

ISKO Low Countries Conference “Morsels of Knowledge”
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Information and Data in Allergology

Theoretical and Methodological Proposals to Build a Knowledge Organization Model dedicated to the Design of Info-Communication Devices

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Adam, Polish, 28 years old

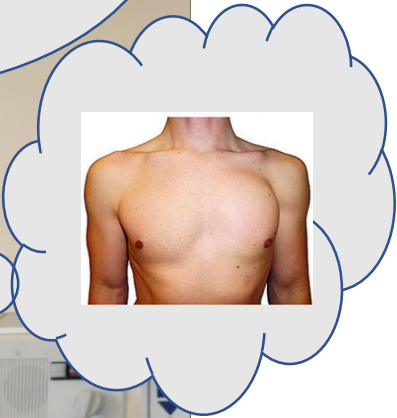




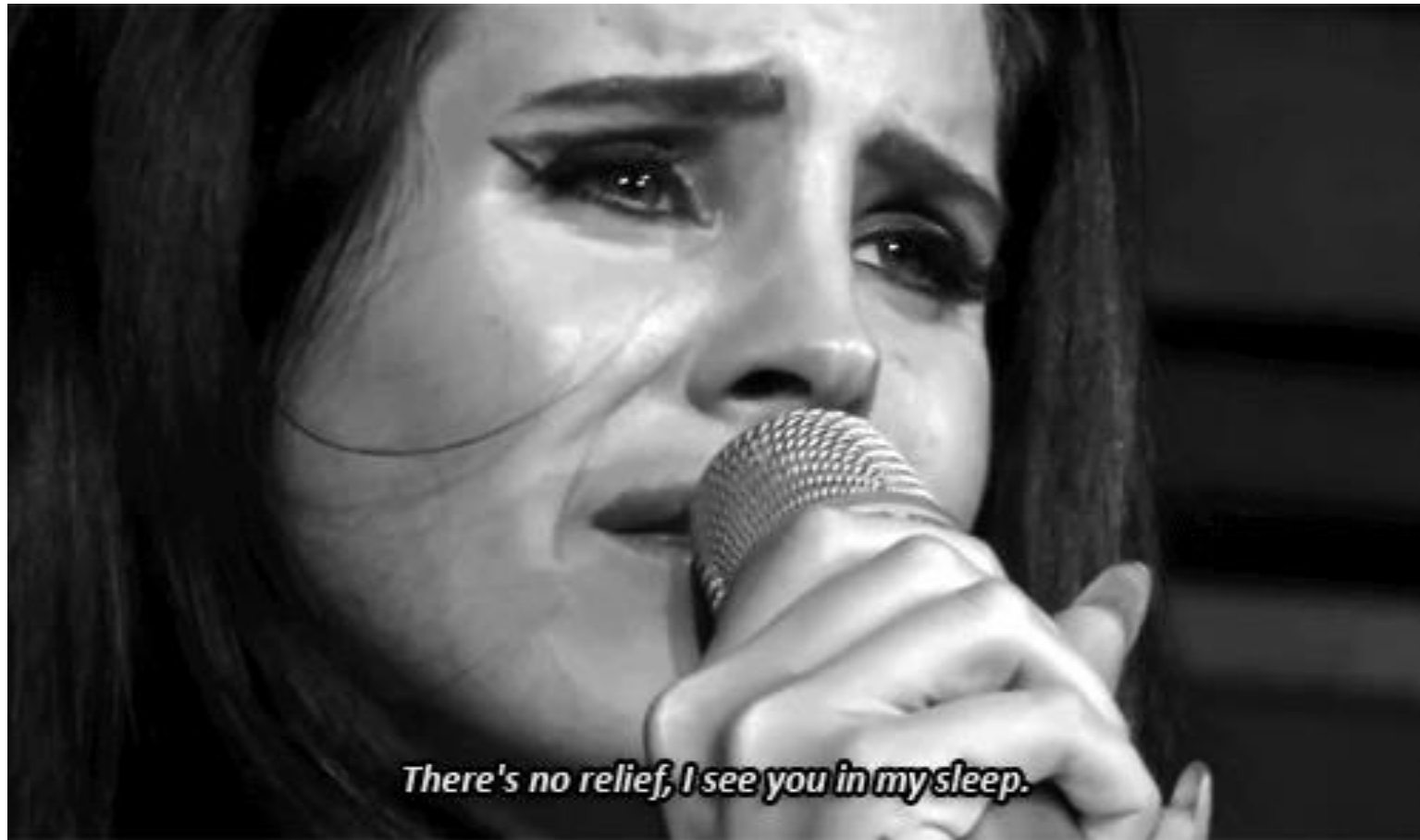
OK doctor!



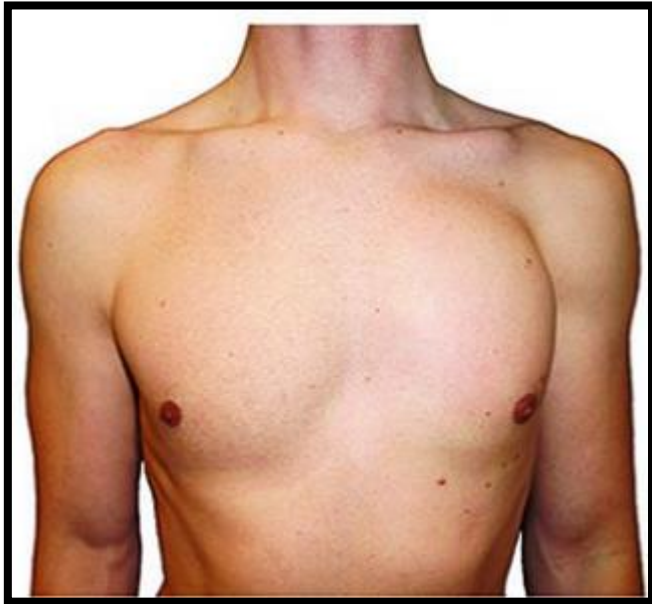
You have the Poland syndrome, Sir!



Adam got well, but never returned to Poland



There's no relief, I see you in my sleep.

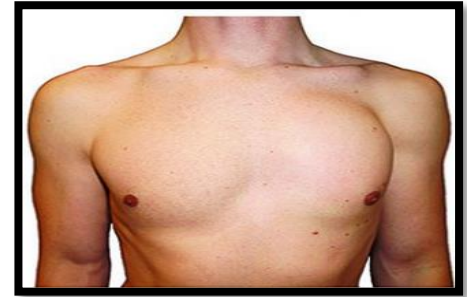


What can we learn from Adam's history?

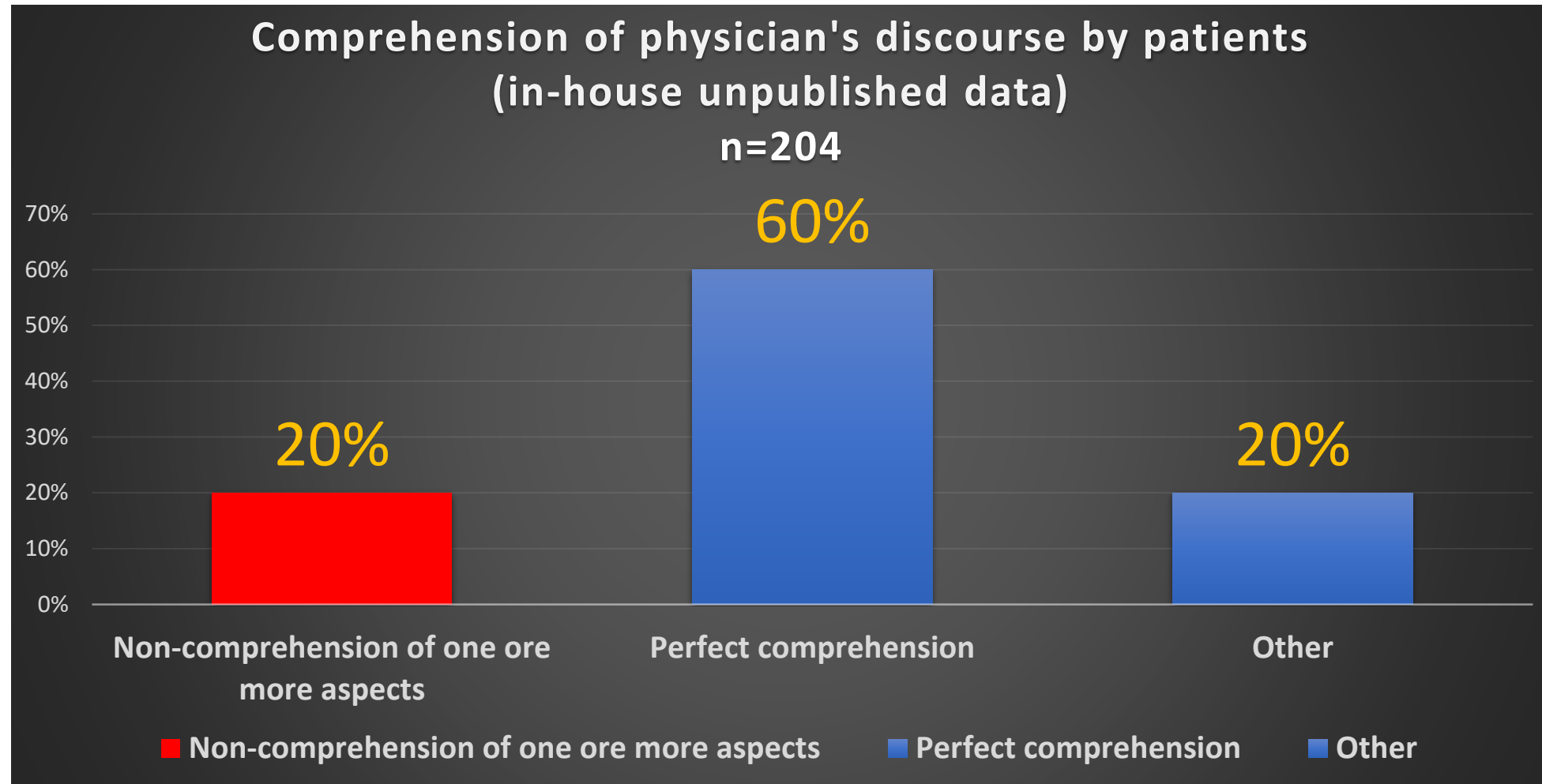
One medical concept may have different meanings and interpretations

A poor communication may have serious consequences in healthcare settings

Poland syndrome



Misunderstandings in Allergy

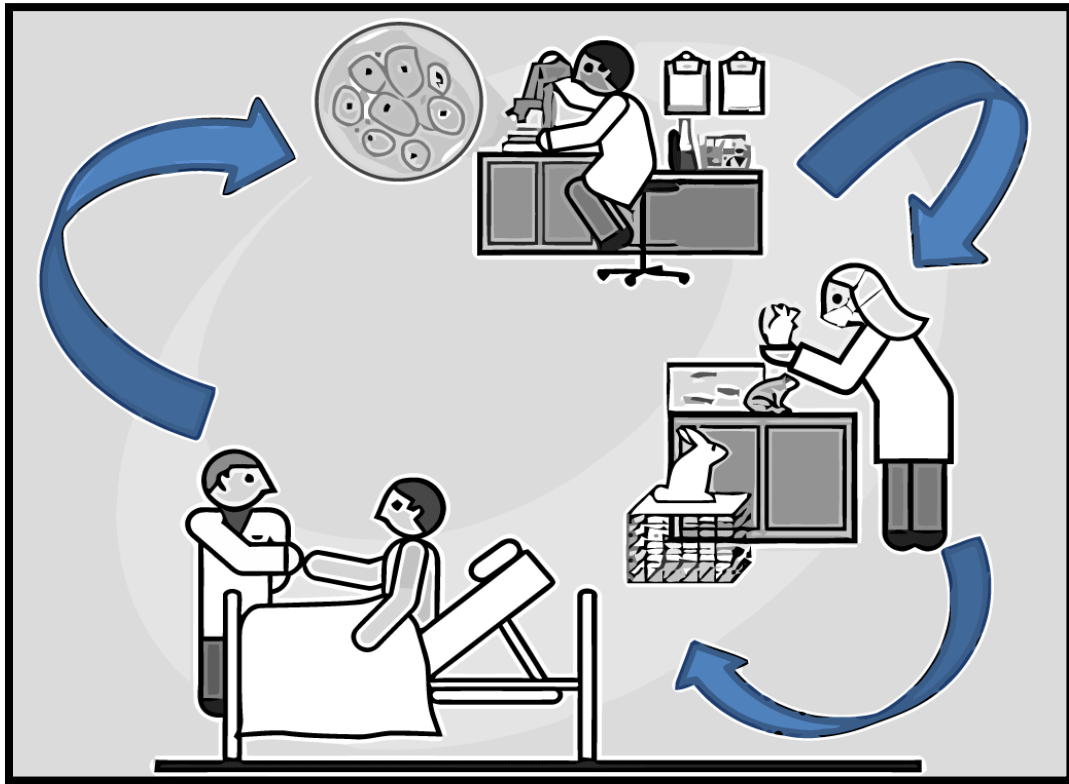


Misunderstandings in Allergology

Major research themes in allergy

- Mechanisms
- Prevention
- Epidemiological surveillance - Registries
- Biomarkers for prediction, diagnosis, classification, treatment response
- Phenotypes / Endotypes
- Severe Disease/Exacerbations
- Novel treatments (biologicals, vaccines, new drugs)

Papadopoulos NG, *et al.* (2012)



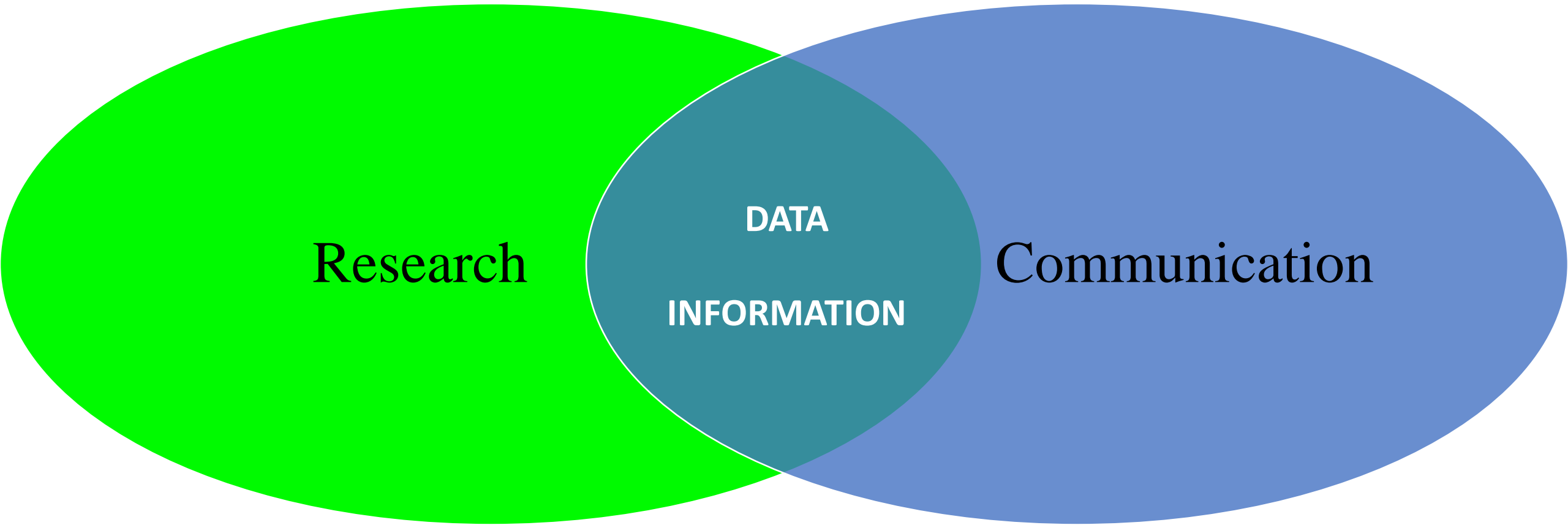
Need for understanding of the 21th century epidemic



Allergy is the most common chronic disease in Europe

Allergic diseases cost EU between 55 and 151 billion € per year

Keywords to improve Allergy prevention and care



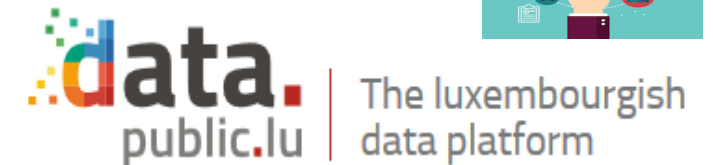
Open data and information in Allergology



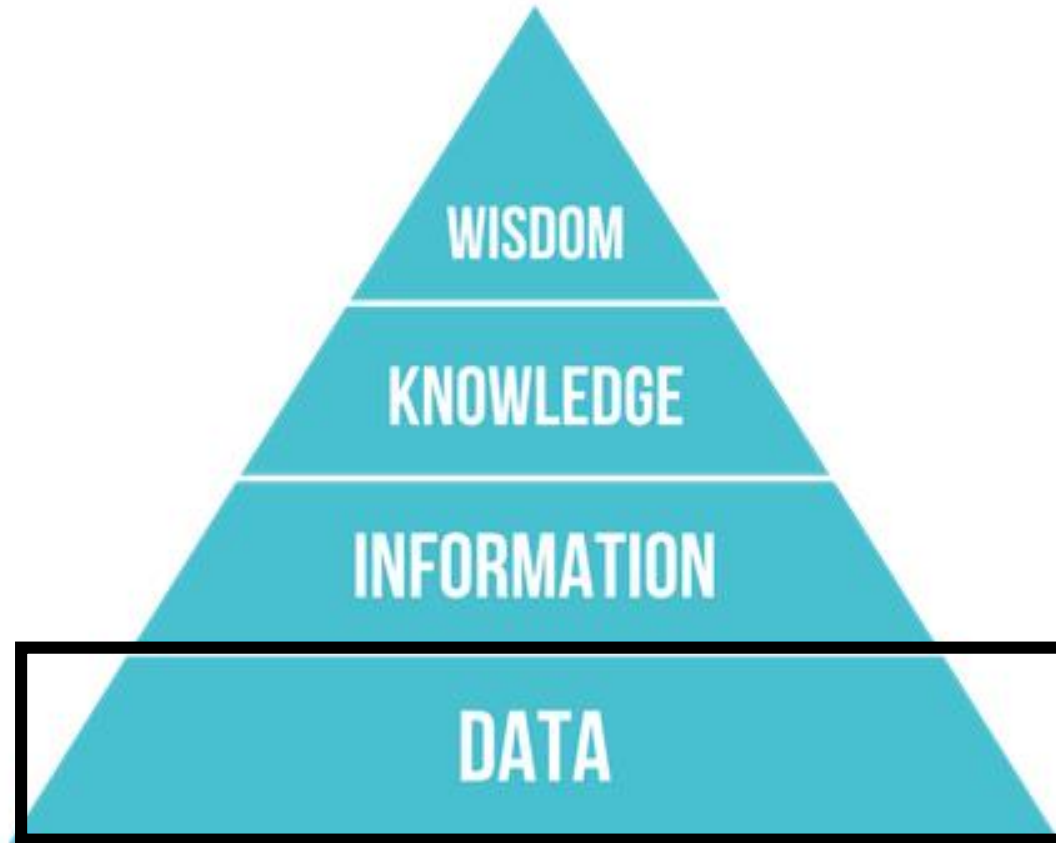
data.gov.fr



Prévision des émissions de pollen de cyprès en régions Languedoc-Roussillon et PACA*



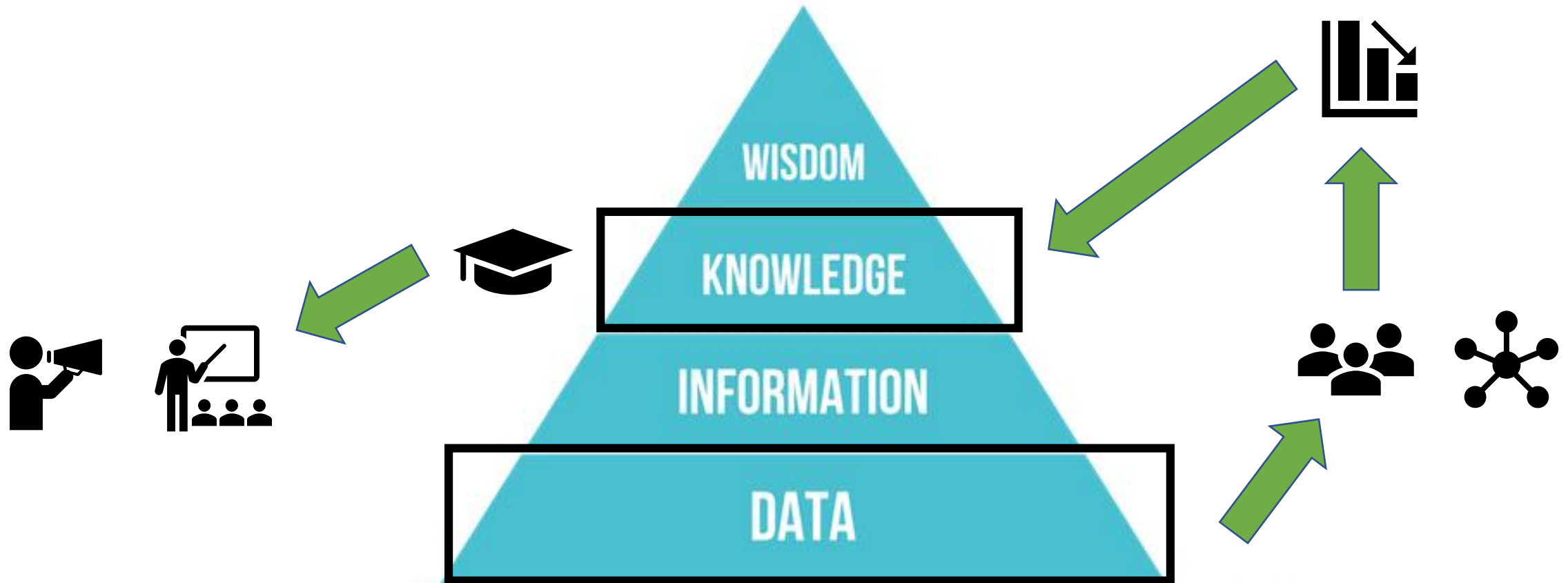
Data in DIKW hierarchy



The Knowledge Pyramid (Wikimedia Commons, by Longlivetheux, CC-BY-SA)

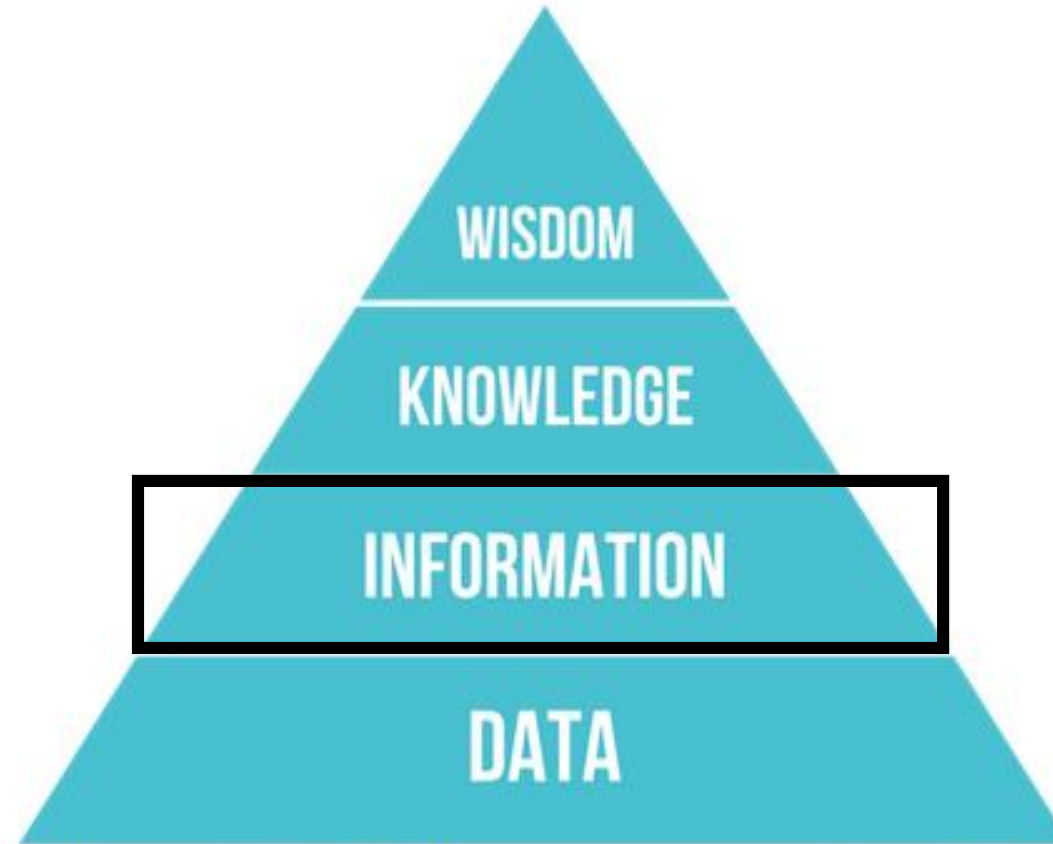
Frické M (2019)

1st strategy: the use of big open data in Allergology



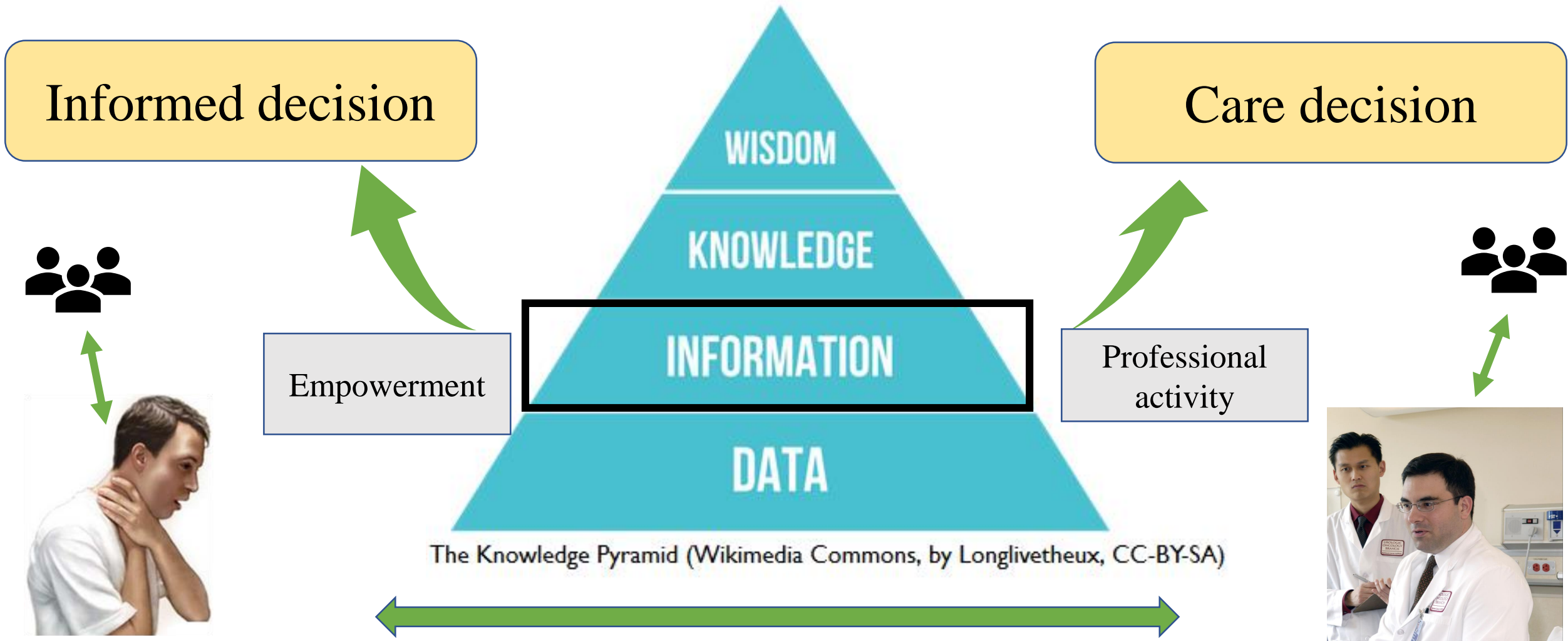
The Knowledge Pyramid (Wikimedia Commons, by Longlivetheux, CC-BY-SA)

Information in DIKW hierarchy



The Knowledge Pyramid (Wikimedia Commons, by Longlivetheux, CC-BY-SA)

2nd strategy: the use of health information in Allergology



Info-communication devices needed in Allergy

Dissemination of information and data

Websites and portals for understanding and learning

Open data repositories

Communication towards allergy actors

Websites and portals

Health applications

Forums

Knowledge management

Knowledge bases for information extraction

Knowledge bases for question answering

Knowledge extraction

Text and data mining tools

Big data analytic tools

Machine learning tools

To build info-com devices in Allergy, we should think before on KOS

Theory must be present at all the levels of data-centric research.

Leonelli (2019)



“Theories are the point of departure of any KOS.”

Hjørland (2015)

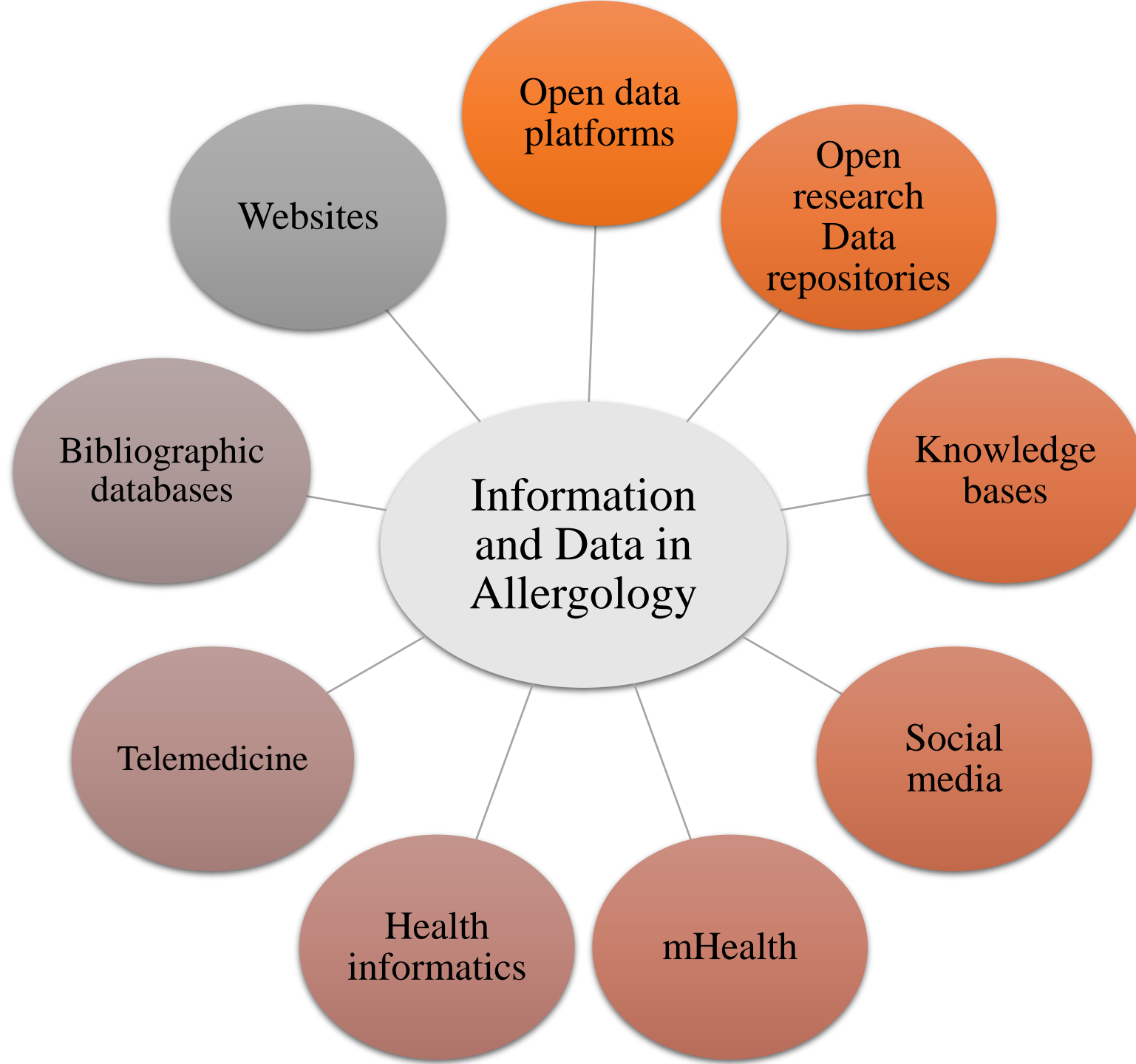
Soergel (2015)

KOSs may unleash the power of data.

Hedden (2016)

KOSs are necessary for information indexing, retrieval, organization and navigation support.

Name of KOS	Allergy Ontology Yu A, <i>et al.</i> (2012)	Allergy information ontology for enlightening people Velmurugan <i>et Ravi</i> (2016)	Allergy Detector II Quevedo (2015)	Allergy in ICD-11 Tanno <i>et al.</i> (2015)
Language	Available only in English	Available only in English	Available only in Spanish	Multilingual
Missing concepts	<ul style="list-style-type: none"> - Predisposition - Management - Patient 	<ul style="list-style-type: none"> - Predisposition - Several divisions seem to not respond to current scientific theories 	<ul style="list-style-type: none"> - Allergic diseases - Predisposition - Diagnosis interventions - Management - Patient 	<ul style="list-style-type: none"> - Predisposition - Diagnosis interventions - Management - Patient
Management of heterogeneity of allergy-concept representation	X	X	X	X
Access	?	?	Free	UMLS license



Heterogeneity of the forms and formats of documents

Sheets

Free texts

Images

Videos

Genomic sequences



Heterogeneity of the information at the level of the terminology

Physician's terms

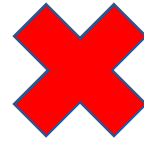
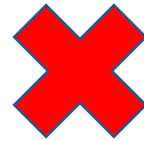
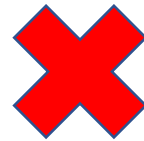
rhinite allergique

asthme allergique

médicaments

antihistaminique

salbutamol



Patient's terms

rhume des foins

asme

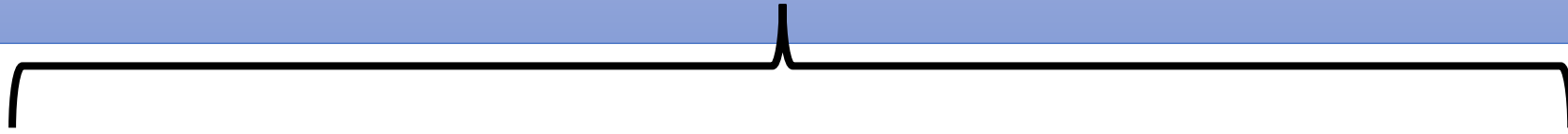
medocs

Cétirizine

Ventoline

Name of KOS	Allergy Ontology <i>Yu A et al. (2012)</i>	Allergy information ontology for enlightening people <i>Velmurugan et Ravi (2016)</i>	Allergy Detector II <i>Quevedo (2015)</i>	Allergy in ICD-11 <i>Tanno et al. (2015)</i>
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Management of heterogeneity of allergy-concept representation	X	X	X	X
Access	?	?	Free	UMLS license

Knowledge Organization Model (KOM) of Allergy



Predisposition

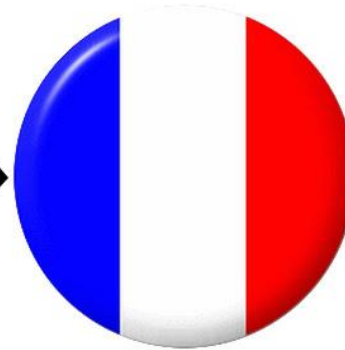
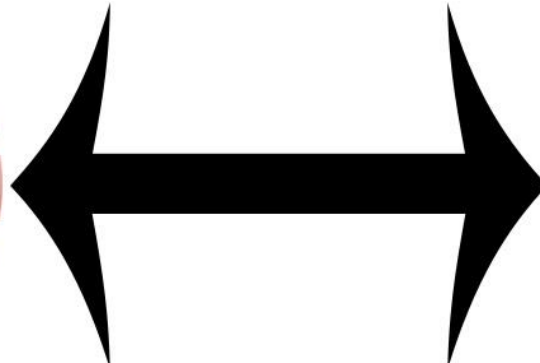
Diagnosis

Symptoms

Management

Patient

Types



Concepts that will be developed in future KOM of Allergy

Future management of heterogeneity of the information at the level of the terminology

Physician's terms

Patient's terms

rhinite allergique



rhume des foins

asthme allergique



asme

médicaments



medocs

antihistaminique



Cétirizine

salbutamol



Ventoline

Methodology to build a Knowledge Organization Model of Allergy

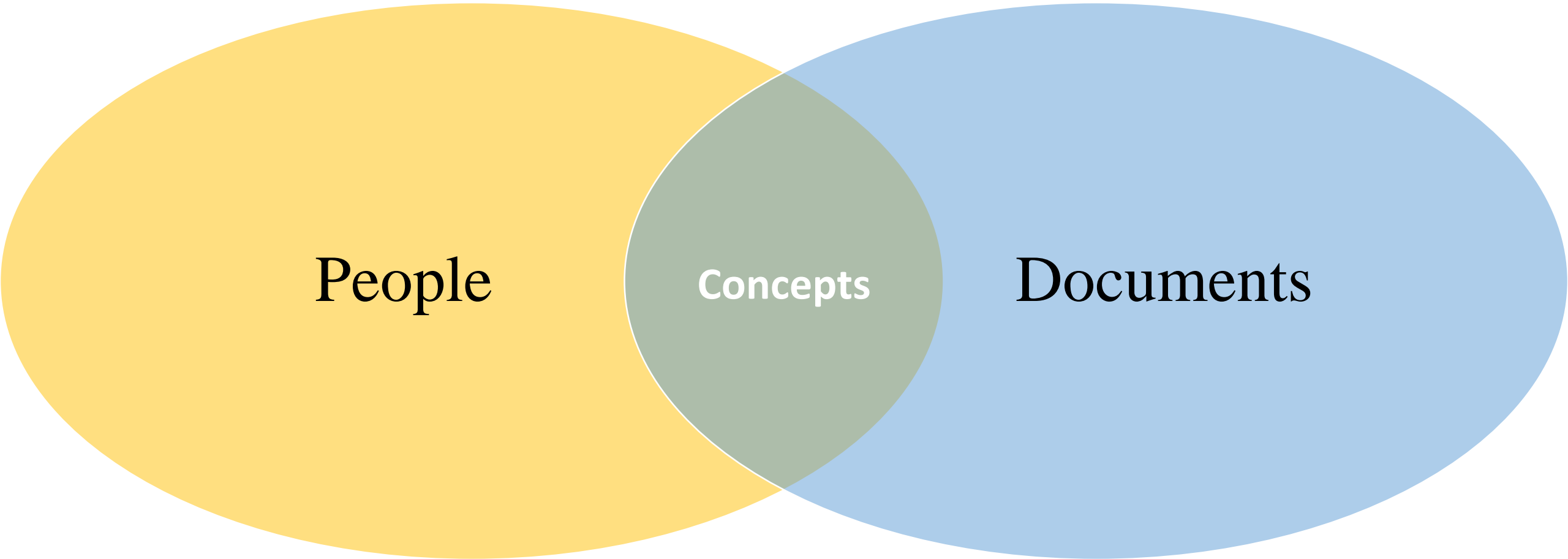
α	reality in itself	mysticism
β	phenomena	ontology
γ	perspectives	epistemology
δ	documents	bibliography, epigraphy etc.
ε	collections	library, archive and museum science
ζ	information needs	cognitive and information science
η	people	sociology

Table 1. Dimensions of knowledge organization and corresponding fields

Dimensions of KO	Questions to answer before gathering concepts
Phenomena	<i>e.g.</i> Which phenomena exist in Allergology?
Perspectives	<i>e.g.</i> What are current theories in Allergology?
Documents	<i>e.g.</i> Which documents can provide concepts and their different representations ?
Collections	<i>e.g.</i> What type of collections have to be organized?
Information needs	<i>e.g.</i> What are info-communication expectations and needs of Allergy community?
People	<i>e.g.</i> What are their representations of allergy-related knowledge?

Dimensions of KO	Principes
Phenomena	<p data-bbox="1116 376 1582 458">Warrants:</p> <ul data-bbox="996 501 2040 1143" style="list-style-type: none"><li data-bbox="996 501 2040 582">• Scientific & educational<li data-bbox="996 615 1498 696">• Academic<li data-bbox="996 729 1498 811">• Epistemic<li data-bbox="996 843 1416 925">• Literary<li data-bbox="996 958 1676 1039">• Organizational<li data-bbox="996 1072 1294 1143">• User
Perspectives	
Documents	
Collections	
Information needs	
People	

Identifying concepts



Content as a source of concepts

Content analysis of current documentation

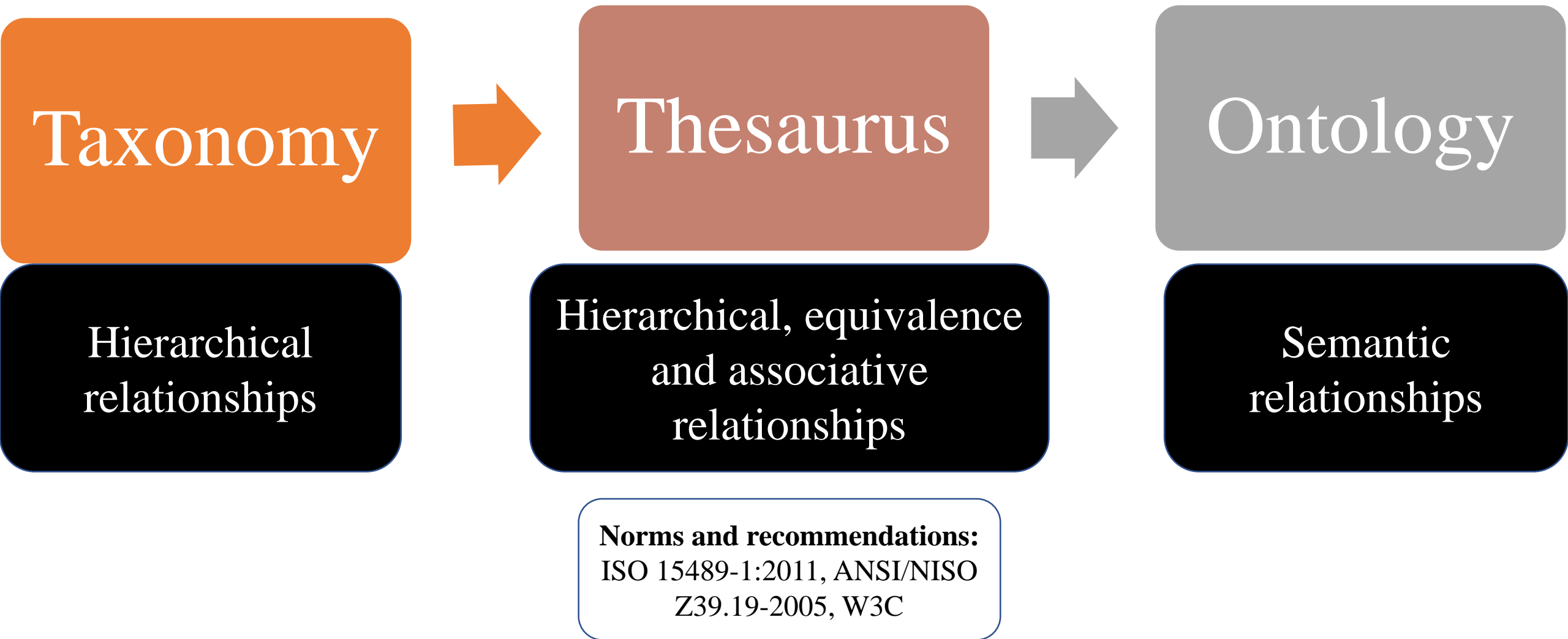
Content analysis of EHR and social media

People as a source of concepts

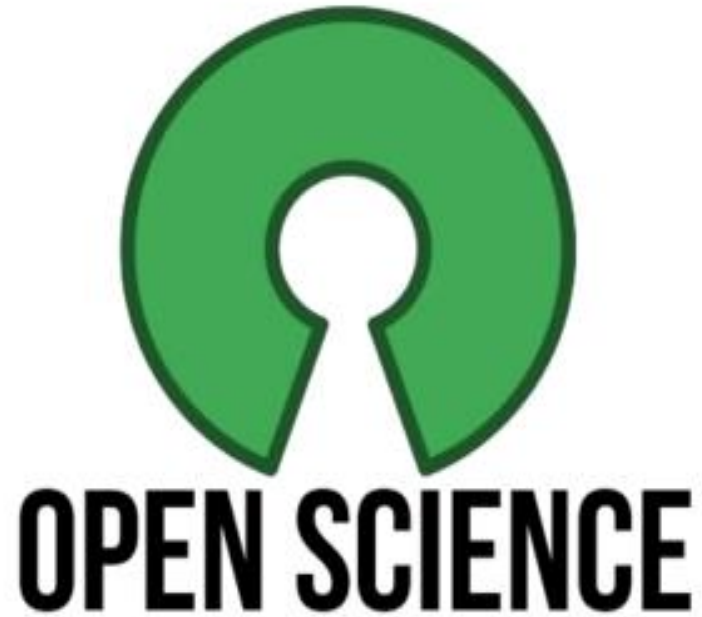
Questionnaire survey to gather concepts and terms

Consultation of allergology experts to validate concepts and terms

Steps into a KOM of Allergy



KOM of Allergy available in open access



*Plan national pour la science
ouverte (2018)*



Evaluation

Automatic term recognition

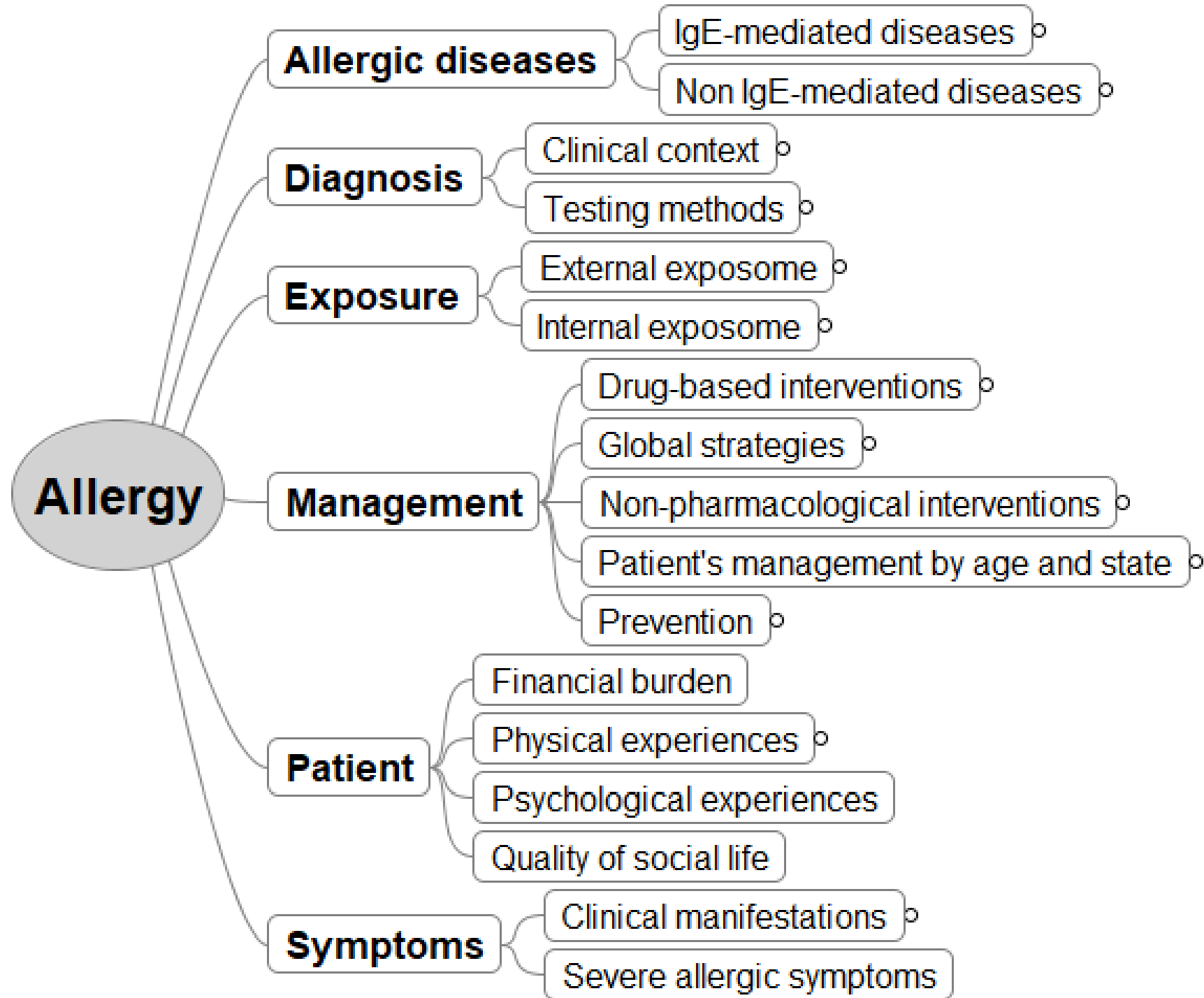
Raad J, Cruz C (2015)

- Recognize Allergy-related terms in texts
- Compare the score of KOM with scores obtained by KOSs golden standard

Survey interview

Information-Communication
Approach

- See how the KOM integrates everyday practices of allergy actors
- See how the KOM integrates info-com devices



First ideas: Allergy taxonomy draft

First findings

Labels for concepts	KOM Terms
Preferred term	rhinite allergique
Non-preferred terms	SYNONYMS: rhume des foins, allergie au pollen, fièvre des foins, allergie pollen, rhinite due au pollen, allergie saisonnière, rhinite INCORRECT TERMS: rhinittes, rhinites, rinithe, rhinites allergiques, rinite, rhum de foin
Broader terms	allergie, allergie respiratoire, réaction allergique respiratoire
Narrower terms	rhinoconjunctivite allergique
Foreign language terms	allergic rhinitis

ALLERGIDOC staff



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References (1)

- 1) Alvarez-Perea *et al.* (2019). Impact of eHealth in Allergic Diseases and Allergic Patients. *J Investig Allergol Clin Immunol* 29, no. 2:35.
- 2) *ANSI/NISO Z39.19-2005 Guidelines for the Construction, Format, and Management of Monolingual Controlled Vocabularies.*
- 3) Barité M (2018). Literary warrant, *Knowledge Organization* 45, no. 6:517-536.
- 4) Couzinet V (2009). Introduction. Dispositifs info-communicationnels : contributions à une définition. In : *Dispositifs Infocommunicationnels : questions de médiations documentaires*, (dir.) Couzinet V. Paris : Hermès science publications:19-30.
- 5) EAACI (2015). Advocacy Manifesto: Tackling the Allergy Crisis in Europe – Concerted Policy Action Needed.
- 6) Frické M (2019). The knowledge pyramid: the DIKW hierarchy. *Knowledge Organization* 49, no. 1:33-46.

References (2)

- 7) Gnoli C (2016). Classifying Phenomena Part 1: Dimensions. *Knowledge Organization* 43, no. 6:403-415.
- 8) Hedden H (2016). *Accidentally Taxonomist*. Medford New Jersey: Information Today, Inc.
- 9) Hjørland B (2015). Theories of Knowledge Organization – Theories of Knowledge, *Knowledge Organization* 40, no. 3:169-181.
- 10) *ISO 15489-1:2011 Information et documentation – Thesauri and interoperability with other vocabularies -- Thesauri for information retrieval*.
- 11) Leonelli S (2019). *La recherche scientifique à l'ère des Big Data. Cinq façons dont les Big Data nuisent à la science et comment la sauver*. Sesto S. Giovanni: Éditions MIMESIS.
- 12) Papadopoulos NG *et al.* (2012). Research needs in allergy: an EAACI position paper, in collaboration with EFA. *Clin Transl Allergy* 2, no. 1:21.

References (3)

13) Ministère de l'Enseignement Supérieur de la Recherche et de l'Innovation (2018). *Plan national pour la science ouverte*. Available at: https://cache.media.enseignementsup-recherche.gouv.fr/file/Actus/67/2/PLAN_NATIONAL_SCIENCE_OUVERTE_978672.pdf.

Accessed 10 April 2019.

14) Quevedo N (2015). Allergy Detector II. Available at: <https://bioportal.bioontology.org/ontologies/ALLERGYDETECTOR>. Accessed 28 June 2019.

15) Raad J, Cruz C (2015). A Survey on Ontology Evaluation Methods. *Proceedings of the International Conference on Knowledge Engineering and Ontology Development*. 7th International Joint Conference on Knowledge Discovery, Knowledge Engineering and Knowledge Management, November 2015, Lisbon.

16) Soergel D (2015). Unleashing the Power of Data Through Organization: Structure and Connections for Meaning, Learning and Discovery. *Knowledge Organization* 42, no. 6:401-427.

References (4)

- 17) Soergel D, Tse T, Slaughter L (2004). Helping Healthcare Consumers Understand: An “Interpretative Layer” for Finding and Making Sense of Medical Information. In: *Proceedings of the International Medical Informatics Association's Conference (IMIA) 2004*:931-935.
- 18) Tanno LK, Calderon MA, Goldberg BJ, Gayraud J, Bircher AJ, Casale T, Li J, Sanchez-Borges M, Rosenwasser LJ, Pawankar R, Papadopoulos NG, Demoly P (2015). Constructing a classification of hypersensitivity/allergic diseases for ICD-11 by crowdsourcing the allergist community. *European Journal of Allergy and Clinical Immunology* 70, no. 6:609-615.
- 19) Trzmielewski M, Caimmi D, Tanno LK, Ferrando L, Ducarteron D, Demoly P (2019). What did the doctor say? Patients’ comprehension of allergy consultations in a French university hospital. *WAO Journal*. [In press]
- 20) Velmurugan A, Ravi T (2016). Allergy Information Ontology for Enlightening People. In: *2016 International Conference on Computing Technologies and Intelligent Data Engineering (ICCTIDE’16)*, Kovilpatti, India.

References (5)

- 21) W3C Wide Web Consortium (2012,1). SKOS Simple Knowledge Organization System Reference. Available at: <https://www.w3.org/TR/2009/REC-skos-reference-20090818>. Accessed 18 June 2019.
- 22) W3C Wide Web Consortium (2012, 2). OWL Web Ontology Language Primer (Second Edition). Available at: <https://www.w3.org/TR/.owl2-primer>. Accessed 18 June 2019.
- 23) Yu A, Smith B, Schwartz S (2012). Formal and Computable Representations of Allergic Diseases in the Electronic Health Record: An Approach Based on the Ontology of General Medical Science. In: *Annual Meeting of the American College of Allergy, Asthma & Immunology (ACAAI) 2012*, Anaheim, USA.

Images & photos (1)

- Slide no. 2
 - Wikipedia. Map indicating locations of United Kingdom and Poland. Available at: https://en.wikipedia.org/wiki/Poland%E2%80%93United_Kingdom_relations#/media/File:United_Kingdom_Poland Locator.png. Accessed 17 June 2019.
 - Careers in Poland. Polish wedding guide. Available at: <https://www.careersinpoland.com/article/free-time/polish-wedding-guide>. Accessed 17 June 2019.
- Slide no. 3
 - Anatomic Modeling. Behandlung des Poland-Syndroms. Available at: <https://www.anatomikmodeling.com/de/Behandlung-poland-syndrome>. Accessed 17 June 2019.
 - Wikimedia. Doctor consults with patient. Available at: [https://upload.wikimedia.org/wikipedia/commons/6/64/Doctor_consults_with_patient_\(4\).jpg](https://upload.wikimedia.org/wikipedia/commons/6/64/Doctor_consults_with_patient_(4).jpg). Accessed 17 June 2019.

Images & photos (2)

- Slide no. 4
 - Rebloggy. gif celebrities sadness lana del rey sorrow. Available at: <http://rebloggy.com/post/gif-celebrities-sadness-lana-del-rey-sorrow/75908110696>. Accessed 17 June 2019.
- Slide no. 5
 - Wikimedia. Alfred Poland. Available at: https://upload.wikimedia.org/wikipedia/commons/8/88/Alfred_Poland_Photo.jpg. Accessed 18 June 2019.
 - Wikimedia. Flag of Poland. Available at: https://upload.wikimedia.org/wikipedia/en/thumb/1/12/Flag_of_Poland.svg/1200px-Flag_of_Poland.svg.png. Accessed 17 June 2019.
- Slide no. 6
 - Parole d'enfants. Doser la relation : entre « bonne distance » et juste présence. Available at: http://www.parole.be/actes/doser_la_relation.pdf. Accessed 01 June 2019.

Images & photos (3)

- Slide no. 8
 - EUPATI. [Research in medicine]. Available at: <https://3qksc436bu713cqimwcfglyj-wpengine.netdna-ssl.com/wp-content/uploads/2015/07/translational-medicine-v1.png>. Accessed 17 June 2019.
- Slide no. 9
 - BuzzFeed. 31 Allergic Reactions That Actually Hurt to Look At. Available at: <https://www.buzzfeed.com/carolinekee/crazy-allergic-reactions-from-everyday-things>. Accessed 17 June 2019.
 - Clodinary. [Fatigue]. Available at: https://res.cloudinary.com/people-matters/image/upload/q_auto,f_auto/v1512924297/1512924295.jpg. Accessed 17 June 2019.
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