Misinformation in Atopic Dermatitis and Digital Tools to address it

Objective: To have a better understanding of how misinformation affects
AD management and how to address it

Pr. Jean-François STALDER

Emeritus Professor. Nantes University Hospital. Nantes, France.

jfstalder@mac.com

Fanny SENTENAC

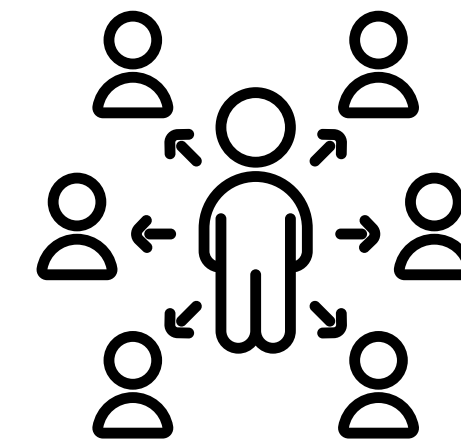Expert Patient and Eczema France President. Toulouse, France.

www.eczemafrance.fr / contact@eczemafrance.fr

Medical misinformation: a worrying online phenomenon

Social medias are a megaphone

Health-related misinformation often circulates rapidly and globally via platforms like TikTok, Instagram, and Reddit.
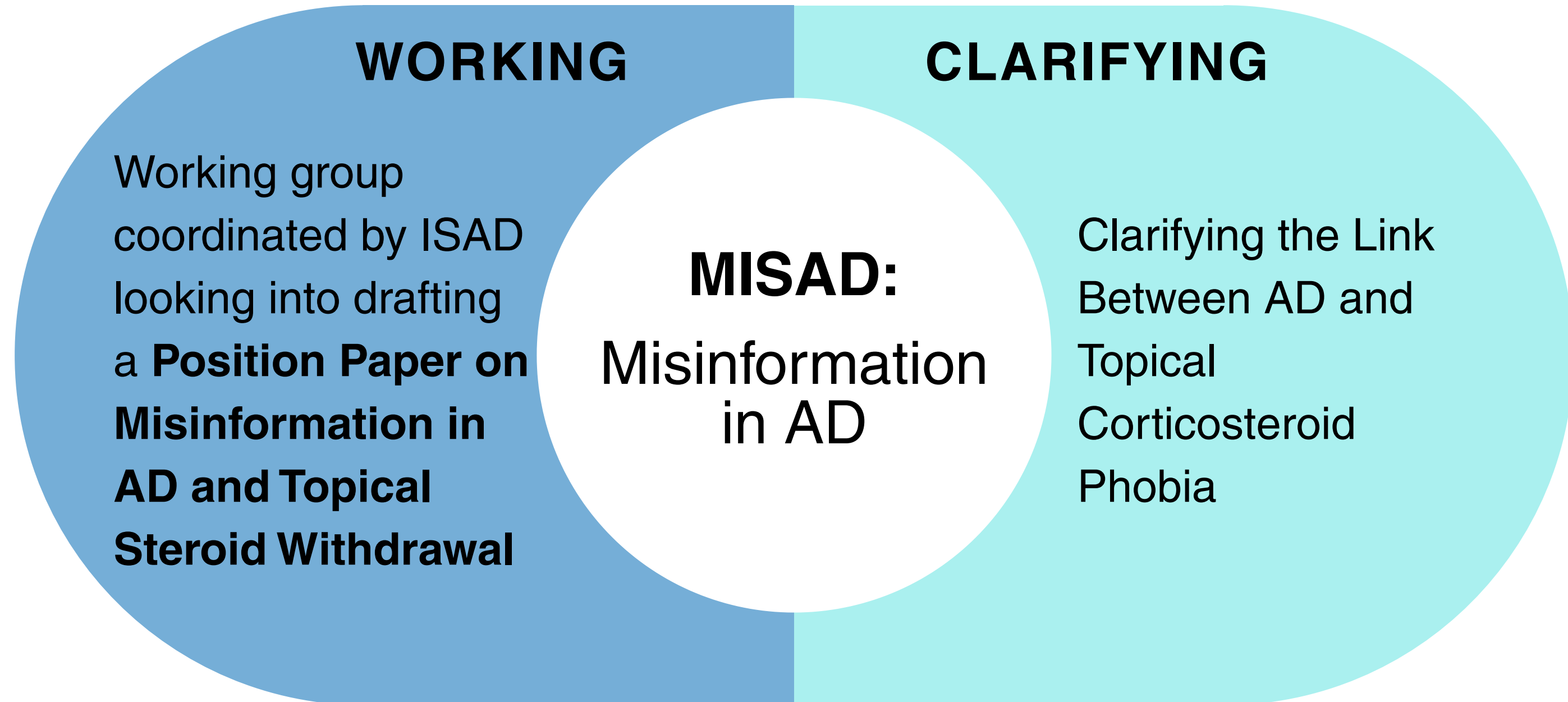
YouTube and X (Twitter) are super-spreaders

A small group of ~800 Twitter superspreaders accounted for ~35% of all retweets of low-credibility misinformation.

References:
- WHO https://www.who.int/news-room/questions-and-answers/item/disinformation-and-public-health
- Pierri F, DeVerna MR, Yang KC, Axelrod D, Bryden J, Menczer F. One Year of COVID-19 Vaccine Misinformation on Twitter: Longitudinal Study. J Med Internet Res. 2023 Feb 24;25:e42227. doi: 10.2196/42227. PMID: 36735835; PMCID: PMC9970010.

WORKING

CLARIFYING

Working group coordinated by ISAD looking into drafting a **Position Paper on Misinformation in AD and Topical Steroid Withdrawal**

MISAD:

Misinformation in AD

Clarifying the Link Between AD and Topical Corticosteroid Phobia

References:

- Pediatric Topical Steroid Withdrawal Syndrome: Kripa Ahuja and Peter Lio
- What Is Known, What Is Unknown Pediatric Dermatology, 2024; 0:1–7

Misinformation on social medias: a vicious circle of causes and consequences

Erosion of trust:

- Mistrust in medical professionals and institutions.
- Accumulation of bad experiences, not being heard (gaslighted) in one's feelings and patient knowledge.

Induction of psychological vulnerabilities :

- confirmation bias
- lack of media literacy
- belief in anecdotal evidence
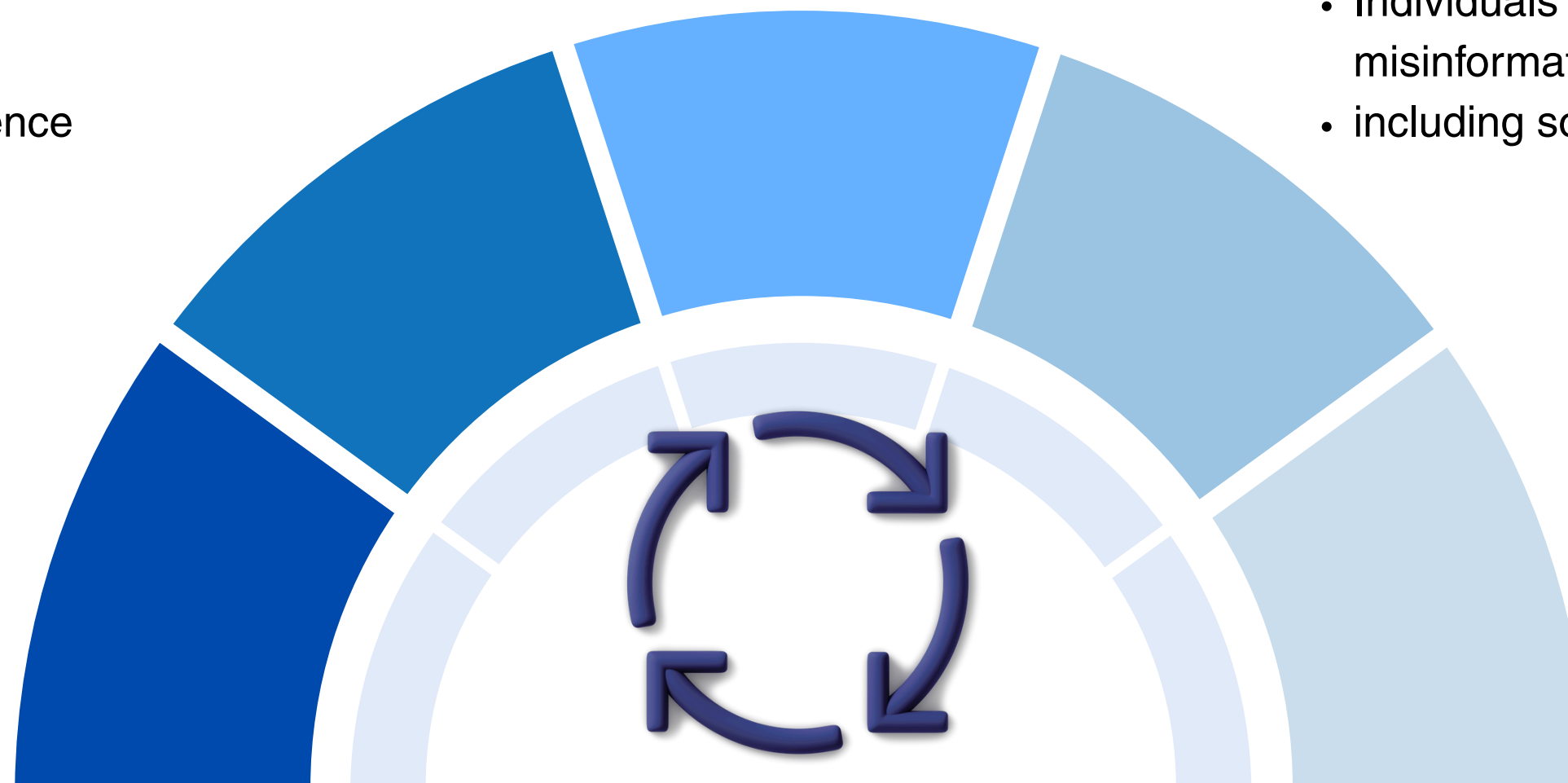
Monetization of falsehoods :

- Individuals or groups may profit from misinformation through ad revenue, donations
- including social medias themselves
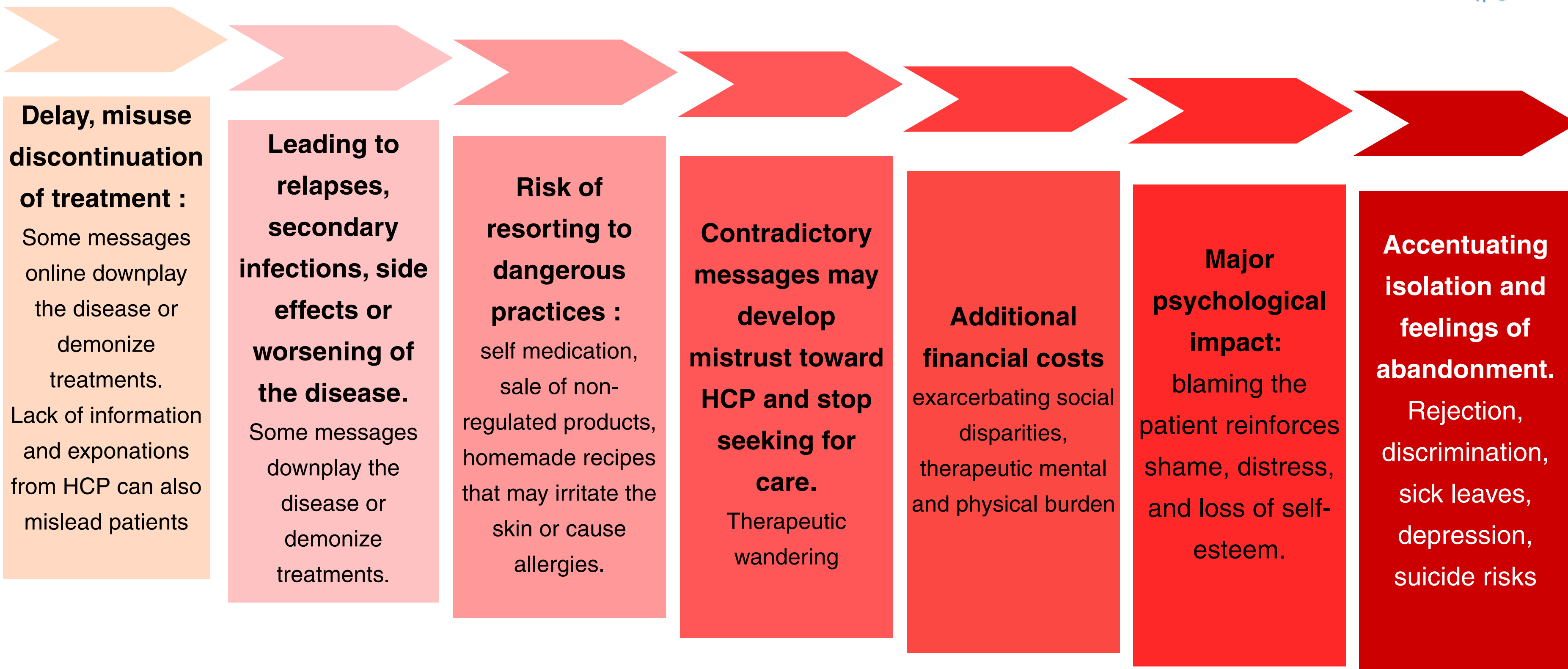
Social media architecture :

- Algorithms prioritize engagement *(frequency, trends, generating reactions)*
- Regardless of truth (no sources)
- Amplifying controversial, sensational or emotionally charged content (fear is powerful)
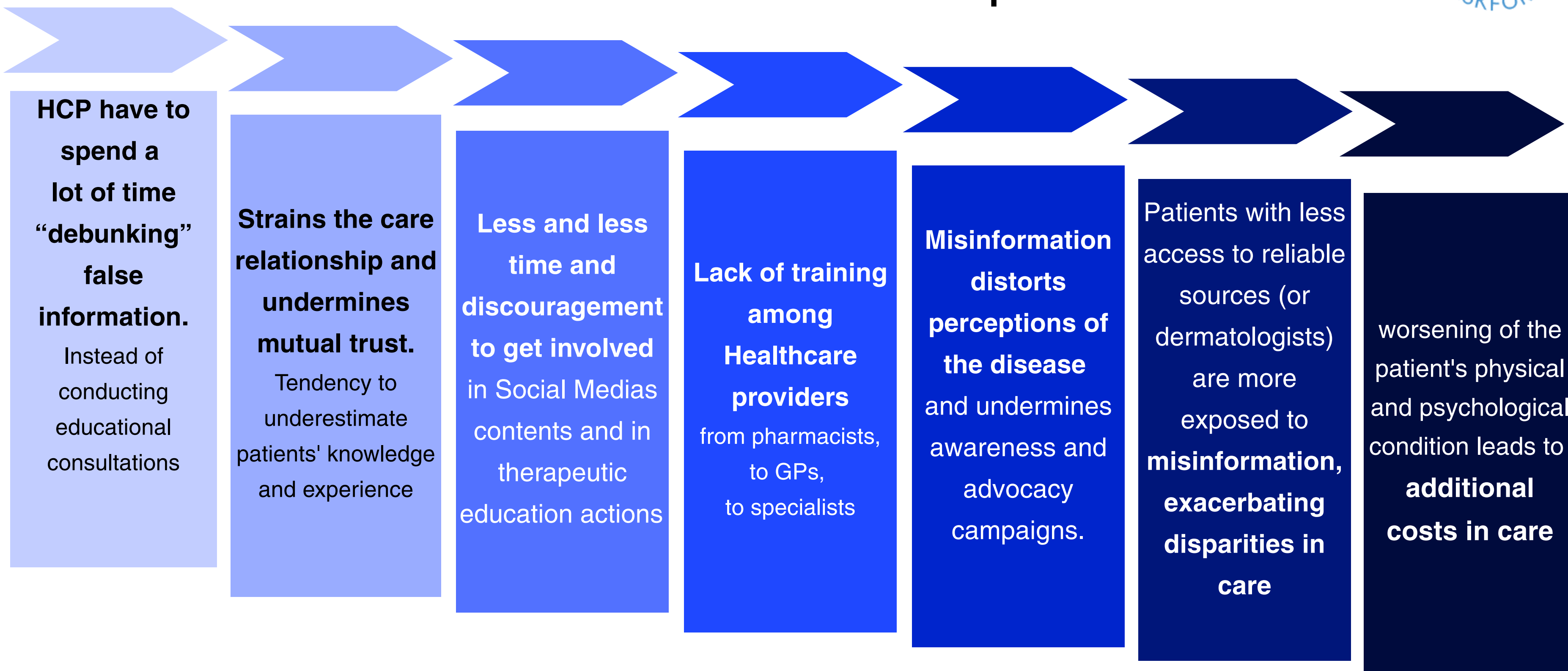
Historical persistence:

- False claims—like the debunked theory linking MMR vaccines to autism—have a lasting impact despite retraction and correction
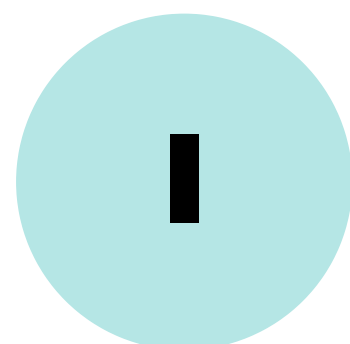
Risk of misinformation for patients

Delay, misuse discontinuation of treatment :
Some messages online downplay the disease or demonize treatments.
Lack of information and exponations from HCP can also mislead patients

Leading to relapses, secondary infections, side effects or worsening of the disease.
Some messages downplay the disease or demonize treatments.

Risk of resorting to dangerous practices :
self medication, sale of non-regulated products, homemade recipes that may irritate the skin or cause allergies.

Contradictory messages may develop mistrust toward HCP and stop seeking for care.
Therapeutic wandering

Additional financial costs
exarcerbating social disparities, therapeutic mental and physical burden

Major psychological impact:
blaming the patient reinforces shame, distress, and loss of self-esteem.

Accentuating isolation and feelings of abandonment.
Rejection, discrimination, sick leaves, depression, suicide risks

Risk of misinformation for HCP and public health

HCP have to spend a lot of time "debunking" false information. Instead of conducting educational consultations

Strains the care relationship and undermines mutual trust. Tendency to underestimate patients' knowledge and experience

Less and less time and discouragement to get involved in Social Medias contents and in therapeutic education actions

Lack of training among Healthcare providers from pharmacists, to GPs, to specialists

Misinformation distorts perceptions of the disease and undermines awareness and advocacy campaigns.

Patients with less access to reliable sources (or dermatologists) are more exposed to **misinformation, exacerbating disparities in care**

worsening of the patient's physical and psychological condition leads to **additional costs in care**

Mitigation strategies : I.M.P.A.C.T
fight misinformation with reliable information

ISAD — INTERNATIONAL SOCIETY OF ATOPIC DERMATITIS

ISad-OPened TASKFORCE

I — INFORM

Create reliable, evidence-based content to strengthen confidence and understanding of the disease and treatments.

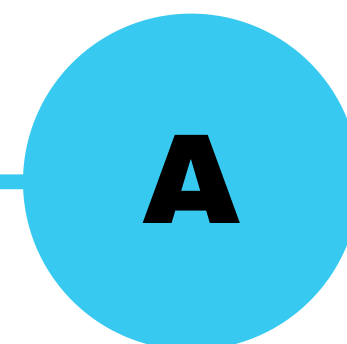Empower patients to help them make informed health choices

M — MOBILIZE

Bringing together patients, caregivers, patient organizations, content creators, and institutions around a common goal: accurate information that is accessible to all.
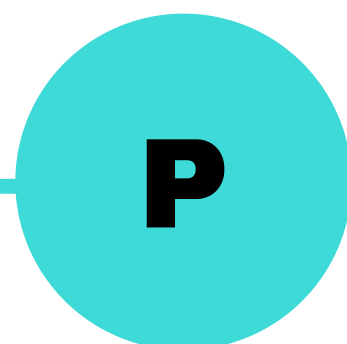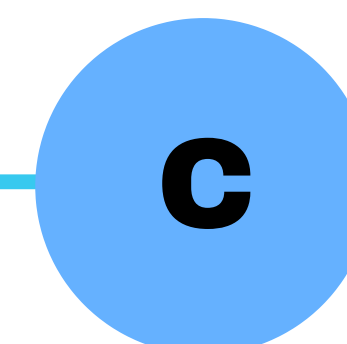
P — PROMOTE

Highlight credible sources, best practices, and positive initiatives related to skin health.

A — ACT

Develop concrete actions in the field and online: awareness campaigns, workshops, training sessions, discussion groups.
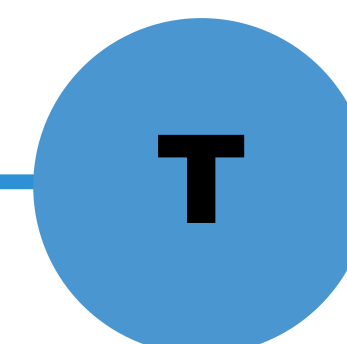Engage on social medias

Report fake news and problematic information without sources

C — CO-BUILD

Work together to create appropriate tools and messages, drawing on the complementary expertise of patients/caregivers and HCP

No patient centricity without patient involvement at every stages

T — TRAIN

Patients: large-scale therapeutic education online, outside hospital walls.
Peer support groups

HCP : training, awareness-raising, and support at all levels (pharmacists, general practitioners, specialists), strenghten listening skills and educational posture.