

The intersection of psychology and medicine : how patient reported outcome measures (PROMs) can influence research, practice, and policy.

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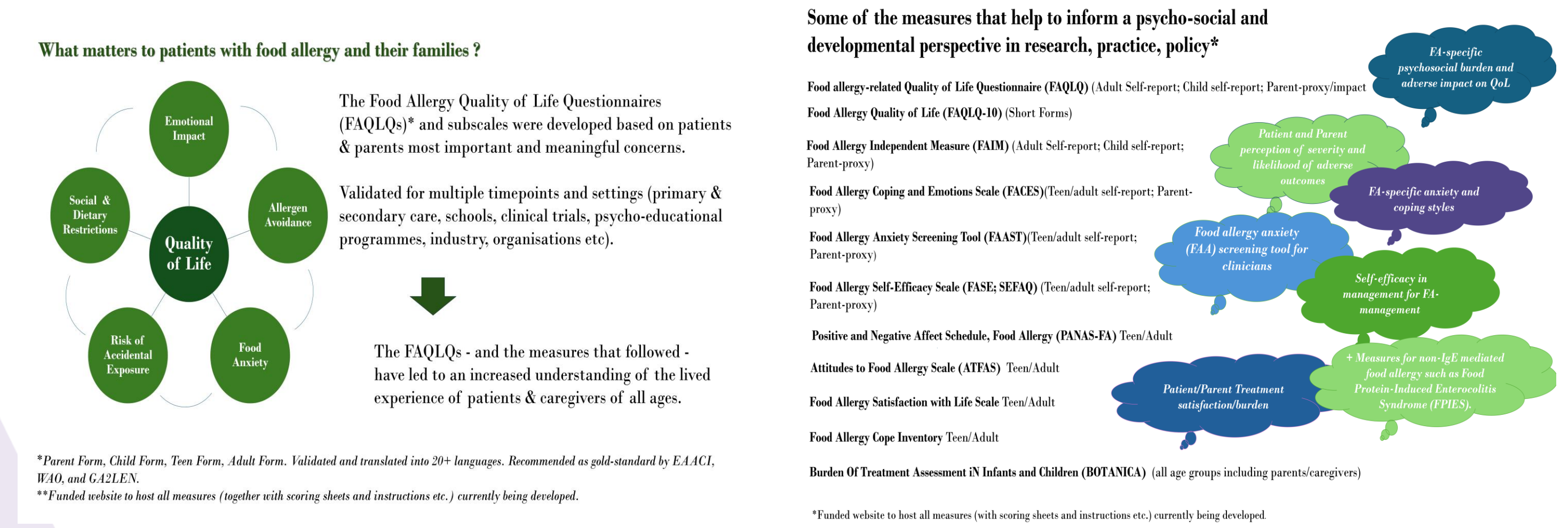
WHAT DID WE DO?

What matters to patients with food allergy and their families ?

The overall goal of this research pathway lay in promoting positive psycho-social development in children with allergic diseases, using a patient centered, multi-system, life-course, and trans-disciplinary approach.

What matters to patients & caregivers can be very different to what matters from a medical perspective- to be patient-centered, an outcome must actually be meaningful to patients & caregivers.

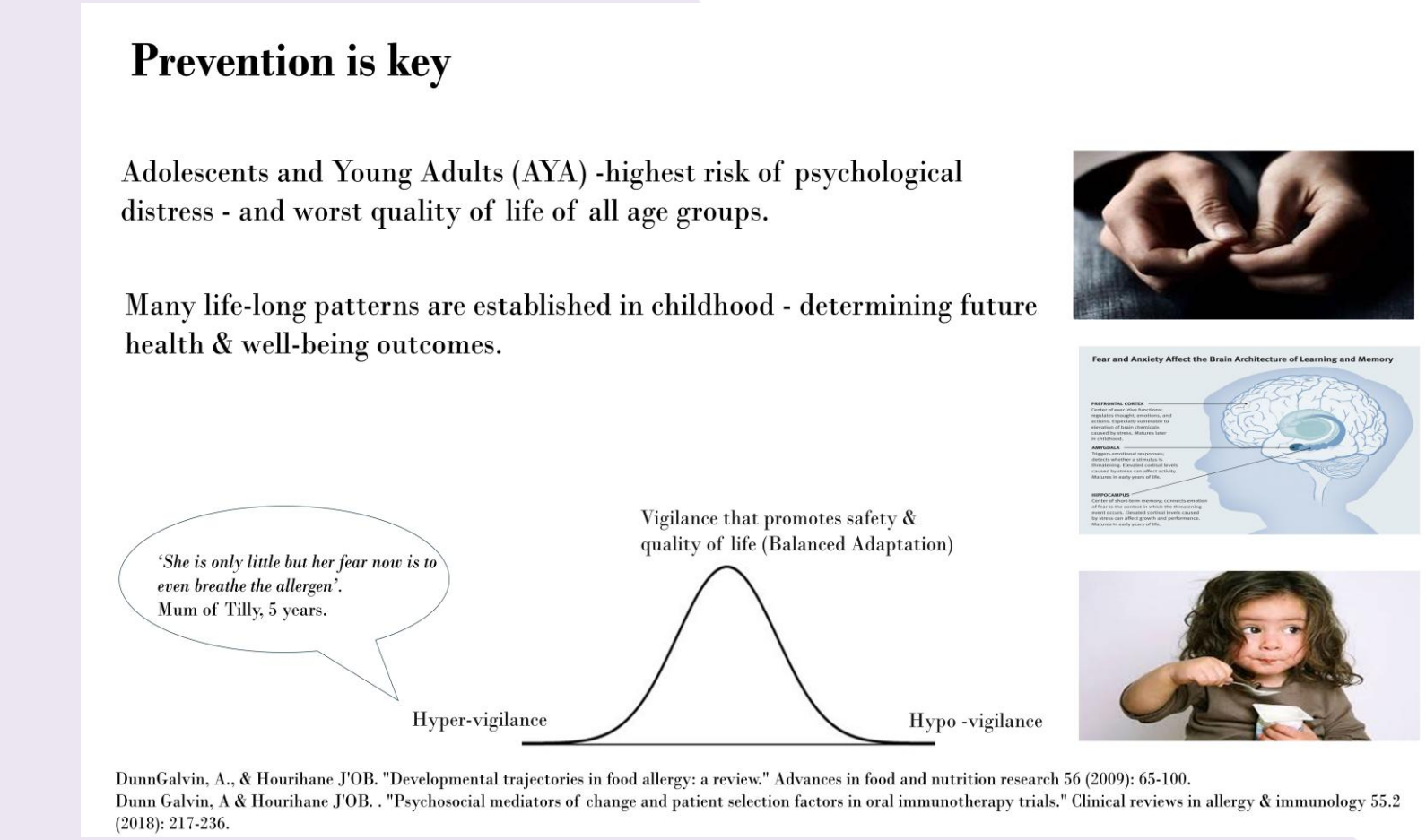
“In value-based care, the only true measures of quality are the outcomes that matter to patients”
Pantaleon L. 2019 Mar;33(2):356-362.



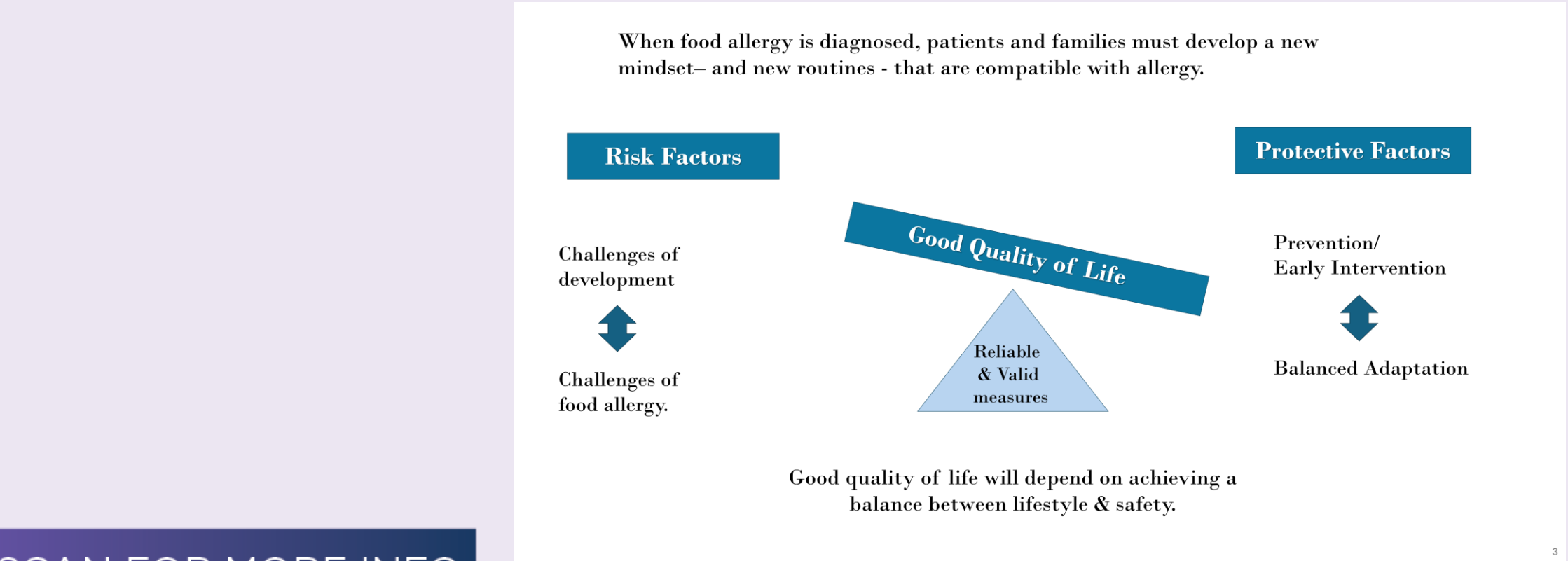
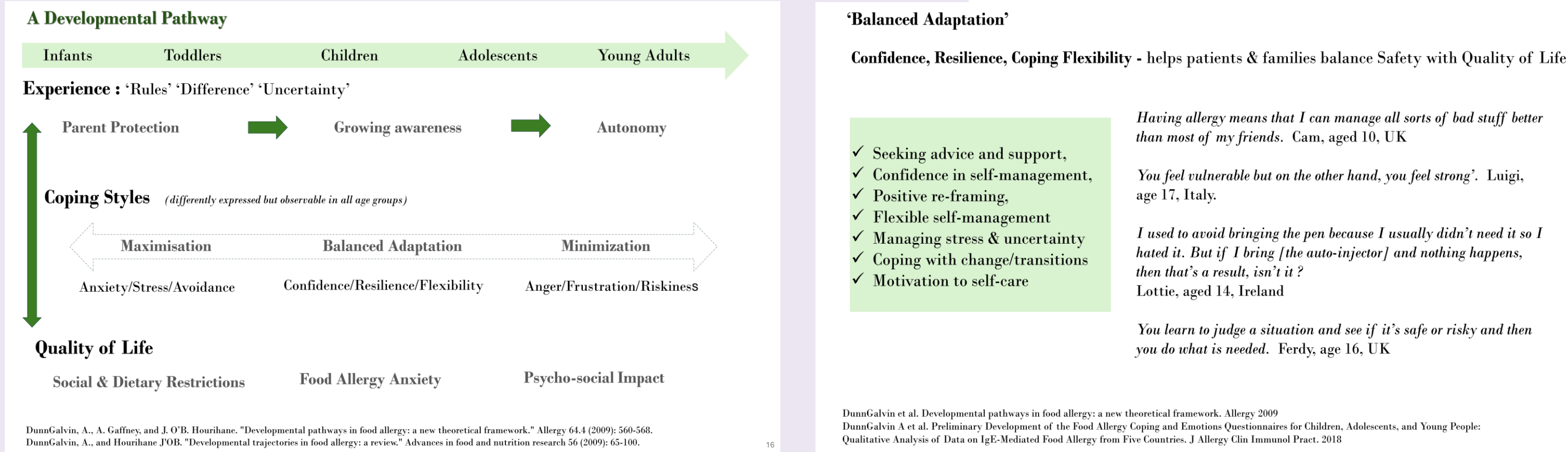
Precision/personalized medicine & care

The FAQLQ allergy specific subscales allowed us to delve more deeply into the impact of allergy on everyday living for different groups.
For example...
Food allergy-anxiety (FAA)* - a psychological condition characterized by excessive worry and fear surrounding potential allergic reactions to food.

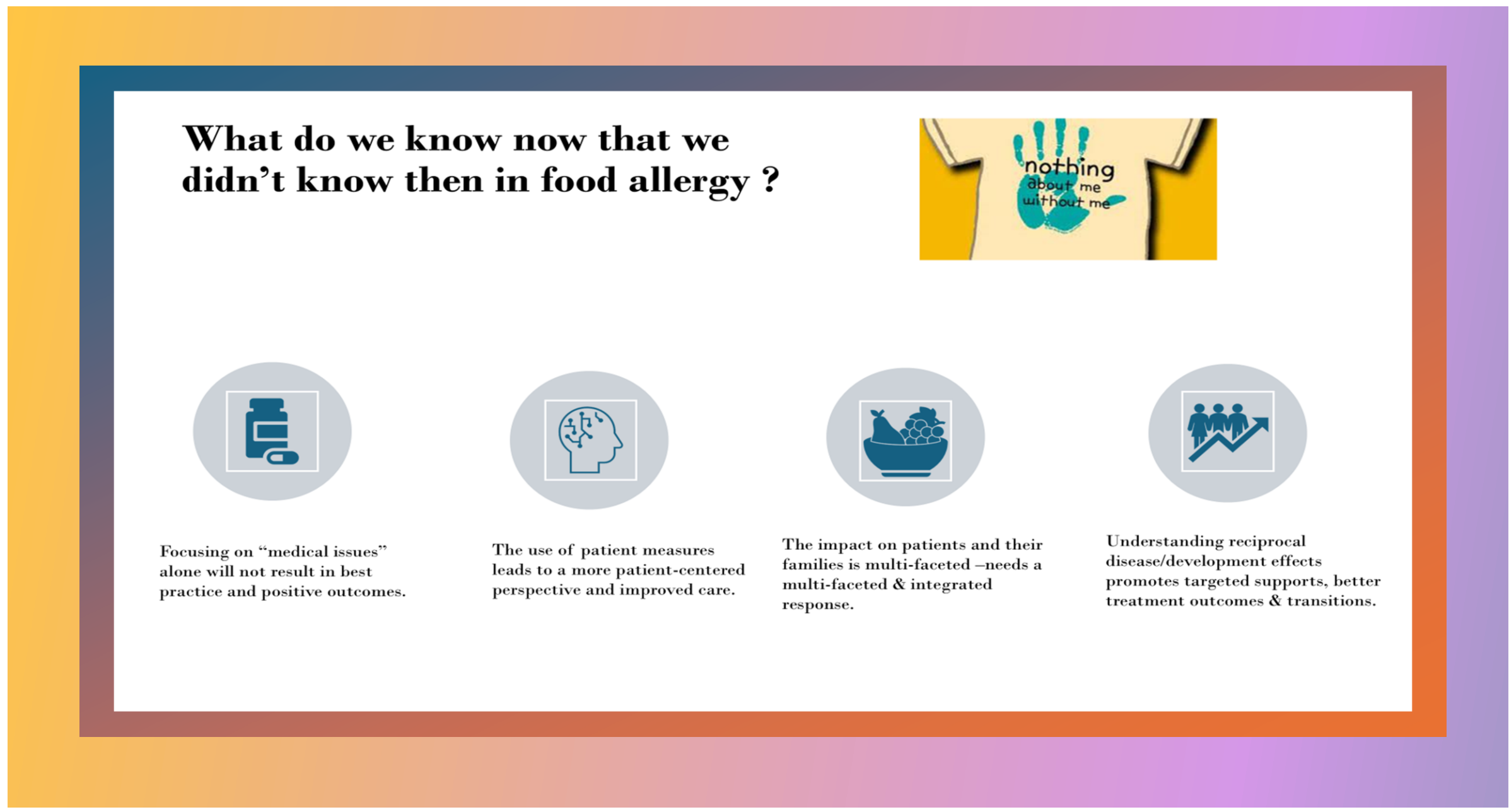
*Screening tool developed for FAA – (FAAST)



Developmental Pathway & Balanced Adaptation



SCAN FOR MORE INFO



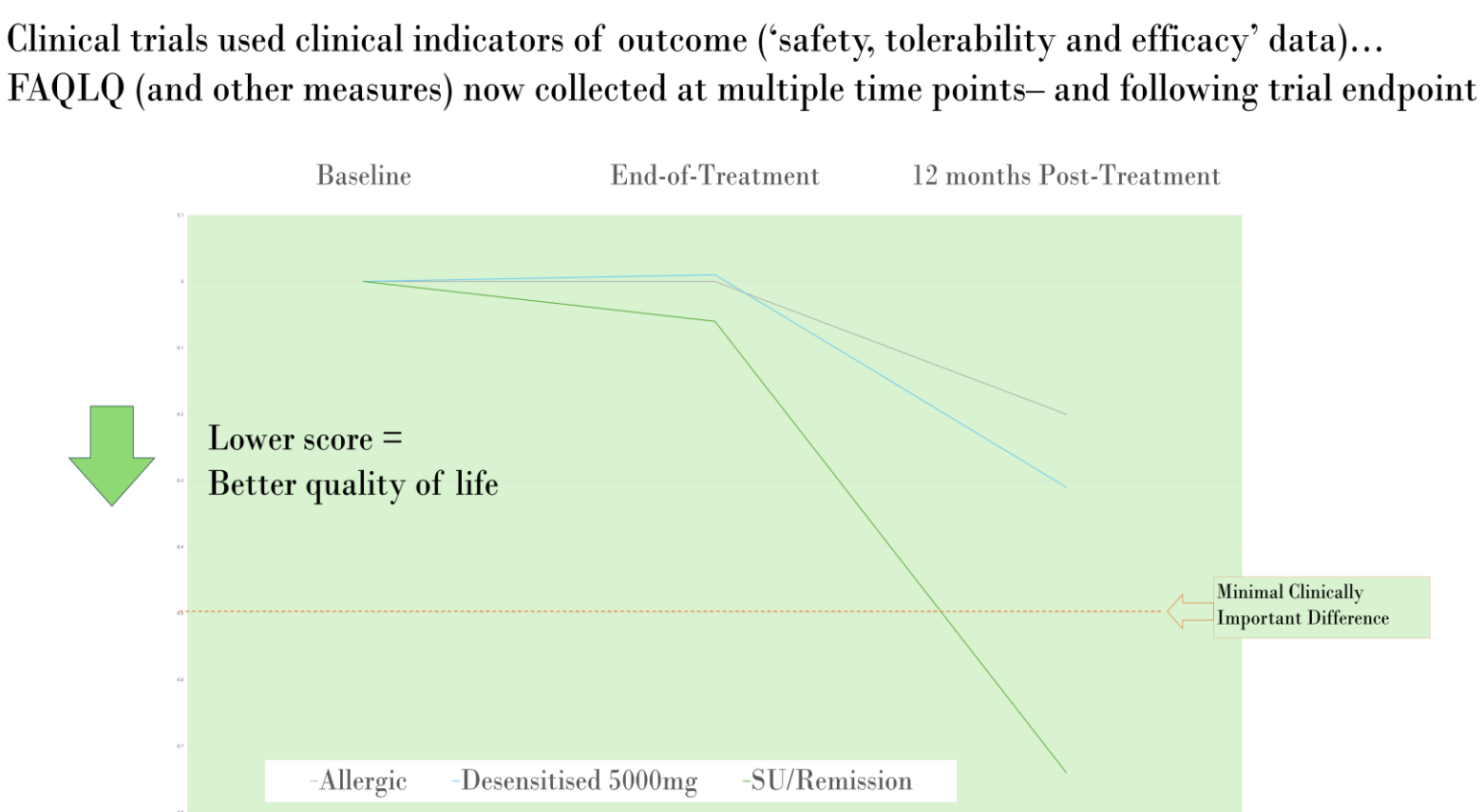
WHY IS IT IMPORTANT?

Rather than a singles level analysis or ‘one size fits all’ approach, the use of patient report measures has led to a more patient-centered and integrated perspective contributing to improved care, patient experience and outcomes.

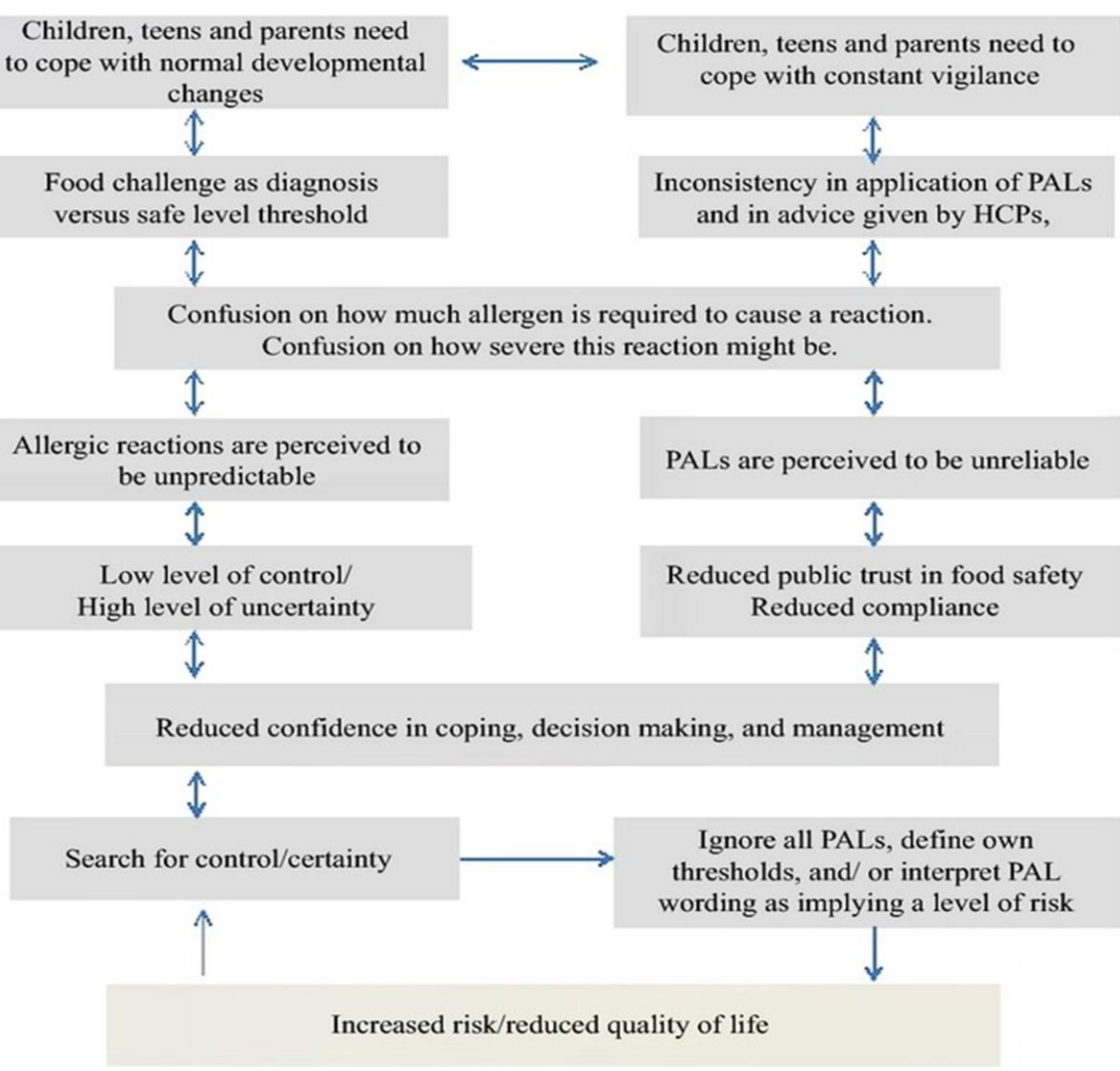
The identification of psycho-social and developmental issues impacting management, confidence and quality of life is now seen as a priority and unmet need that must be addressed by health care professionals in coordination with governmental and non-governmental organisations (e.g. patient advocacy groups).

This transformation can be seen across the field in allergy.

For example, early studies of allergen immunotherapy used only limited clinical indicators of outcome (‘safety, tolerability; efficacy’). More recent studies have collected quality of life at multiple time points througho the clinical trial and (for the first time) followin trial endpoint, ensuring treatments are benefici beyond the research setting.



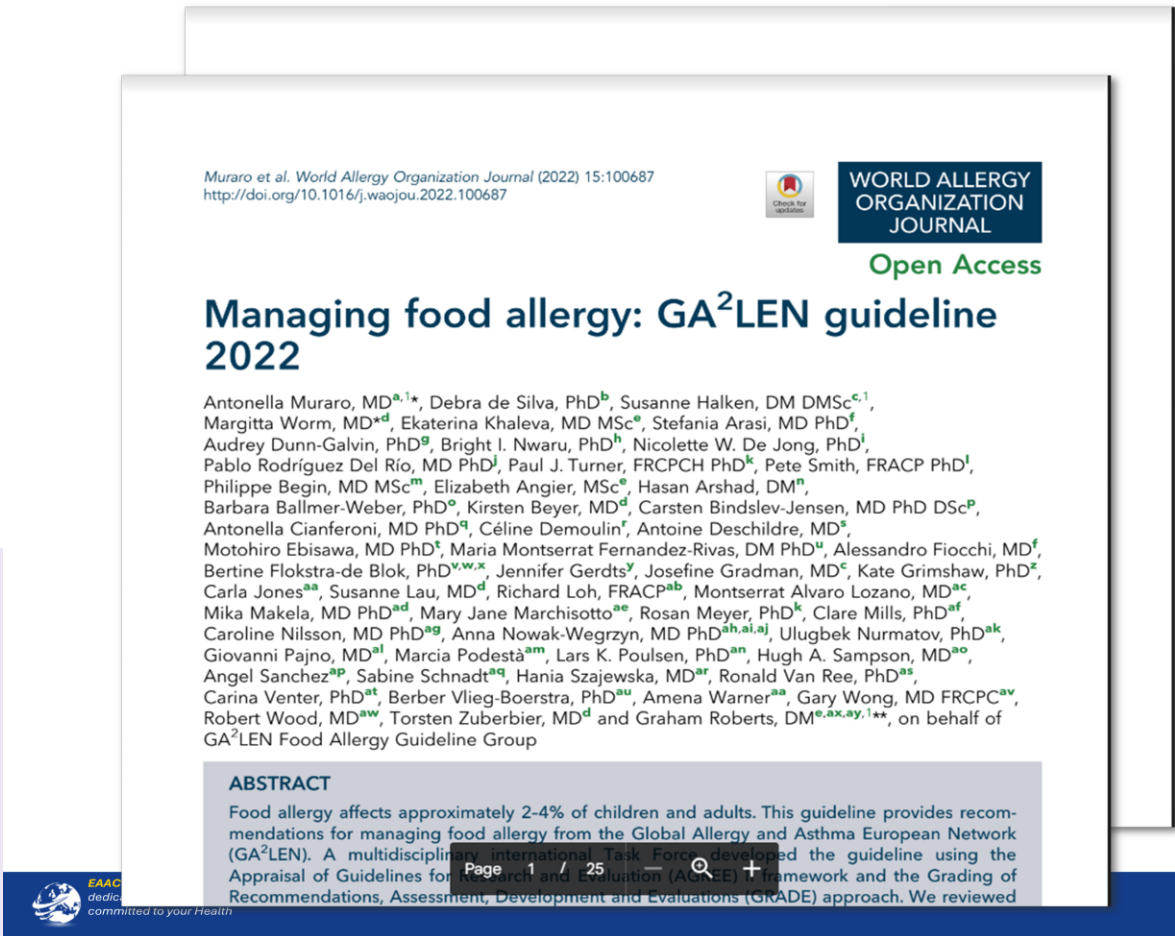
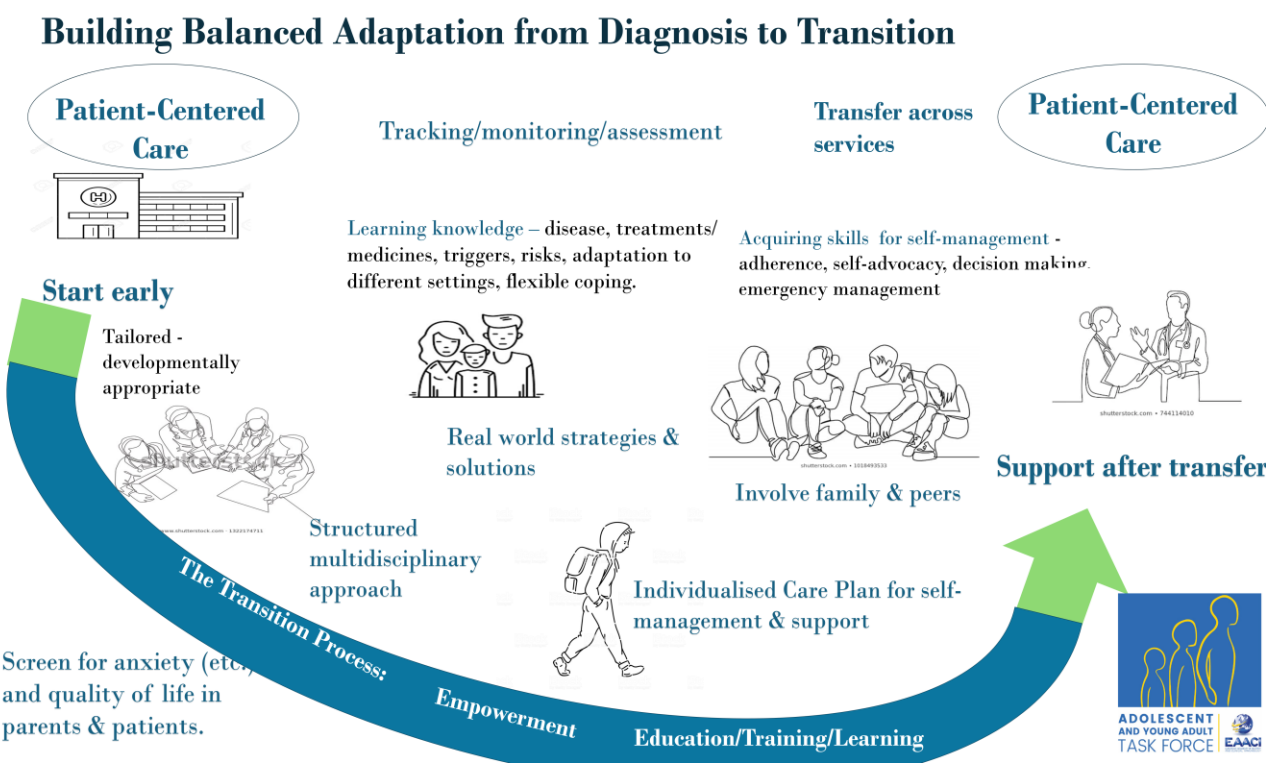
Precautionary allergen labelling: mapping perspectives from key stakeholder groups



Research on preferences and risk assessments for precautionary allergen labelling (PAL) with patients and parents, and other stakeholders(e.g. manufacturers & regulators) agreed on the need for a more consistent, evidence-based approach.

We also found that this would improve trust safety and quality of life those living with food allergy.

Based on the findings of patient measures, the EAACI Adolescent & Young Adult Task Force created to push for best practice in psychological services to support self-management and transition.
A practical toolbox was developed for asthma and allergies (+series of EAACI Position papers).



This research pathway - which began with the development of a single patient reported measure - led to the inclusion of psycho-social and patient-centered perspectives in guidelines by the European Academy of Allergy and Clinical Immunology(EAACI), the World Allergy Organisation (WAO), and the Global Allergy and Asthma European Network’s (GA2LEN).

Recommendations included the development of a multi/trans-disciplinary team approach to diagnosis and management of allergic disease and the value of allied health professionals.