

### Spotlight on data

Pradnya Sri Rahayu Irvin has been working as a biostatistician for the Cancer Registry Division of the Dharmais National Cancer Centre in Indonesia for the past nine years under supervision from Evlina Suzanna, MD, Path. Indonesia is the fourth most-populated country in the world, and its population extends over hundreds of permanently inhabited islands, making the task of maintaining a cancer registry difficult. Despite this, Ms. Irvin is committed to representing cancer incidence in Jakarta to set an example for other regions in Indonesia.



In 2012, she completed a UICC fellowship with Dr Rajesh Dikshit at the Tata Memorial Hospital in Mumbai, India in order to learn how they have conducted population-based cancer registries (PBCRs) in both urban and rural areas. Ms. Irvin chose Tata Memorial Hospital as a host institution for her fellowship study because of its success in the running of PBCRs and its similar set up to Indonesia in terms of population size, urban-rural distribution and similar dietary patterns.

### Lessons learned from the fellowship

Ms. Irvin arrived in India hoping to gain transferable skills regarding how to conduct PBCRs in urban and rural settings. These skills included how to seek out and obtain cooperation and support from the local community, how to select the right geographic regions to study, and how to ensure the necessary budget and infrastructure to set up the registries, including the appropriate human resources able to carry out accurate reporting of cancer data and able to perform the necessary quality controls.

During her fellowship, Ms. Irvin visited cancer registries in both urban (Mumbai Cancer Registry) and rural areas (Barshi Cancer Registry), and underwent training in different methodologies regarding case-finding, data collection and follow-up. Ms. Irvin has since transferred this knowledge back to Dharmais.

### Successes and challenges in achieving a PBCR

Calculating cancer incidence in such a largely populated country as Indonesia is no easy feat, but can be accomplished step by step. What began as a hospital-based cancer registry in Dharmais has since become one of multiple sites working with the National Cancer Control Committee, formed in 2014, together with the Referral Health Facility Division and Cancer Control Division. Today, there are six national cancer control programmes in Indonesia, and a National Cancer Registry in 14 provinces and conducted by 14 national referral hospitals, covering about 14% of the population. The programme is improving through efforts in advocacy, socialisation, convening workshops and online tutorials. Challenges to overcome on the road ahead include the following:

- Improved population coverage and representation
- Increased, more complete data collection
- Additional advocacy and support from all levels of the community to highlight the importance of cancer data in understanding and addressing the country's cancer burden.

### The role of data in Treatment for All

Ms. Irvin's fellowship in India gave her the skills needed for her to contribute to the cancer registry implementation in more districts and provinces of Indonesia so that a greater portion of population is covered. Cancer registries are a crucial component to improving our understanding of a country's cancer burden, and therefore allow the country to make evidence-based decisions and identify targeted solutions and the resources required to support the treatment and care of patients.

*"No data is still better than misleading data. That's why we keep reminding the team about how to control the quality of their data, which we verify. Cancer control programs, from early detection to rehabilitation and palliative care, will work more efficiently, effectively and right on target with high quality cancer registry data."*