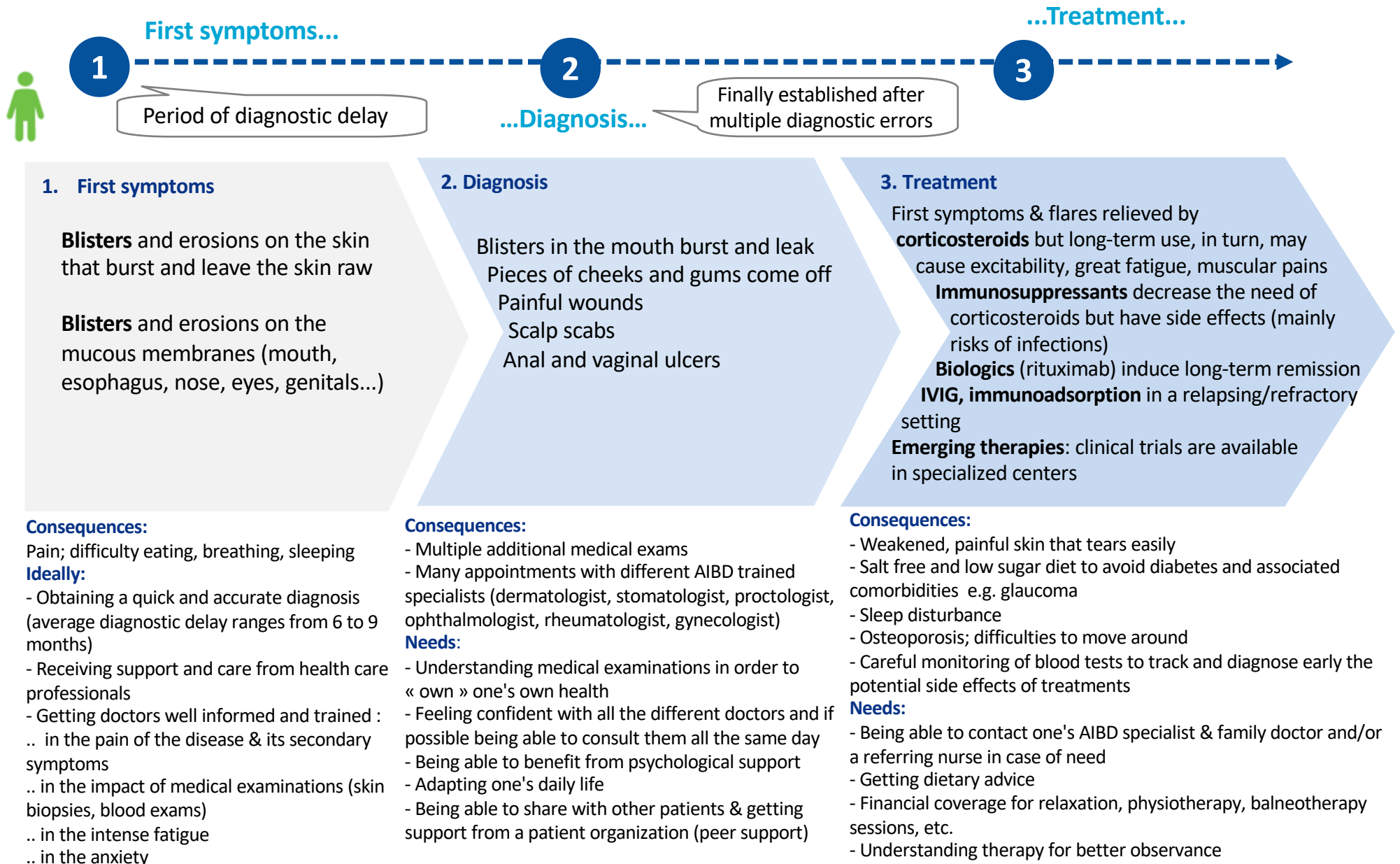


Pemphigus Vulgaris (auto-immune blistering disease - AIBD)

PATIENT JOURNEY

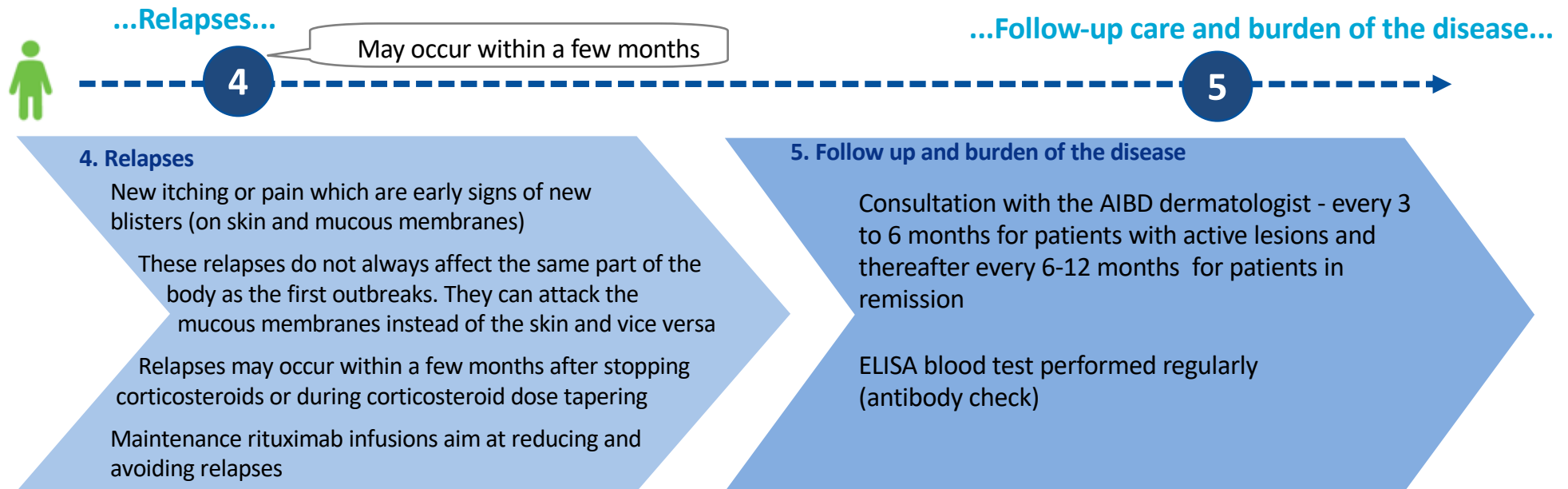
A rare skin and or mucous membrane autoimmune disease that affects people of all ages but primarily those over 50



Pemphigus Vulgaris (auto-immune blistering disease - AIBD)

PATIENT JOURNEY

A rare skin and or mucous membrane autoimmune disease that affects people of all ages but primarily those over 50



Consequences:

- Figuring out how many new blisters it takes, in a given time, to consider it a relapse and notify doctors
- Learning to know how to recognize a relapse if it is located in a place that has not been affected previously

Needs:

- Having the possibility to contact the specialist doctor or a referring person in order to know if the relapse is minor and only requires monitoring, or, if a quick consultation with an AIBD trained specialist (dermatologist, ENT specialist, gynecologist, dentist, etc.) is needed
- For patients who have received rituximab as a first-line treatment, understanding why the dermatologist suggests a preventive infusion if necessary or just regular monitoring

Consequences:

- Skin & mucous membranes remain fragile even after the disappearance of blisters & lesions
- Risk of bacterial or viral superinfections
- Other people's gaze - self-image; deterioration of intimate life
- Administrative problems related to the disease (difficulty in obtaining loans; additional costs from private insurance companies)
- Difficulty in combining work, family life and personal life
- Financial problems, outstanding balances due to out of cost care
- Organisation of arrangements if travelling abroad

Needs:

- Getting support from administrative medical staff
- Getting support from occupational physicians
- Keeping medical records in case of emergencies or relapses while away from home
- Getting help with household chores
- Getting support from official patient organizations (peer support)

This patient journey represents the collective patients perspective and experience, and, was prepared by the ERN SKIN AIBD ePAG representative from France with the help of the Italian, UK and German patient groups and in cooperation with the ERN SKIN AIBD doctors.

For more information and a detailed version, please contact us: coordination@ern-skin.eu