



ISAR Mission Statement: Key statements

Sept 2019



The need for ISAR

Pre ISAR

- Local national registries may be limited in scope, have insufficient statistical power to answer many research questions, lack intra-operability to share lessons learned and collect different data, making cross comparisons difficult

What was needed?

- A worldwide registry which brings all severe asthma data together in a cohesive way, under a single umbrella, based on standardized data and collection protocols, permitting data to be shared seamlessly.

What ISAR brings

- ISAR is the first global adult severe asthma registry. Its strength comes from collection of patient level, anonymous, longitudinal, real-life, standardized, high quality data from countries across the world, combined with organizational structure, database experience, inclusivity/openness and clinical, academic and data base expertise

The logo for the International Severe Asthma Registry (ISAR) is displayed within a large, light blue circular graphic that has a splatter-like, watercolor-like edge. The letters 'I', 'S', and 'R' are in a dark blue, bold, sans-serif font. The letter 'A' is replaced by two stylized, overlapping orange shapes that resemble the lobes of an asthma inhaler or the shape of lungs.

It's a partnership

- ISAR is a **joint initiative** and would not exist without the data provided by local registries.
- **ISAR acts as a data custodian**, collecting, collating, exploring, and analyzing standardized data provided by these local registries.
- **Local registries retain ownership** of their own data, but benefit from ISAR in terms of the analytical power it provides and cross comparisons with data from other countries
- **ISAR already partners with 20 national or regional registries** in: Europe, The Americas, Asia Pacific, and the Middle East, with planned expansion to other regions of the world – including Africa.

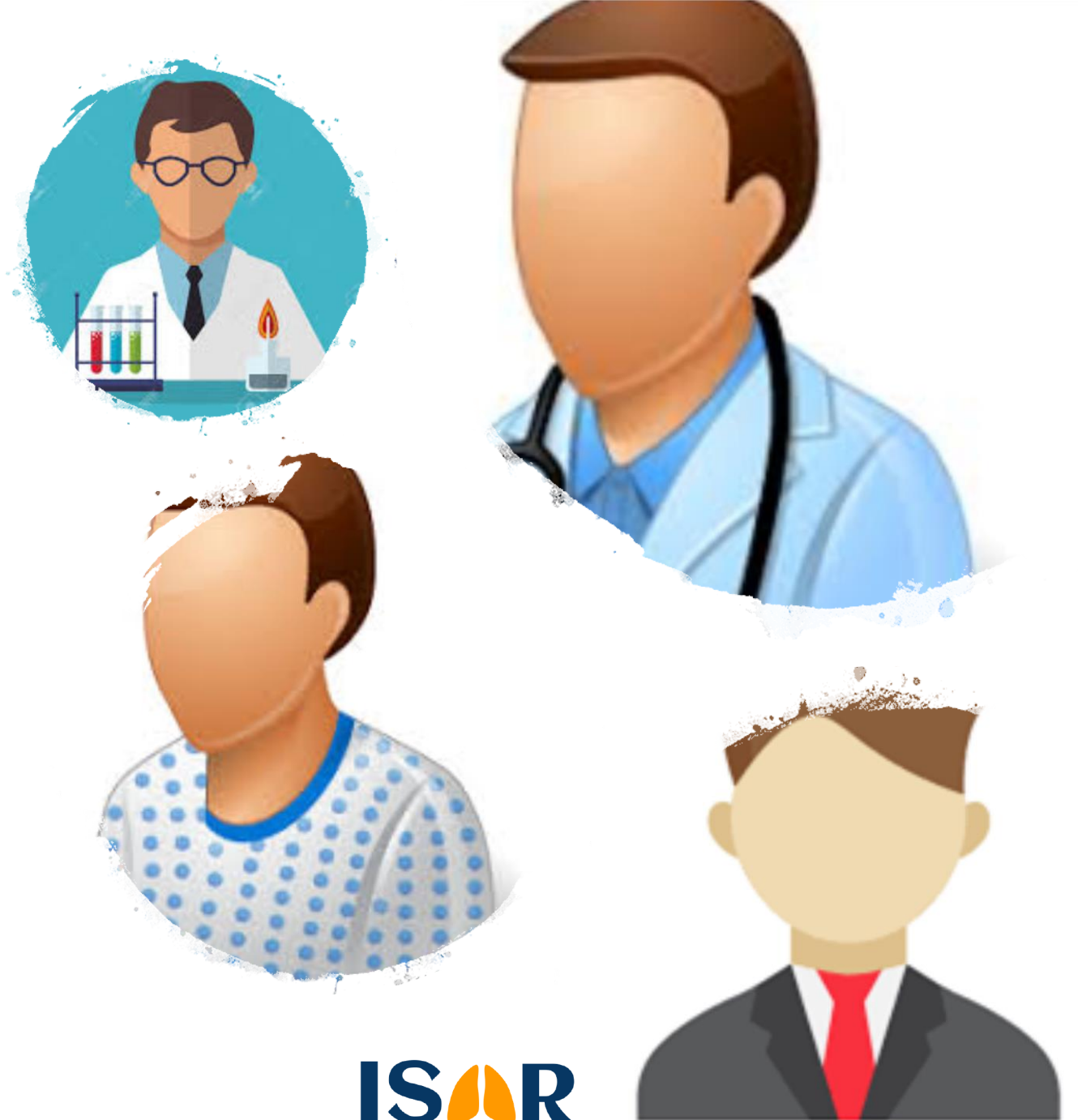


What makes ISAR unique?

- ISAR has **sufficient statistical power** to answer important research questions in the field of severe asthma, **sufficient data standardization** to compare across countries and regions, and the **structure and expertise** necessary to ensure its continuance as well as the **scientific integrity and clinical applicability** of its research.
- ISAR offers a **unique opportunity** to implement existing knowledge, generate new knowledge, and identify the unknown, therefore promoting new research in severe asthma.
- ISAR has a **strong academic focus**. Research projects are prioritized each year, with ethical oversight provided by REG and ADEPT committee,

ISAR: something for everyone!

- **Clinicians** may gain information on patient presentation, knowledge of predictors of treatment success in the era of personalized medicine and predicted outcomes of personalized therapies.
- **Patients** may gain a better understanding of the natural history of their disease, with their collective data used to inform treatment guidelines.
- **Payers** may get evidence on how treatments are used and their effectiveness (both clinical and economic) in different patient populations.
- **The pharmaceutical industry** may assess the effectiveness and long-term safety of therapeutic agents in real-life.



ISAR

5 reasons why ISAR is the go-to severe asthma registry

1. ISAR is a **global registry**; large enough to ensure **sufficient power** to answer numerous important clinical questions.
2. The **data collected** by ISAR are standardized, individualized, and comprehensive
3. ISAR has **scientific, academic, and ethical oversight** providing confidence in data collection, analysis and dissemination, and extensive experience in large data collection and management
4. ISAR operates on the principle of **inclusivity and collaboration**, continually seeking new partners and prioritizing relevant research pertinent to severe asthma.
5. ISAR is a **cross-disciplinary initiative**, holding within it the combined experience of key thought leaders in severe asthma (clinicians & epidemiologists) as well as basic scientists, data analysts, and experts in database management and communication.

Aiming high

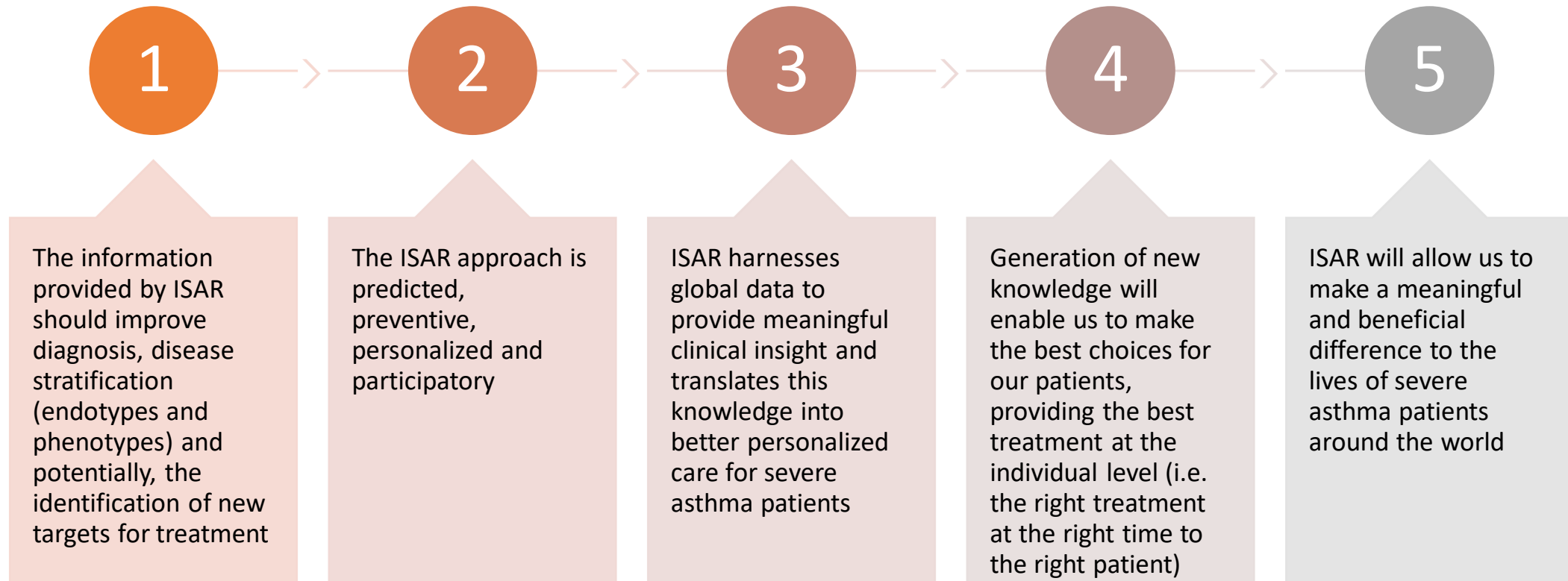
- The aim of ISAR is to **improve the care** of adults with severe asthma globally (both in primary and secondary care).
- This aim will be achieved via provision of a rich source of real-life data for scientific research which will enable:
 - A **better understanding** of the epidemiology, burden and clinical evolution of severe asthma
 - An **assessment of the real-world efficacy and safety** of new treatments and patient outcomes for severe asthma
 - The **exploration of management patterns** of severe asthma (exploring differences across healthcare systems)



The ISAR vision

- ISAR permits the **implementation** of existing knowledge in the severe asthma patient population, **generation** of new knowledge, and identification of the unknown, **promoting** new research
- By combining data from small registries into one large standardized registry, ISAR is able to **compare and contrast differences** between countries and care systems, something which until now was not possible in the global severe asthma framework
- ISAR has the potential to **robustly interpret** and **generally apply** observations, but as it continues to grow, the aim is to no longer simply estimate, but rather to **describe the severe asthma population in its entirety**

ISAR's potential



ISAR in the future

- Data provided by ISAR may be helpful in supporting, modifying and improving current severe **asthma guidelines**
- In the future ISAR may be more fully linked with EHRs to **streamline data collection** and with PROs to help patients and physicians make better personalized decisions
- Knowledge gathered by ISAR may be used to improve the management of those with moderate disease, to see whether **better care earlier may lead to better outcomes later**
- The ISAR database could be used to investigate the **effectiveness of novel approaches** to asthma treatment or the feasibility of new asthma treatment paradigms
- ISAR could be used, not only to examine asthma outcomes and identify patients likely to benefit, but also to assess **the cost-effectiveness** of the approach
- Potential benefits of ISAR are many and include **improved adherence and asthma control**, fewer ICS-related side effects and provision of a validated simplified asthma management programme offering greater convenience for patients