Ioana Agache
European Academy of Allergy and Clinical Immunology (EAACI)

Stakeholder perspective –Doctors

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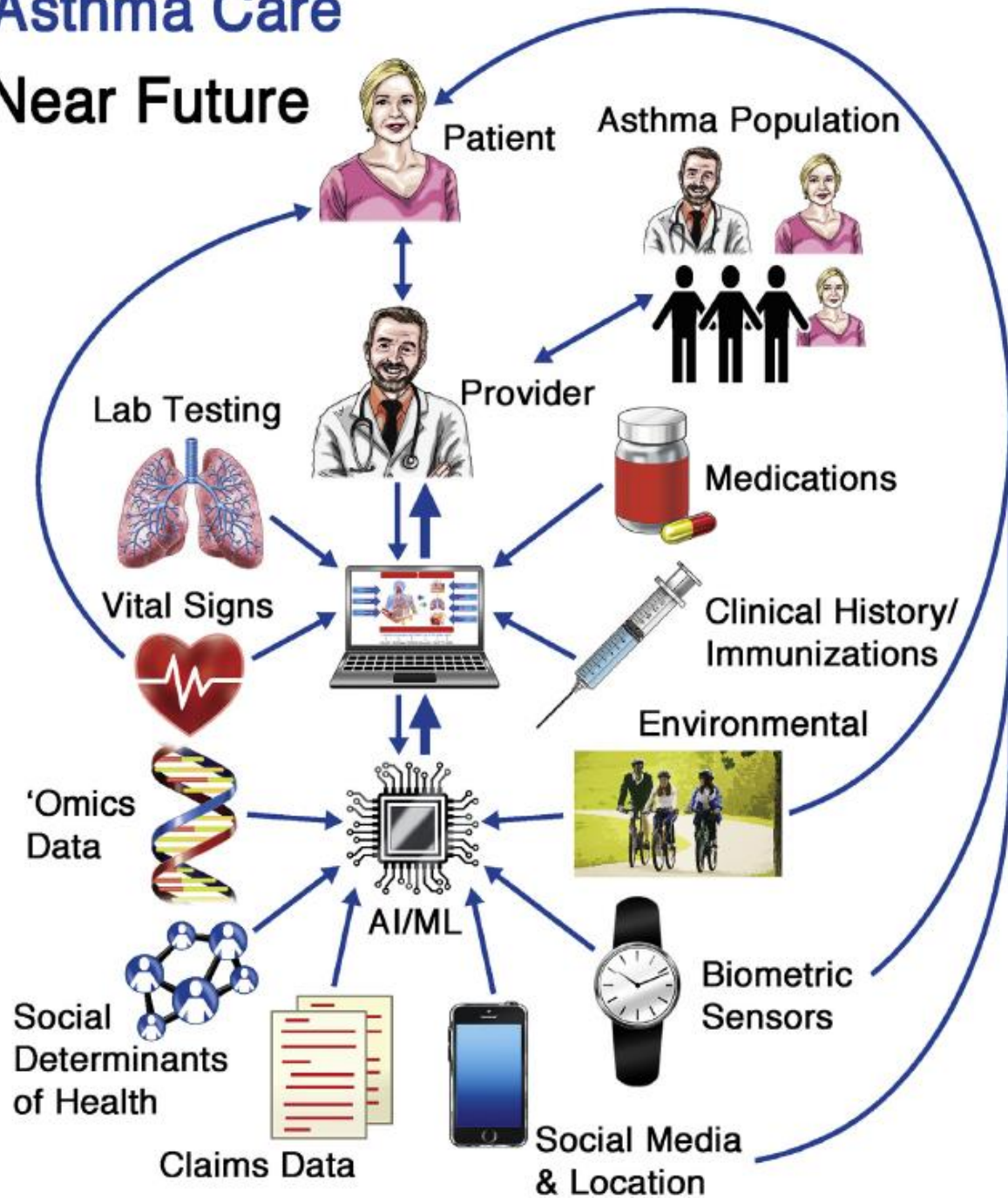*dedicated to Allergy Science,*
committed to your Health
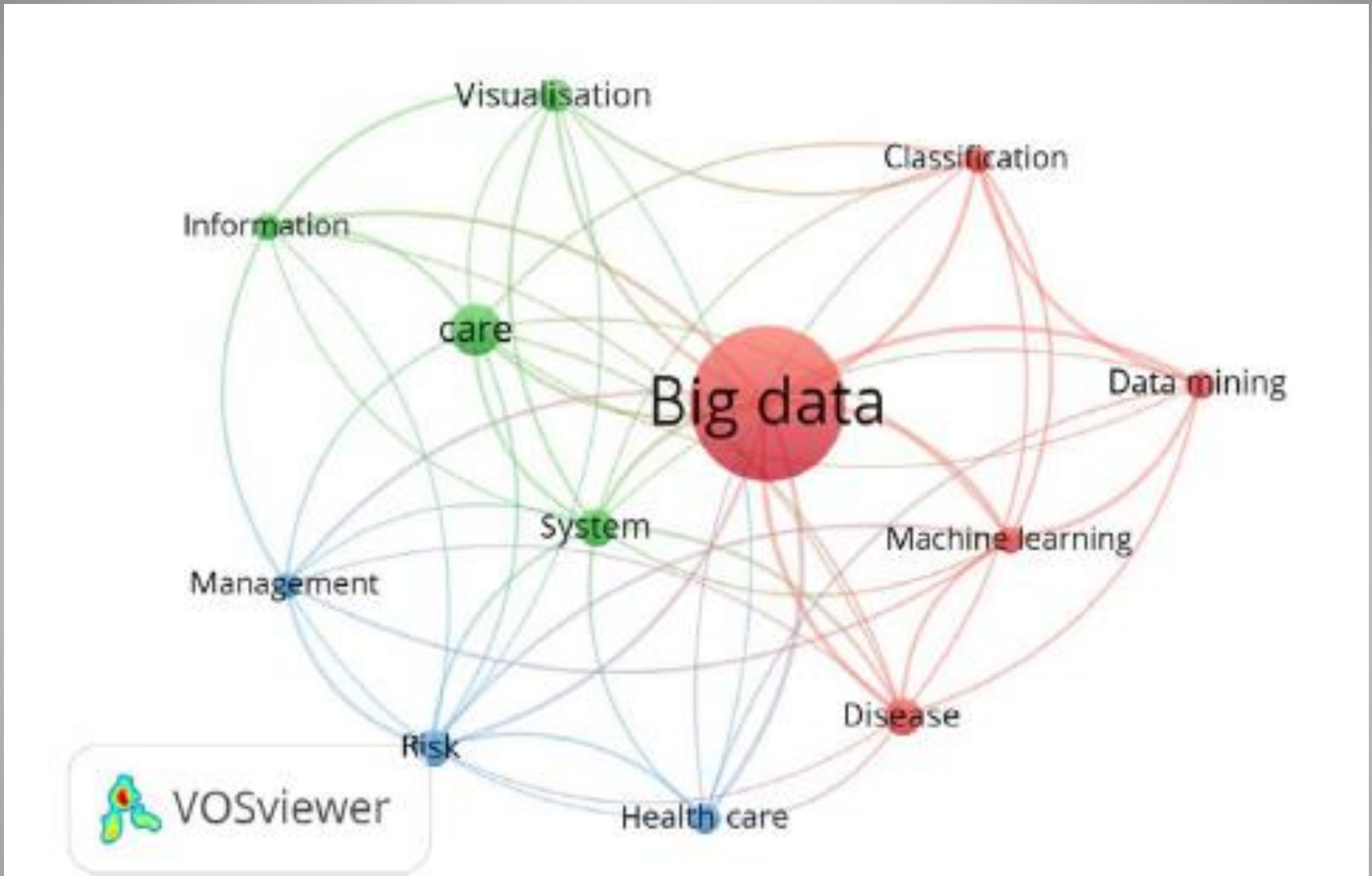
Galetsi P, Katsaliaki K. Health Info Libr J. 2020;37(1):5-25

Asthma Care Near Future

Messinger AI et al.
J Allergy Clin Immunol.
2020;145(2):476-478.

Capabilities of BD for healthcare

1. Current monitoring capabilities to collect and analyse data

2. Information about future outcomes (prediction/simulation)

3. Extraction and categorisation of knowledge

4. Performance of BD techniques; explainability of the outcomes (evaluation)

5. Assembling collected knowledge and provision into an informational format (reporting)

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Current monitoring capabilities – opportunities (1)

AI driving clinical decision support systems

Data collection available from registries, e-records and data bases from laboratories

Primary care observational cohorts and registries that provide quality data.

Development of defined data variable lists for disease-specific areas

Expansion of projects like EDHEN/BD4BO; certification of SME's for conversion of datasets to Observational Medical Outcomes Partnership (OMOP) Common Data Model

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P1: DARWIN/P3: Discoverability

Current monitoring capabilities – opportunities (2)

Better understanding of rarer diseases

Better understanding of expected ADRs

Earlier warning of unexpected ADRs in general and during CMA evaluation where experience with new treatments is limited

Detection of undiagnosed disease by using lab centralized data

Current monitoring capabilities – challenges (1)

- **Sampling bias/quality assurance/incompleteness of datasets**

- **Little standardisation on what to measure in whom and when**

- **Harmonisation of datasets to allow for meaningful analytics**

- **Dictionaries of dataset variables for disease specific areas to facilitate efficient standardisation of datasets**

- **Lack of interoperability and data sharing between different European countries or between primary care and hospital data**

- **Inter-operability of software and devices**

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P2: Data quality /P6: Analytics capability

Current monitoring capabilities – challenges (2)

- GDPR and other privacy legislations. Safe anonymization of data. Transfer of data across borders.

- Obtaining patient consent across healthcare sectors and different countries

- Data ownership
- Best model to allow data providers to utilise Big Data Platforms
- Prioritization of research questions

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P5: Process and transparency/P8: Ethics and security/P9: International

Current monitoring capabilities – challenges (3)

- **Infrastructure: data on-boarding; resources to ensure adequate broadband speed and coverage, especially in rural areas or lower income countries**
- **Training of HCPs**

- **Sustainability planning beyond the lifetime of projects; funding for continual or periodic update of the datasets in Big Data platforms**

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P4: Skills/P6: Analytics capability

Prediction/simulation – opportunities

- **Operational definitions for clinical characteristics & phenotypes.**

- **Development of clinical decision-making tools**

- **Better patient selection for therapies**

- **Core outcome sets for disease-specific areas so clinical trials are collecting the relevant information to feed into big data platforms**

- **Prediction of evolution of incidence of certain chronic diseases pandemics (obesity, diabetes, allergy, asthma) worldwide and at regional level**

Prediction/simulation – challenges

Lack of data in many instances

Risk prediction models may not necessarily apply to individual patients (e.g. certain ethnic groups, age groups, patients with comorbidities etc).

Predictive tools are currently poor and at best enrich groups at risk but not yet fulfilled promise of precision medicine

Extraction and categorisation of knowledge - opportunities

- **Standardization and harmonization of data within and between countries**

- **Improved stakeholder engagement**

- **Development of electronic health records and registries in primary care**

- **Rare diseases**

Extraction and categorisation of knowledge - challenges

- Lack of defined operational definitions and coding systems

- Little standardisation for IT architecture, ontologies with some diseases and many terms having no agreed definitions nor units

- Volume and speed

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P2: Data quality/P4: Skills/P6: Analytics capability

Assembling collected knowledge and provision into an informational format (reporting) - opportunities

- **Unbiased dataset for patient & HCP information**

- **Planification and policy making at regional/national level**

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P1: DARWIN/P4: Discoverability

Assembling collected knowledge and provision into an informational format (reporting) - challenges

- **Information overflow and lack of competence on the user side. Conflicting results from the same data**

- **Expertise required**

- **Implementation of results generated into clinical practice**

A big thank you!

European Haematology Association

European Association of Urology

European Society of Cardiology

European Society of Endocrinology

European Respiratory Society

European Geriatric Medicine Society

European Association for Clinical Pharmacology and Therapeutics

European Academy of Allergy and Clinical Immunology

European Union of General Practitioners

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