

## Response to comments on the Editorial on National Guideline and ILD Pak Registry

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Madam, The author is thankful to Dr. Zubairi for his appreciation of the effort in developing the ILD registry. The establishment and maintenance of a registry demands an investment in time, effort and finances and should ideally be undertaken by the public sector.

ILD PAK registry is an ongoing web based registry, the governance of which is under the auspices of the Pakistan Chest Society (PCS). In the PCS Biennial Conference 2014 ILD session, the registry web interface was introduced and an open invitation was given to all institutions and pulmonologists across the country, interested in research of ILD to join the registry for the collection of a national data base. Gradually, institutions showing interest in subscribing to this registry (9 teaching hospitals: KPK 2, Punjab 3, Federal Capital 1, Sindh 2 and Balochistan 1) were given access codes to the web registry over a period of time.

The ILD PAK registry has a National Coordinator and a Steering committee (page iv of Registry Report) consisting of all principal investigators. Its TOR involves: Quality control (QC), data access and research policies, format and content of future registry reports. The committee presently accommodates maximum representatives of the contributing clinical groups. Already available to the registry is a resource pool of multi specialty

consultants of repute, as listed on the same page.

The ILD PAK registry is in its expanding stage and welcomes pulmonologists from all over Pakistan to participate, given they fulfill record keeping and QC criteria. We agree with Dr. Zubairi and believe that data from a few centers or one institution for that matter, cannot paint a true picture of ILD all over Pakistan, hence this registry was created to encourage collection of data from all provinces for a better understanding of the disease.

As most ILD patients are not hospitalized and encounter travel difficulties, multi locality centres were imperative for data collection in the Karachi metropolis (site map page 14 Registry Report). However, processing and recording was maintained in a central office and for this report, we accepted HRCTs done only from ARC, Dow Rad, AKU, ZMU and LNH often with discussion on reports. The PFTs were done on current Vitalograph Spirotrac 6000 Alpha windows based spirometer and each was invariably supervised and reported by the consultant. Analysis was done by qualified bio-statistician using SPSS version 21. Moreover, all these documents were archived. The present report complies with all above requirements.

It was important to publish this report to give us a sample of local disease profile over a span of time and also to gain and share experience in the genesis of a developing registry wherein greater volume of identical datasets entered from various centers will provide a greater opportunity to understand and resolve issues in the recording of epidemiologically sound information.

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