

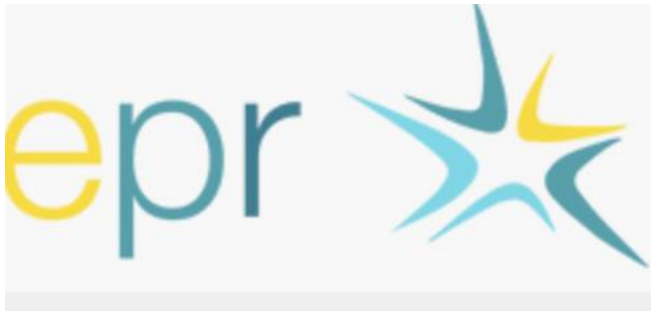
WORKSHOP:

WHEN DOES A PATIENT BECOME A PERSON?

*Moving towards a technology-enabled and
community-based continuity of supporting
services*

- Part 3 -

Mac MacLachlan



Report of the Special Rapporteur on the rights of persons with disabilities,
Gerard Quinn Human Rights Council Fifty-second session, March 2023

9: “A wholly new philosophy of service and support is beginning to emerge and is sharply distinguishable from past models. It is grounded on personhood (autonomy) and social inclusion and must be more clearly articulated in law, policy and programming. Moreover, a new vocabulary is required to optimize the potential of any new approach.”

22: “in addition to the general rejection of the medical model, a web of core rights in the Convention points strongly to the need for the reconceptualization of services. Personhood and moral agency form the bedrock of the Convention. “

93: “New kinds of partnerships are needed to realize this new philosophy. ... Support must shift from medically dominated systems that rely on coercion to support that is freely chosen. Active consultation with persons with disabilities is therefore required, to determine what persons with disabilities need and want.”

*3 main current challenges for us all
– right here, right now !*

- 1. Services delivered at ‘home’ can now be much better than services delivered in hospitals -
e.g. SHAPES project. (ageing)
- 2. Moving from specialization -> personalization
e.g. Digital assessment (neurodiversity)
- 3. Democratizing health from a rights perspective
e.g. Ireland/WHO Report
(rehabilitation/disability/mental health)



SHAPES

Smart and **H**ealthy **A**geing through **P**eople **E**ngaging in supportive **S**ystems

SHAPES in Numbers



48 month project
November 2019 - October 2023

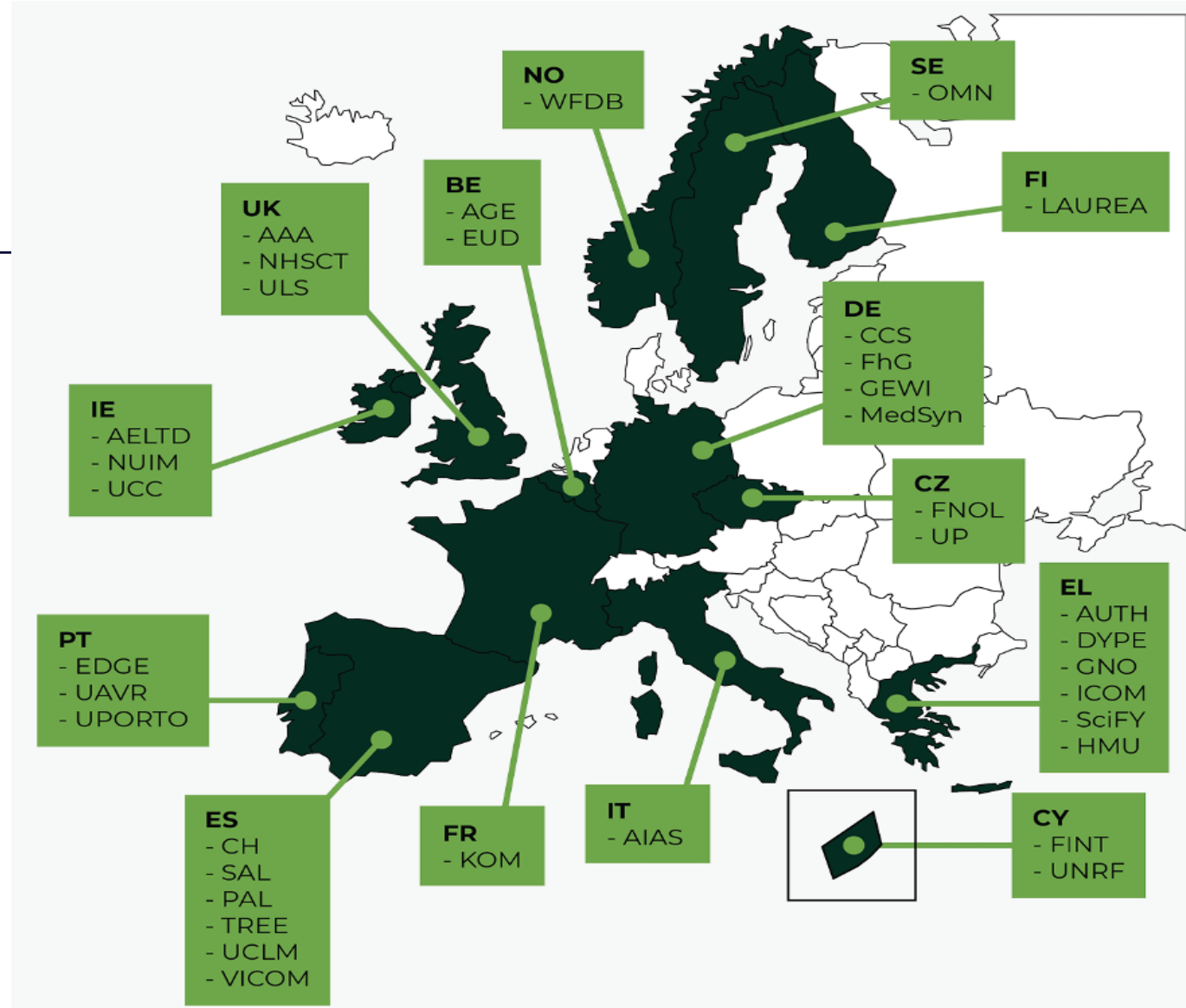
300+ staff
36 Partner organisations
16 Associate organisations
14 Countries

Engages older adults
across 15 pilot sites

10 Work Packages.

€21m in funding.

8 Reference Sites of the
European Innovation
Partnership (EIP) on Active
and Healthy Ageing (AHA),



THE VISION

- The SHAPES Innovation Action (IA) will **build, pilot and deploy a large-scale, EU-standardised, open platform.**
- To facilitate **long-term healthy and active ageing and the maintenance of a high-quality of life, in the community.**



SHAPES DIGITAL TECHNOLOGIES: Include assistive robots, eHealth sensors and wearables, Internet of Things (IoT)-enabled devices and mobile applications.



SHAPES ECOSYSTEM: A network of relevant users and key stakeholders working together to scale-up Platform and digital technologies.

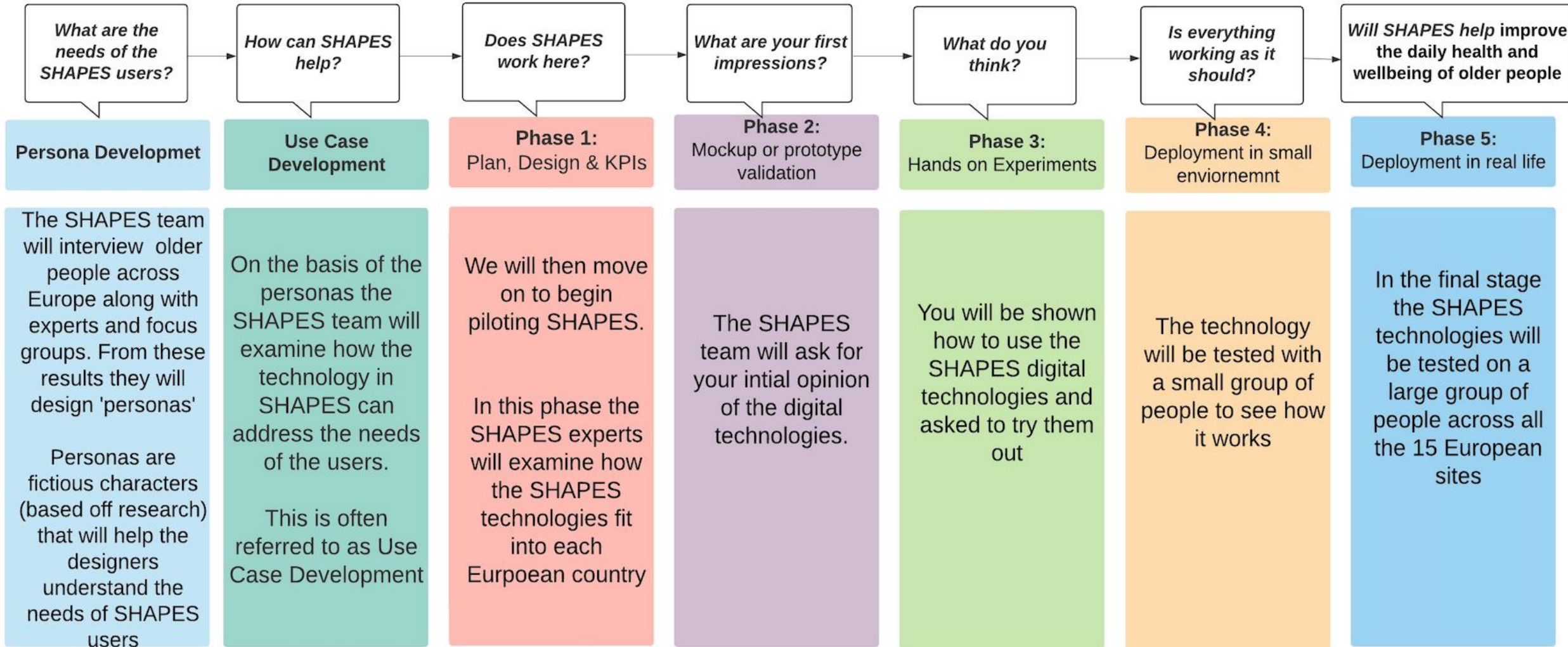


SHAPES MARKETPLACE: Seeks to connect demand and supply across health and social care delivery, and to facilitate the co-creation of affordable, effective and trustworthy solutions.

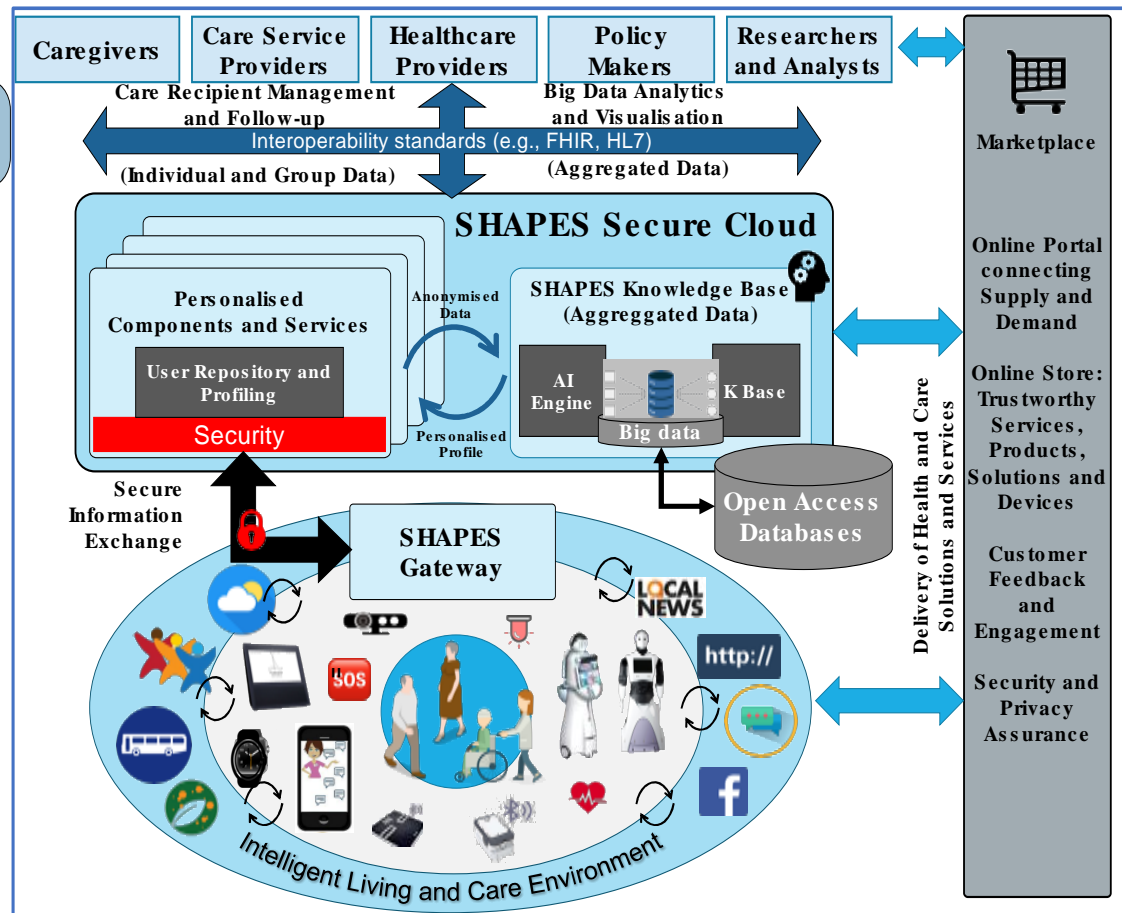
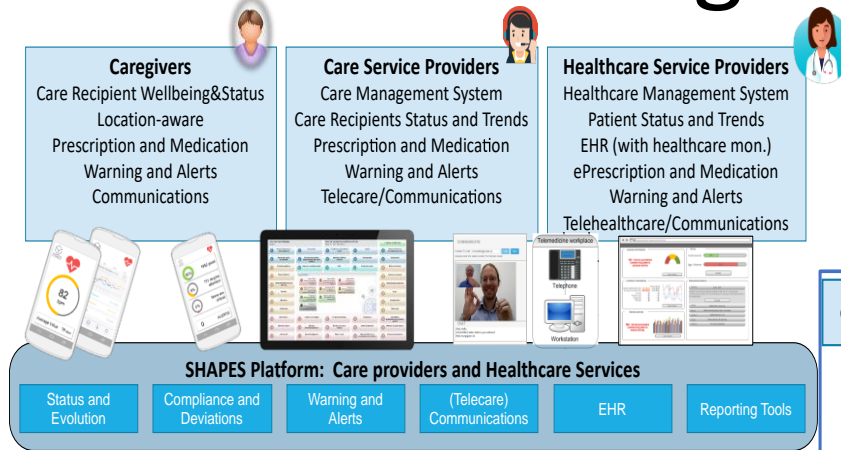


SHAPES RECOMMENDATIONS: Provide guidelines, a roadmap and an action plan, including a set of priorities dedicated to standardization, to support key EU stakeholders to foster the large-scale deployment and adoption of digital technologies and new integrated care services in Europe.

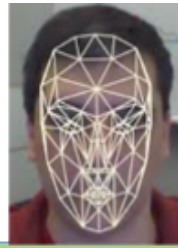
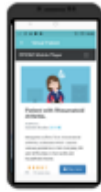
Person or patient?



The Technologies and Digital Solutions



Conversational Assistants & Chatbots

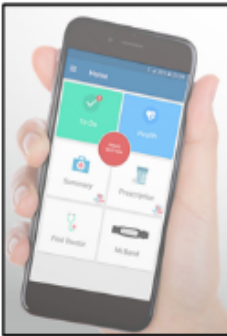


Multimodal Biometrics, Face & Emotion Recognition



Online Communication & Accessibility Tools

Activity Recognition & Wellbeing Assessment



Robots



Clinical Decision Support Systems



Cognitive Stimulation And Rehabilitation



COVID-19 response

Security



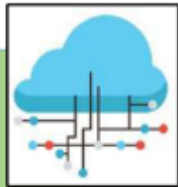
Predictive modelling



Health and Wellbeing Platforms

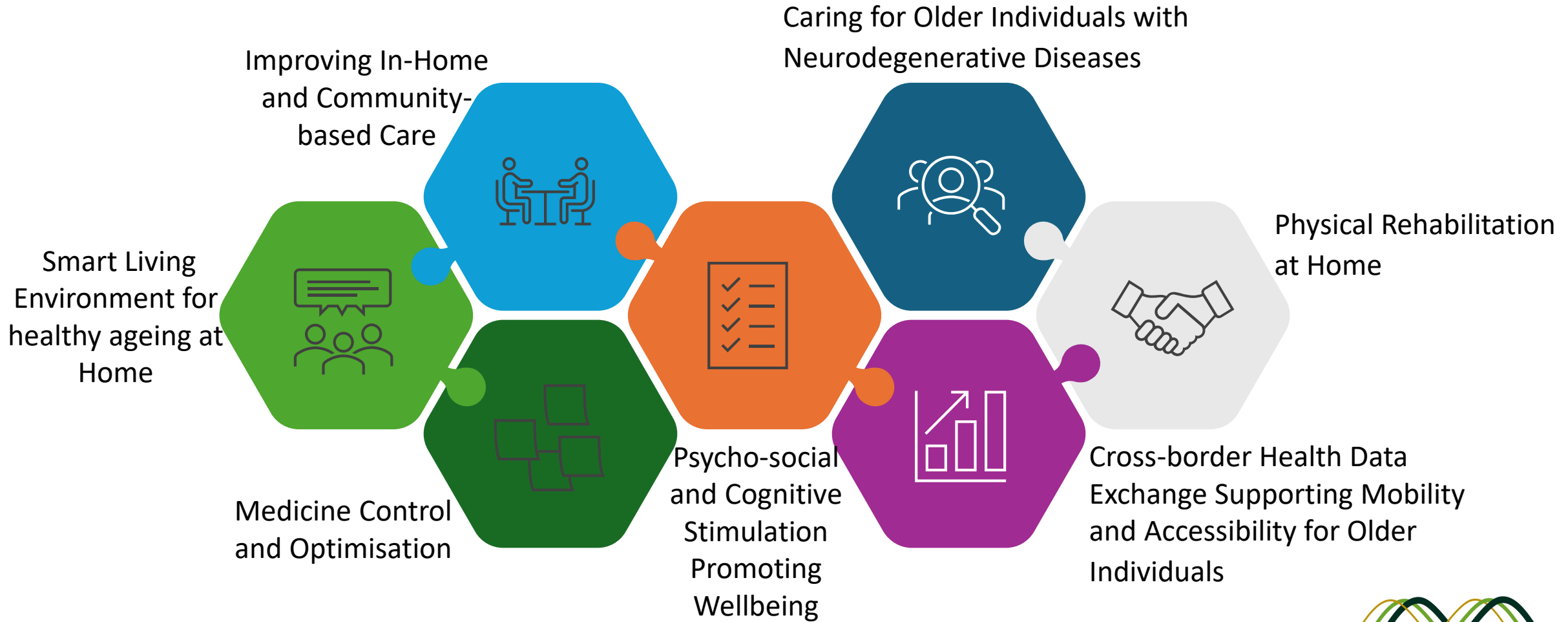


IoT & Big Data Platforms

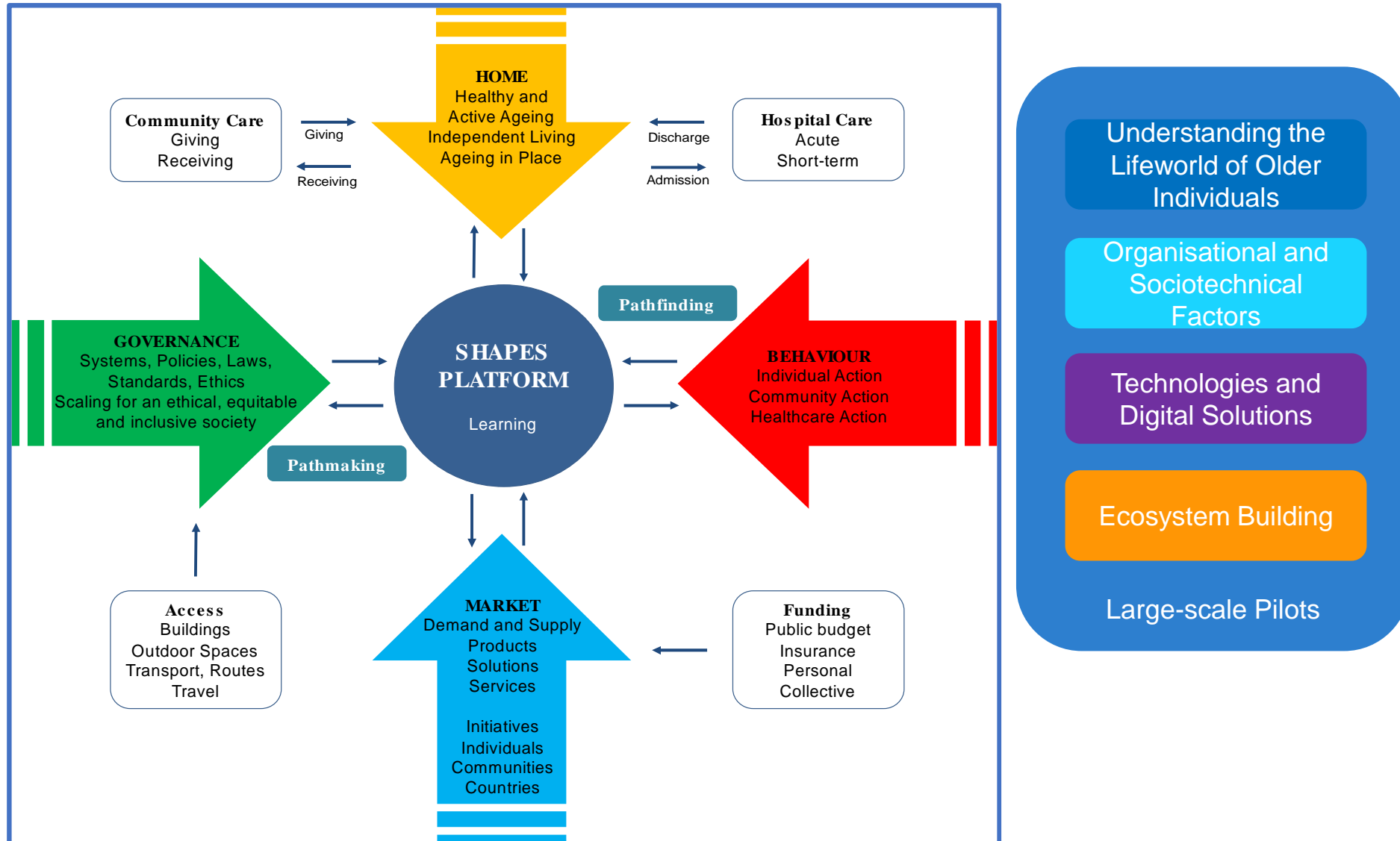


Conversational Assistants & Chatbots

The Pilot Themes



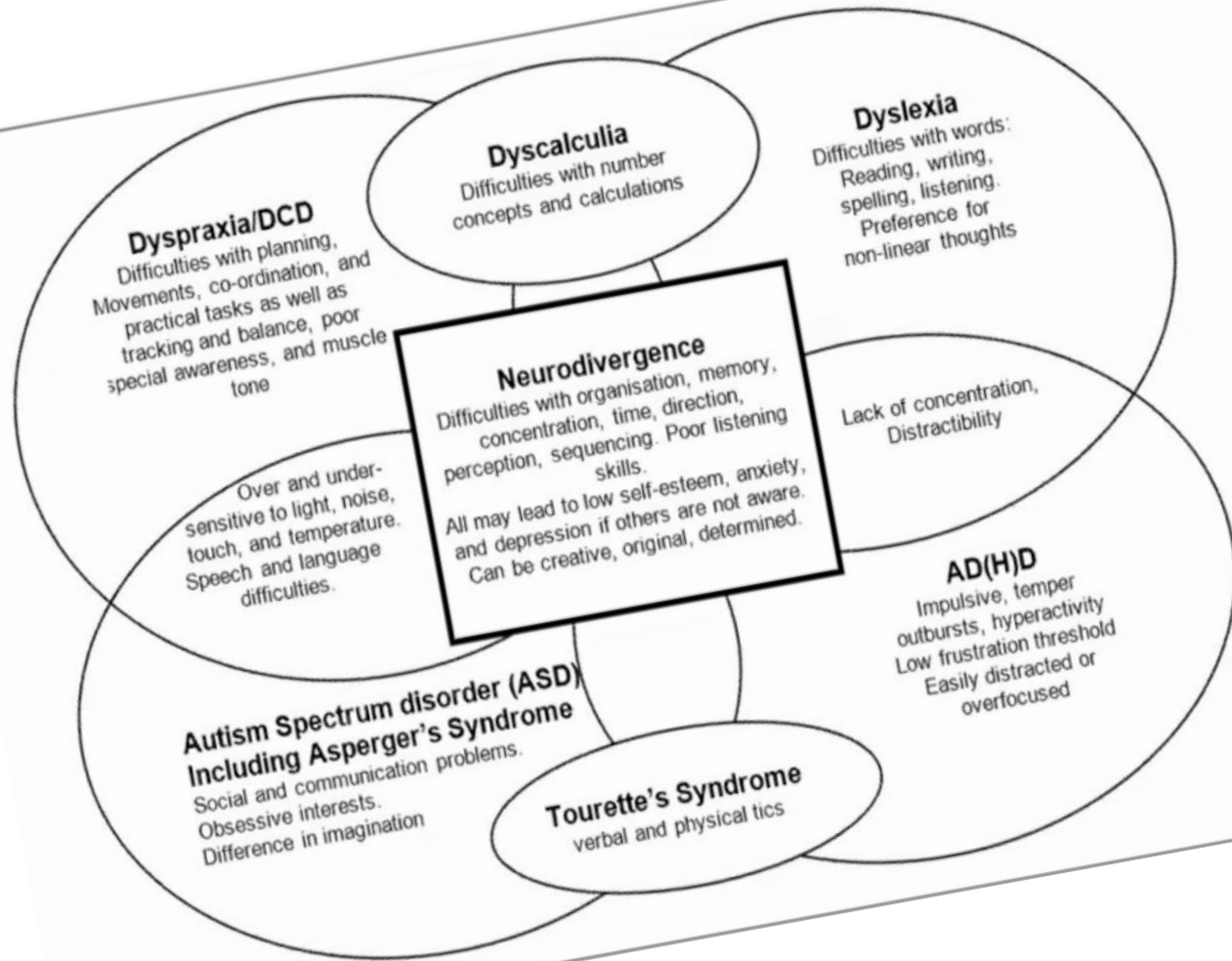
The multiple dimensions of SHAPES



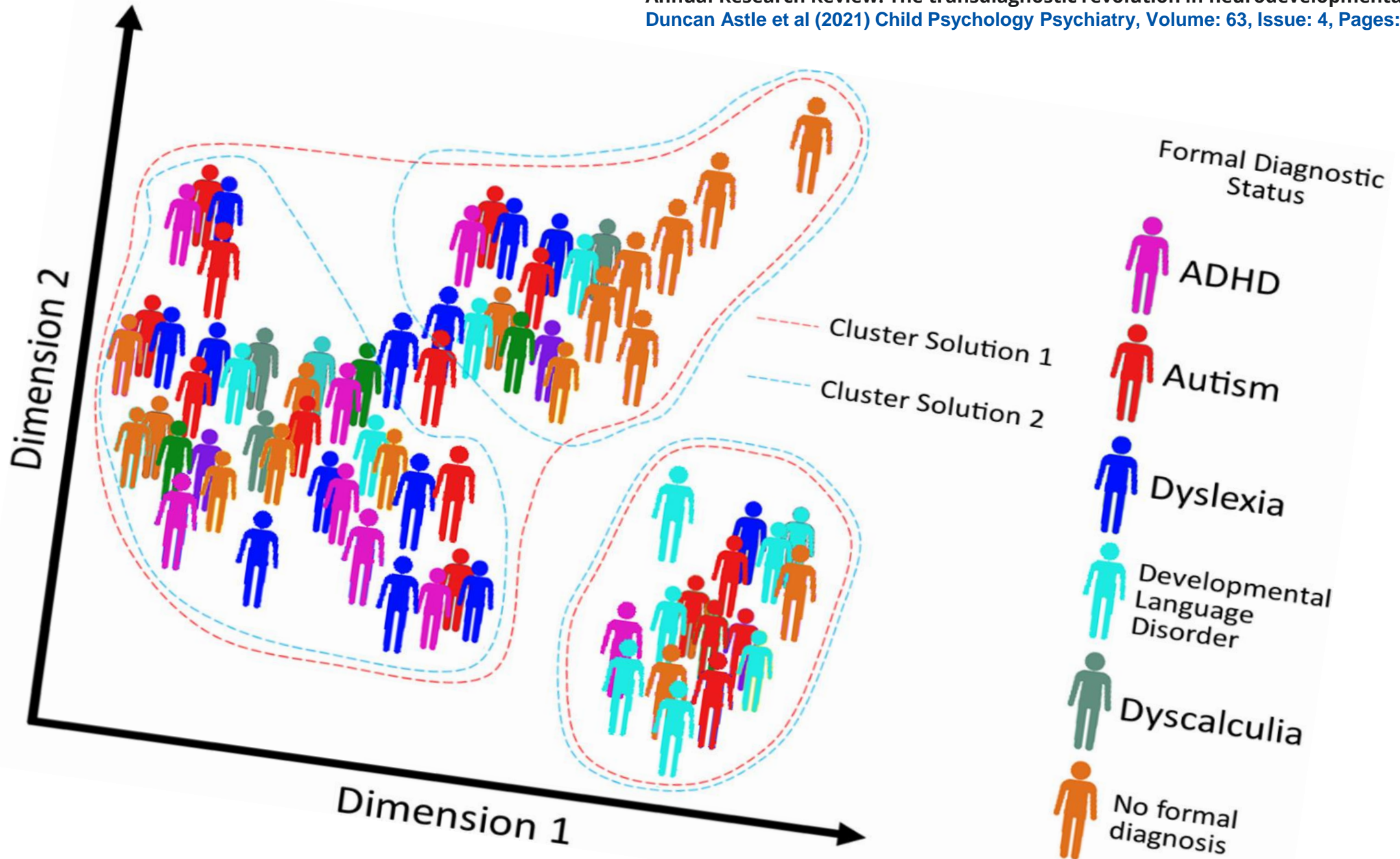
As 'care' reaches across health promotion, illness prevention, treatment, rehabilitation, assistive living ...

- Are we now all “patients” of someone even when we are well?

Person or patient?
Neurodiversity



(Neurodivergent Cluster adapted from Brain. HE, 2017)



Neurodiversity assessment – for what?

- Person focused or profession focused?

Diagnosis – then what?

Digital assessment of the supports and services required to enable participation of neurodiverse children

- **Needs focused** not diagnosis focused
- **Timely interventions** not long waiting lists
- **Supporting personnel** to make better decisions and provide services, not replacing them
 - Resisting Change

Person or patient?

- The digital challenge to health and social care service *hierarchies*

Towards a Rights-based Approach to Strengthening Leadership and Governance in Health Services MacLachlan et al, 2024

1. Citizens must have **accessible information** about and access to the services they need.
2. Citizens must be **central to and involved in the leadership and governance of health services.**
3. Citizens have the right to **have their health services provided through the most effective mechanisms of service delivery**, and especially the most effective ways of teamworking across multi- and inter-disciplinary teams.
4. **People providing services have a right to work in psychologically safe environments**, where they feel valued, and feel empowered to question each other and to advocate for the rights of service users.

Fortunately, all four of these aims can not only be achieved, but each **will reinforce each other**, when services are designed from a rights-based perspective. For this workshop we combine 1+2 into one theme - see how your organisation does – across 17 dimensions (see p. 29-35)

So, when does a patient become a person?