



IMMUNE**HEALTH**XL

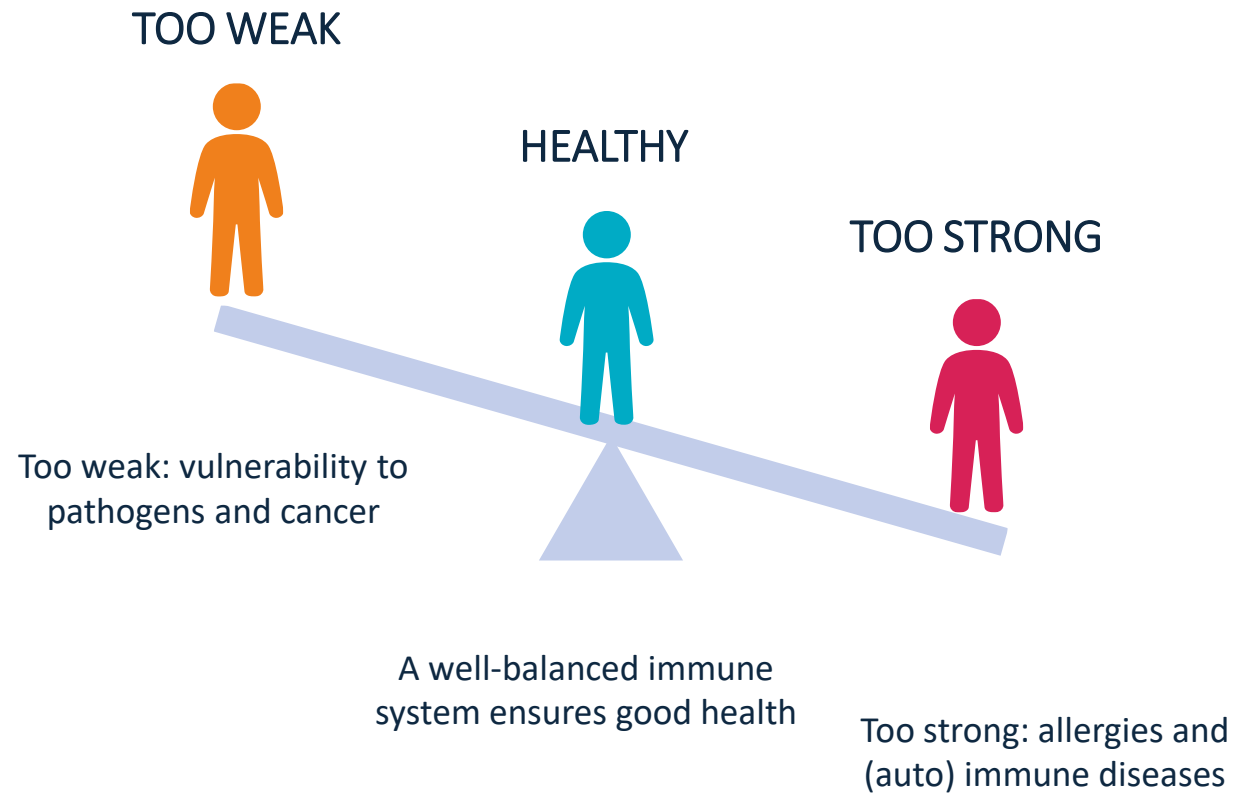
Building ImmuneHealthXL

Janneke N. Samsom

Prof. of Intestinal Immunology, Erasmus MC-Sophia Children's Hospital

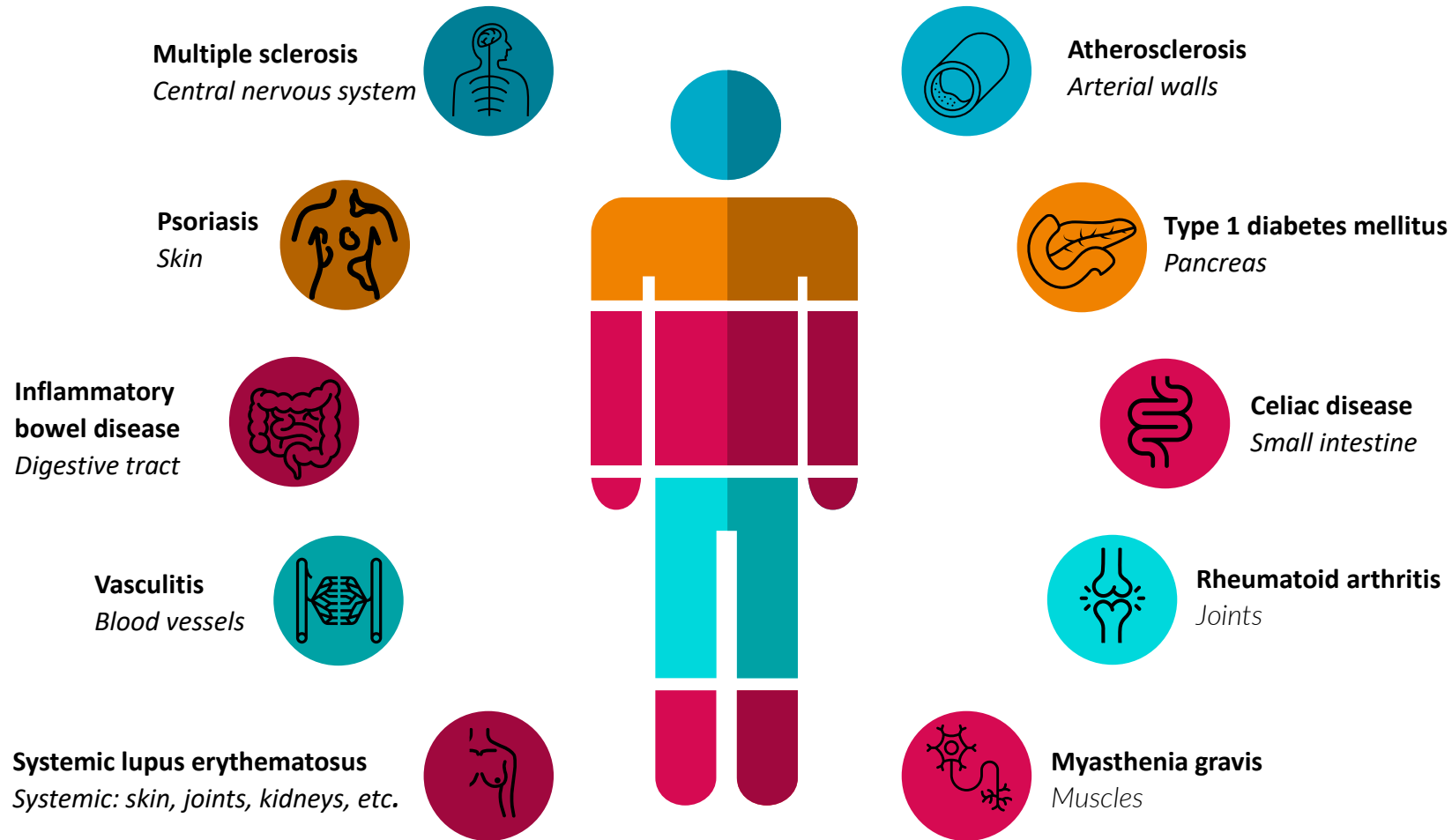
Steering group member of ImmuneHealthXL

The importance of a healthy immune system



Our focus:

Immune Mediated Inflammatory Diseases



In total >80 diseases are classified as IMID

- e.g.
- Axial spondyloarthritis
- Sjögren's syndrome
- Psoriatic arthritis
- Graves' disease
- Hashimoto's thyroiditis
- Scleroderma
- Sarcoidosis
- systemic scleroderma
- Idiopathic pulmonary fibrosis
- IgM nephropathy
-

patients:

- ~5 – 7% of population in developed countries
- ~1 million patients in the Netherlands

The problem

Immune Mediated Inflammatory Diseases

Shared IMID characteristics

Chronic & (often) **disabling diseases**

Chronic inflammation drives **tissue damage** across organs

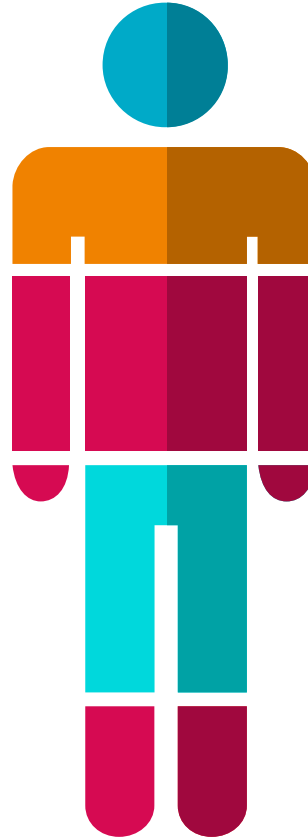
Disease '**flares**' and '**remission**' cycles shape IMID progression

IMID patients face **increased risk of comorbidities**

Genetic and **environmental factors** drive IMID development

Patient heterogeneity shapes IMID presentation and therapy response

IMIDs are often **treated in similar ways**, with similar type of drugs



Consequences of chronic IMID burden

No disease control & constant fear of disease reactivation

Repeated attempts to find **the right medication** (and dosage)

Daily medication intake, including **side effects**

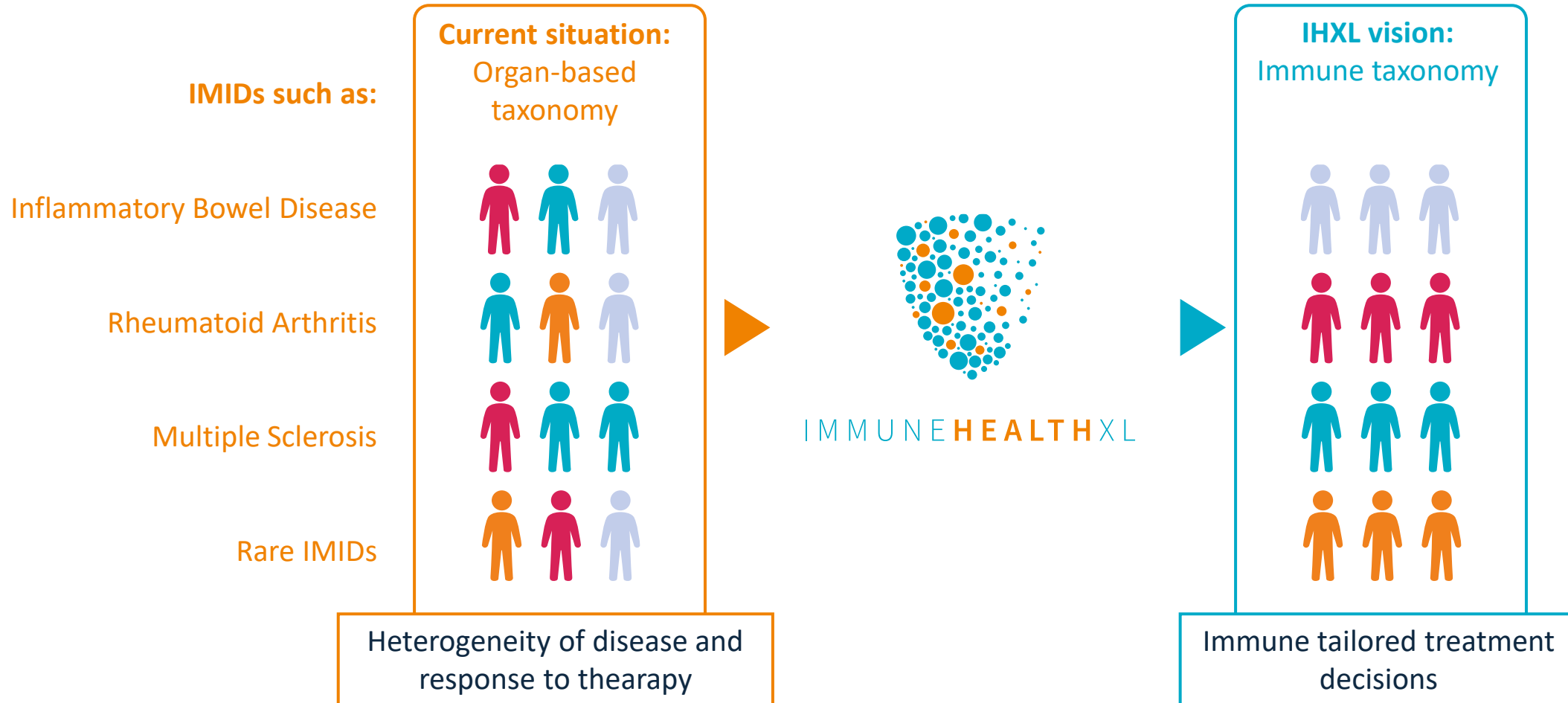
Increasing and lasting **organ and tissue damage**

Limited societal participation

Higher **prevalence of depression and anxiety** disorders

Increase reliance on informal caregiving, social services and benefits

The vision of IHXL



Dutch Society for Immunology (NVVI-DSI) and Samenwerkende GezondheidsFondsen (SGF) join forces.

- SGF society of 23 health foundations who aim to prevent, cure and treat diseases.
- TKI funds.
- Involved Health Holland.
- 2018 Set out a call for nationwide, cross disease immunology research and development.
- 3 PPP projects were granted.

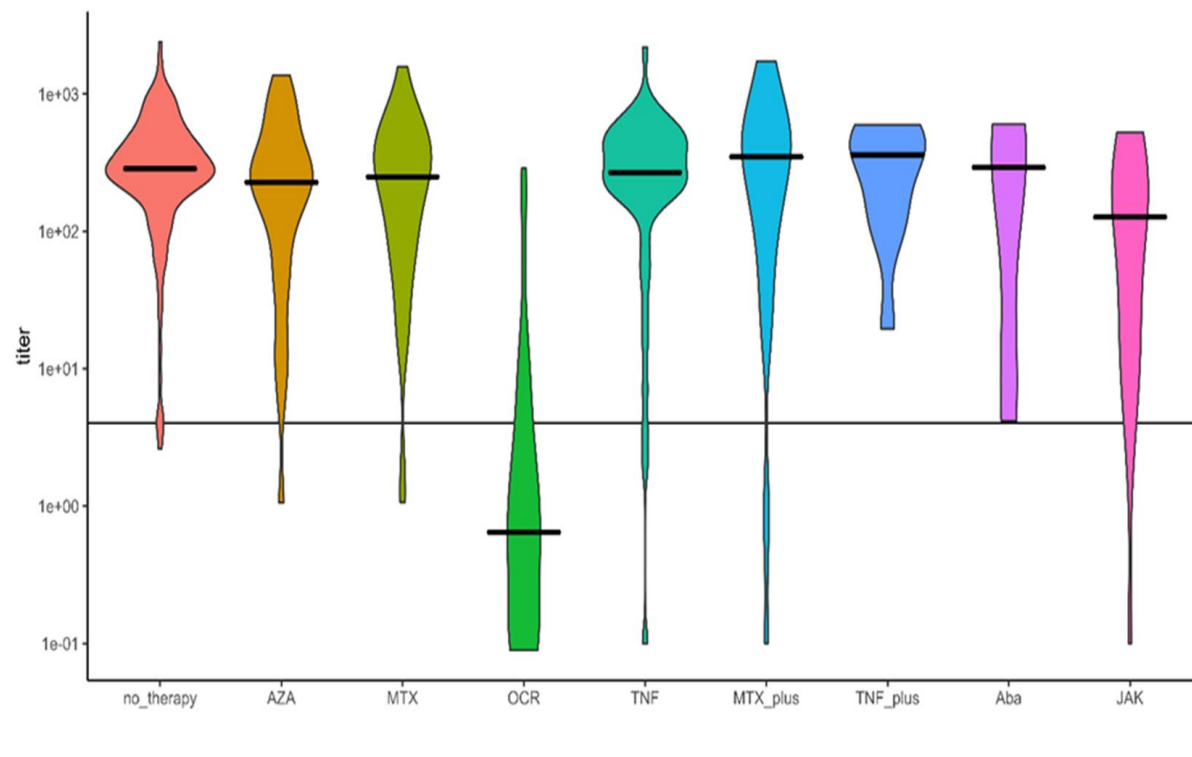


Value of cross-disease IMID research during COVID

IHXL: a flexible network for urgent questions or demands

COVID-19 vaccination

Antibody titers
in IMID patients
on different
treatments



Groups of IMID patients with diverse immune suppressive drugs



Initiating a durable culture shift starting with research

Our legacy
projects

DC Balance

Target 2B

IMID



Ongoing
'bridge' project

ImmuneHealthSeed



Future long-term
strategic partnership



IMMUNE HEALTHXL

Stakeholder interviews and discussion sessions

- Lygature and the DSI conduct interviews with industrial partners.
- IHXL core team initiates round table discussions with foundations, patient representatives, clinician and basic scientist researchers.
- Health Holland denotes ImmuneHealth XL as a strategic PPP
 - Key decision: to focus on IMIDs only
 - Important requirement: support of health foundations and patient societies

Together with Lygature, Ton Rijnders and Tale Sliedrecht,
a *IHXL kwartiermakers phase* was initiated



The partners building IHXL

IHXL steering group



Results of the *IHXL Kwartiermakers phase*

- IHXL to be set up as a **national platform for IMID research**, transcending a single project or research consortium
- The IHXL strategy centres on core elements:
 - **'disease-overarching' approach** embedded in all activities,
 - **moonshot-driven research** agenda
 - integrated **patient involvement**

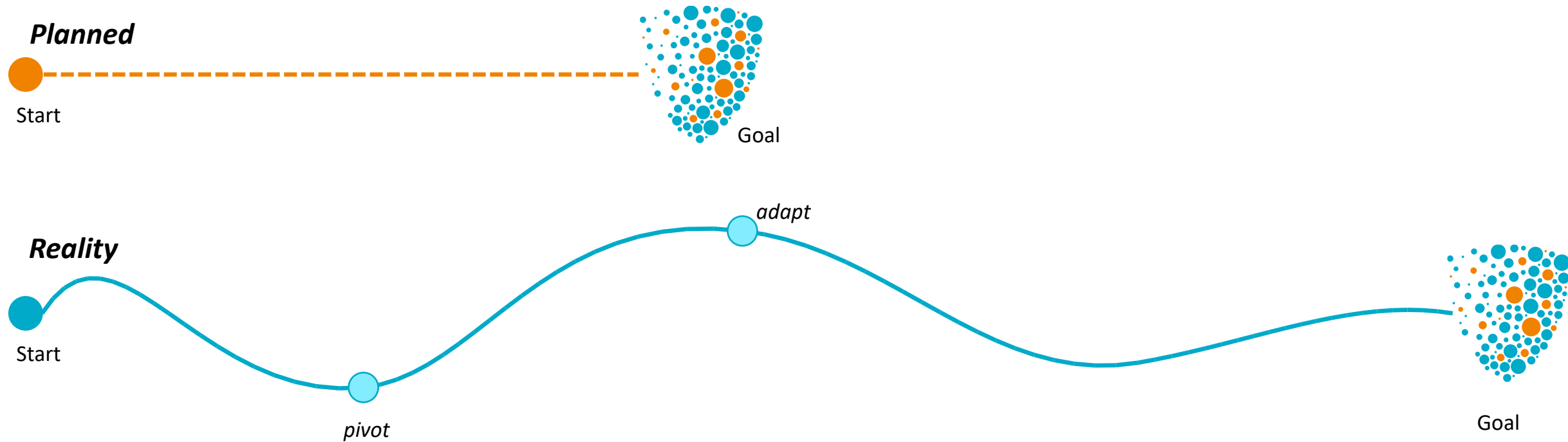


- Established as an independent initiative
- Strategic plan to guide actions
- Open & transparent governance set up
- Core funding to establish core activities & fund research activities



**Go / no-go
funding decision**

The route to your goal is never straight



Recalibrating.....

take the positives and seize the momentum

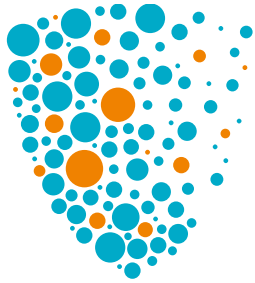
- All partners **acknowledged the importance** of disease-overarching immunological research
- The strategic plan serves as an excellent framework **to guide** a national initiative **and boost** R&D across IMIDs
- A **coalition of partners** is willing to financially support IHXL and help to achieve our goals
- Financial capabilities are limited and thus additional external funding is required to achieve our goals

Re-positioning IHXL

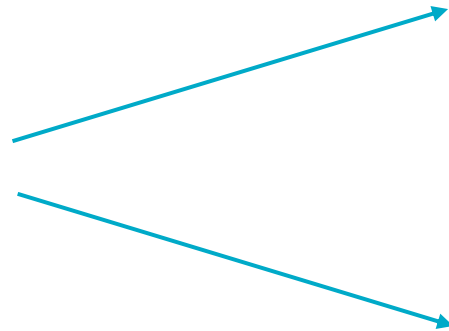
- ImmuneHealthXL will become an independent organisation which **promotes** and **drives** disease-overarching immunological IMID-research
- ImmuneHealthXL's **strategic plan** guides the direction of its activities and priorities :
 - Scientific moonshots
 - Patient involvement & representation
 - Collaboration and community
- ImmuneHealthXL will actively pursue public and private funding opportunities to realise its strategy

Recent momentum

IHXL
kwartiermakersfase



IMMUNE HEALTHXL



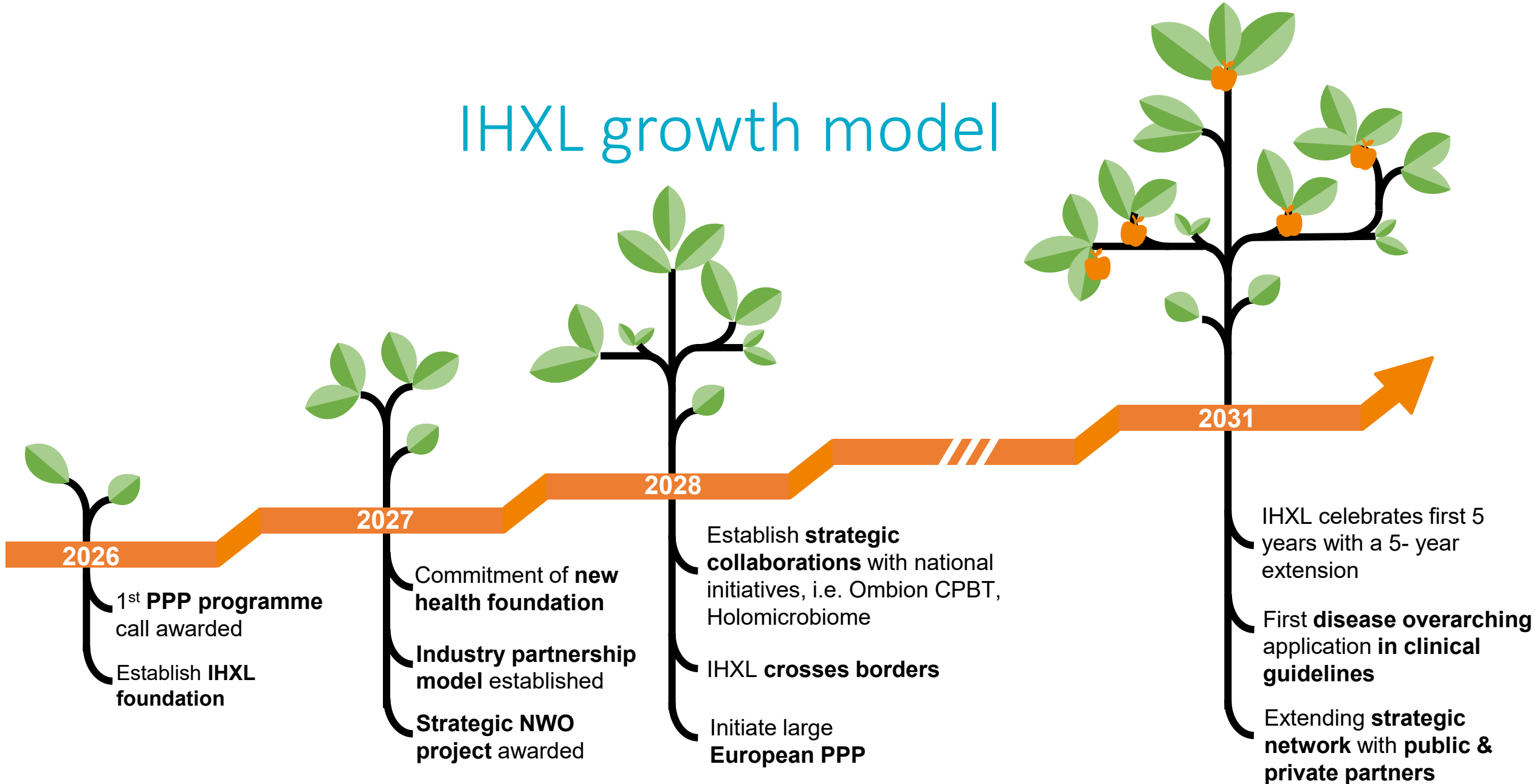
Meta
Immunotypes

NWO
4 years, €6,8M
12 partners

IHXL PPP
Programme

Health~Holland
~6 years, ~€12M
8 partners

IHXL growth model



What defines success?

Consequences of chronic IMID burden

No disease control & constant fear of disease reactivation

Repeated attempts to find **the right medication** (and dosage)

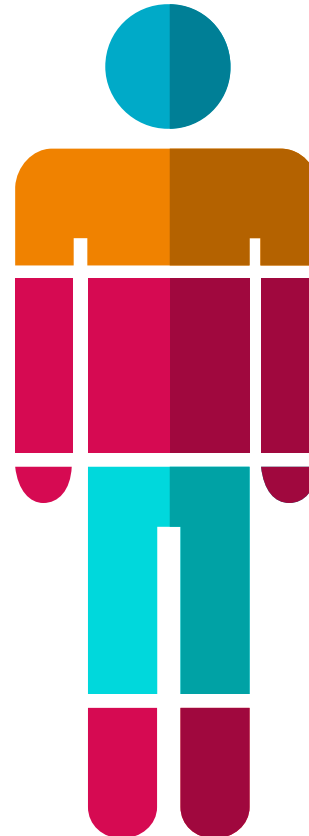
Daily medication intake, including **adverse side effects**

Increasing and lasting **organ and tissue damage**

Limited societal participation

Higher **prevalence of depression and anxiety** disorders

Increase reliance on informal caregiving, social services and benefits



Changes in chronic IMID burden

Better disease control & constant fear of disease reactivation

Fewer attempts to find **the right medication** (and dosage)

Fewer adverse side effects

Less organ and tissue damage

More societal participation

Fewer depression and anxiety disorders

Reduced dependence on informal caregiving, social services and benefits



IMMUNE**HEALTH**XL

