Report Form
PNJR	Pakistan National Joint Registry
PAS	Pakistan Arthroplasty Society
КРК	Khyber Pakhtunkhwa
FWB	Full Weight Bearing
NWB	Non Weight Bearing

### **PAS PARTNERS**





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