


HELLO




DEVELOPING A NATIONAL ASSOCIATION



PRADER - WILLI SYNDROME MALAYSIA

 [PersatuanPraderWilliMalaysia](#)

 [Malaysian_pws](#)

DEVELOPING A NATIONAL ASSOCIATION.

- The importance of setting clear Vision, Mission and Objective.
- The Importance of Strategic Roadmap.
- Action Plan.
- To mobilize, empower and build up a network.

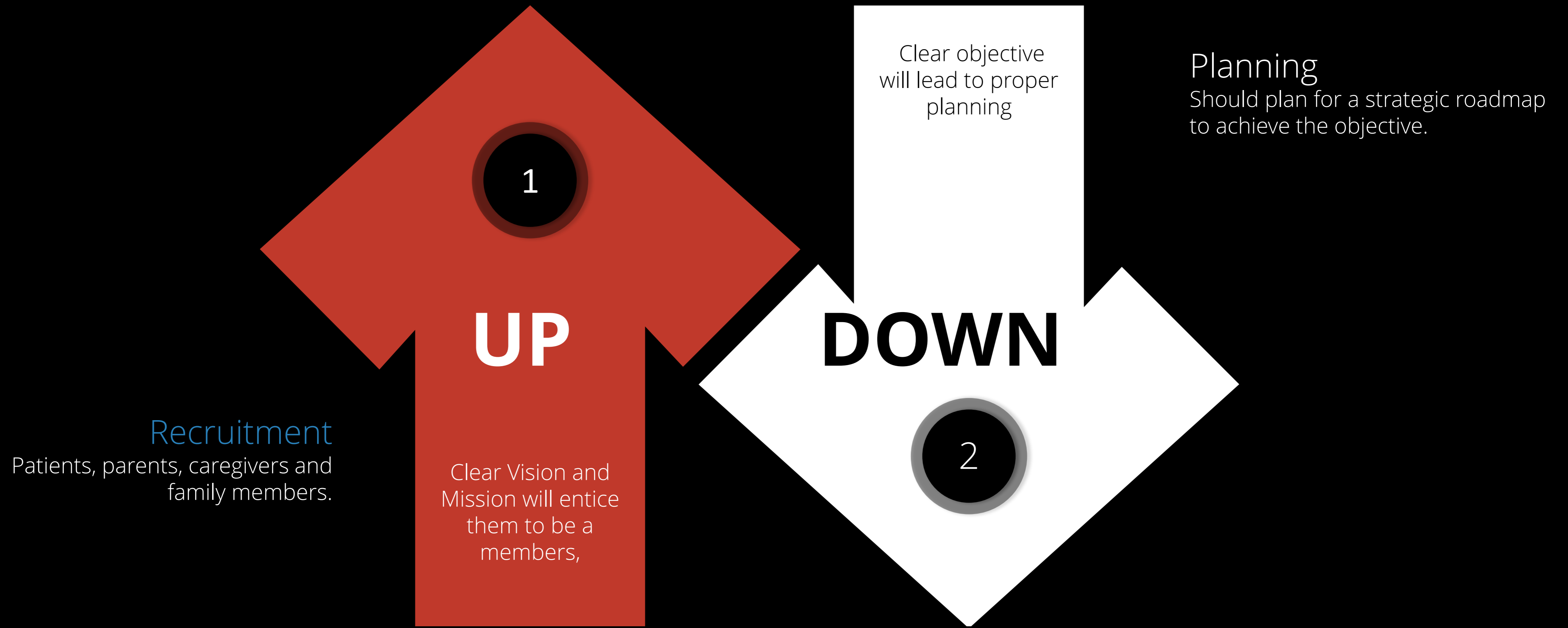
The Importance of



Clear Vision, Mission & Objective

❖ Developing A National Association

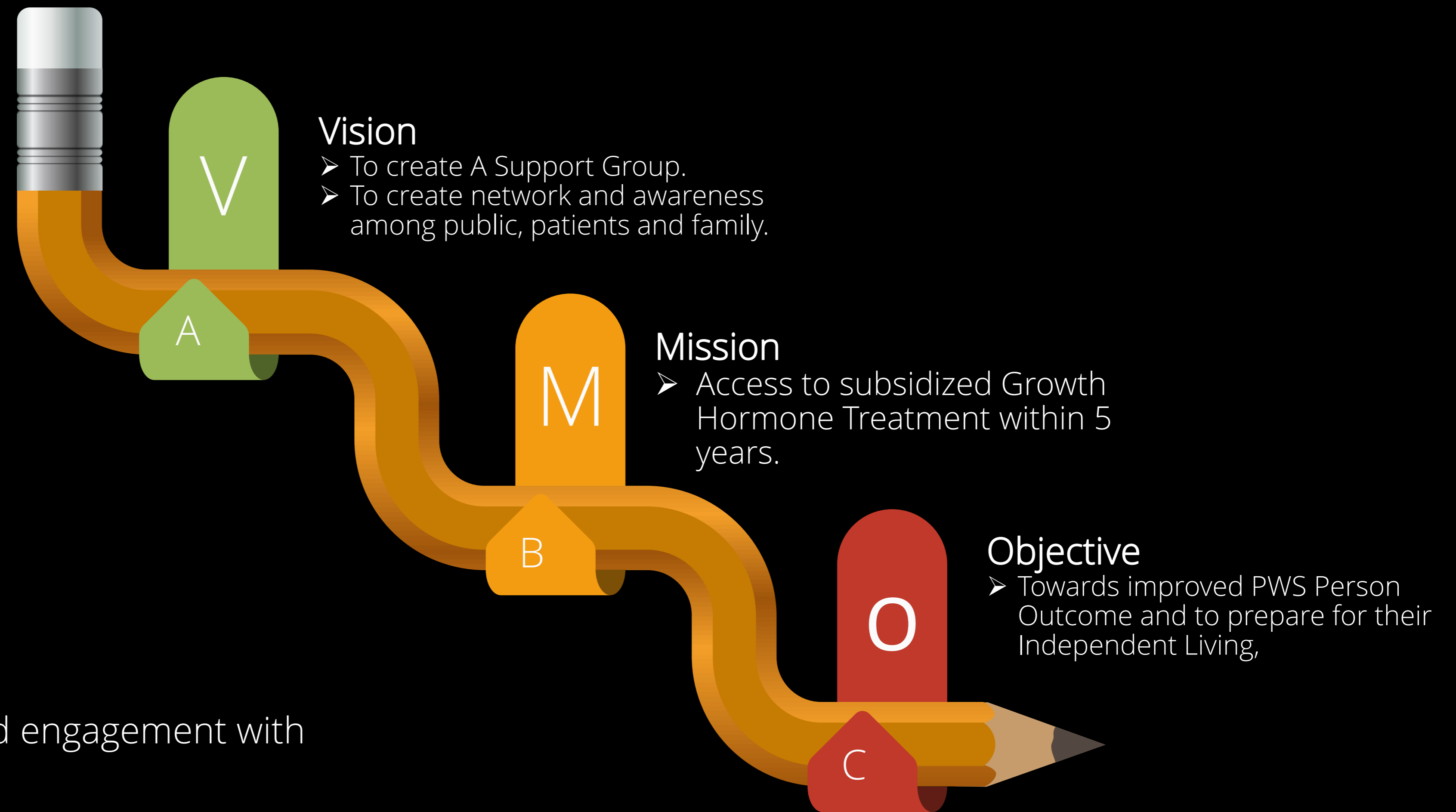
1. Setting clear Vision, Mission and Objective.



TeamWork

Is the keyword for success.

To achieve , we need a good engagement with all parties / stakeholders.



Impactful Awareness

2. Will leverage for supports

Objectives

Towards improved PWS Person
Outcome and to prepare for their
Independent Living,

80%

**INCREASE
awareness**

**Leverage
Network**

20%

Members Recruitment
To create High Impact

**Data
Collection
Our main
priority.**

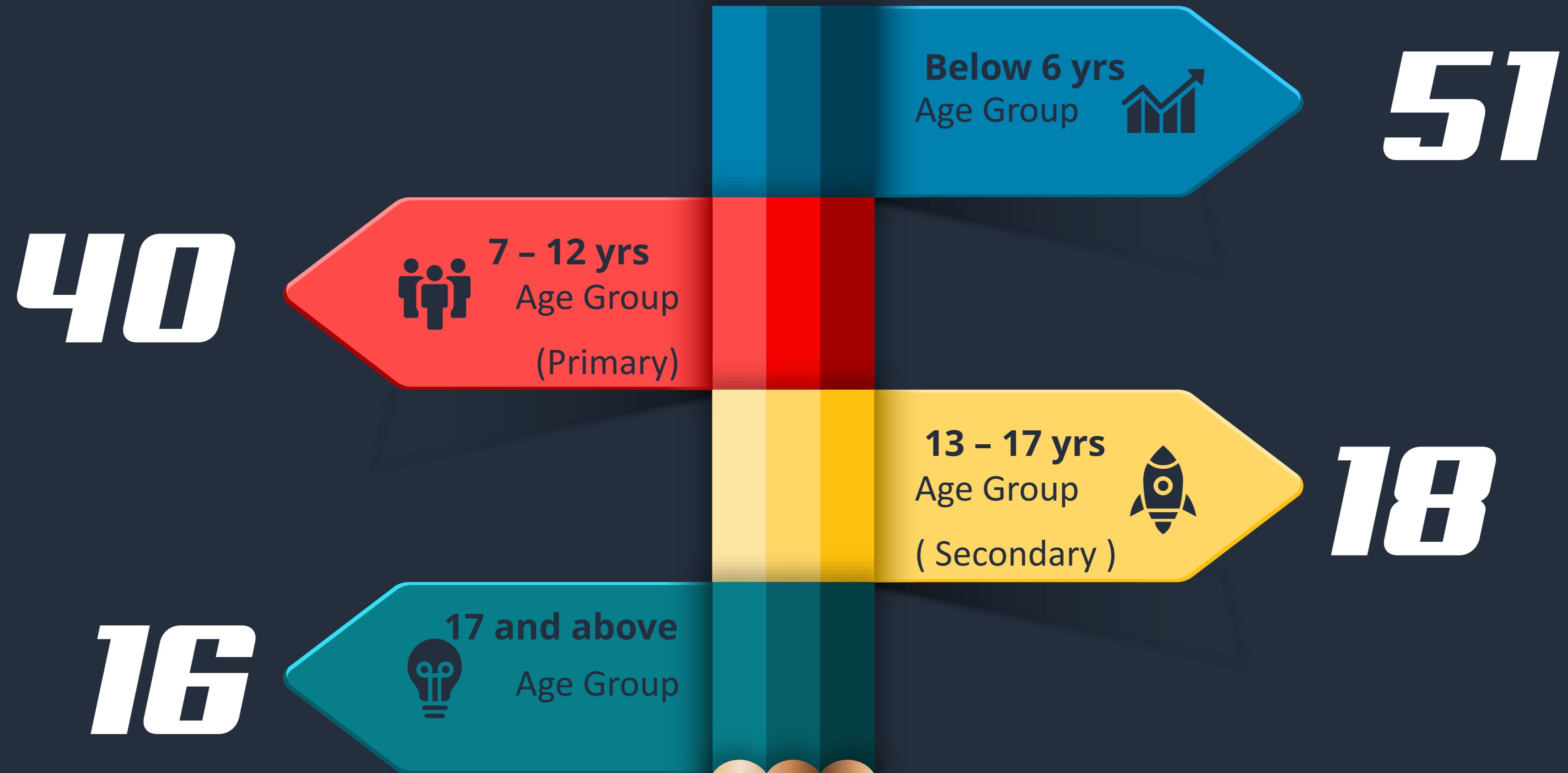
3. DATA MANAGEMENT

Data management is the most important element in our planning processes.

Good data collection will lead to a better planning.



AGE GROUP



TOTAL = 125 Patients

AGE GROUP INFOGRAPHIC

PERCENTAGE CHART



ABOVE 17 YEARS OLD

16 PATIENTS

OLDEST 25 YRS OLD



BELOW 6 YEARS OLD

51 PATIENTS



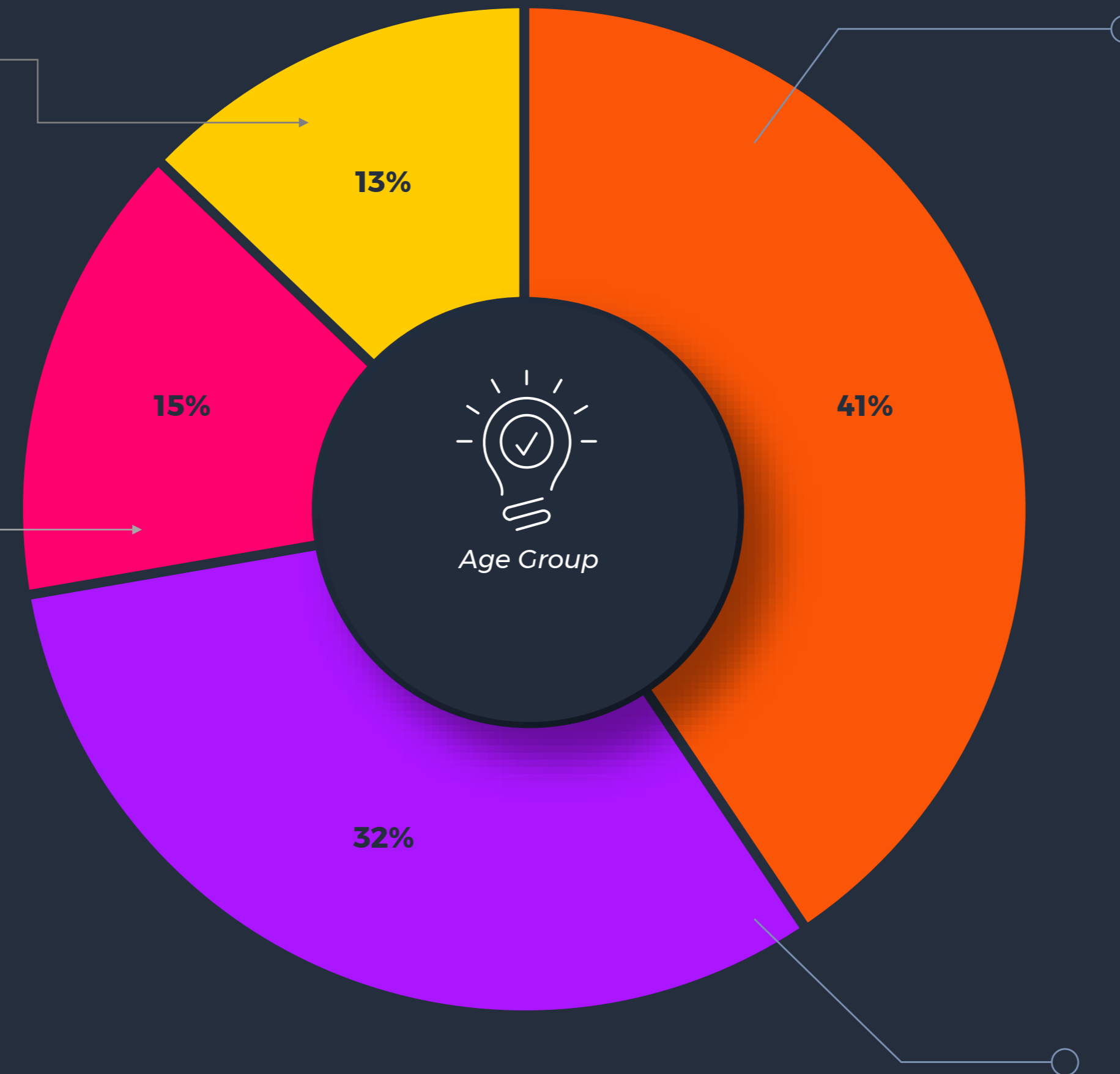
13 - 17 YEARS OLD

18 PATIENTS



7 - 12 YEARS OLD

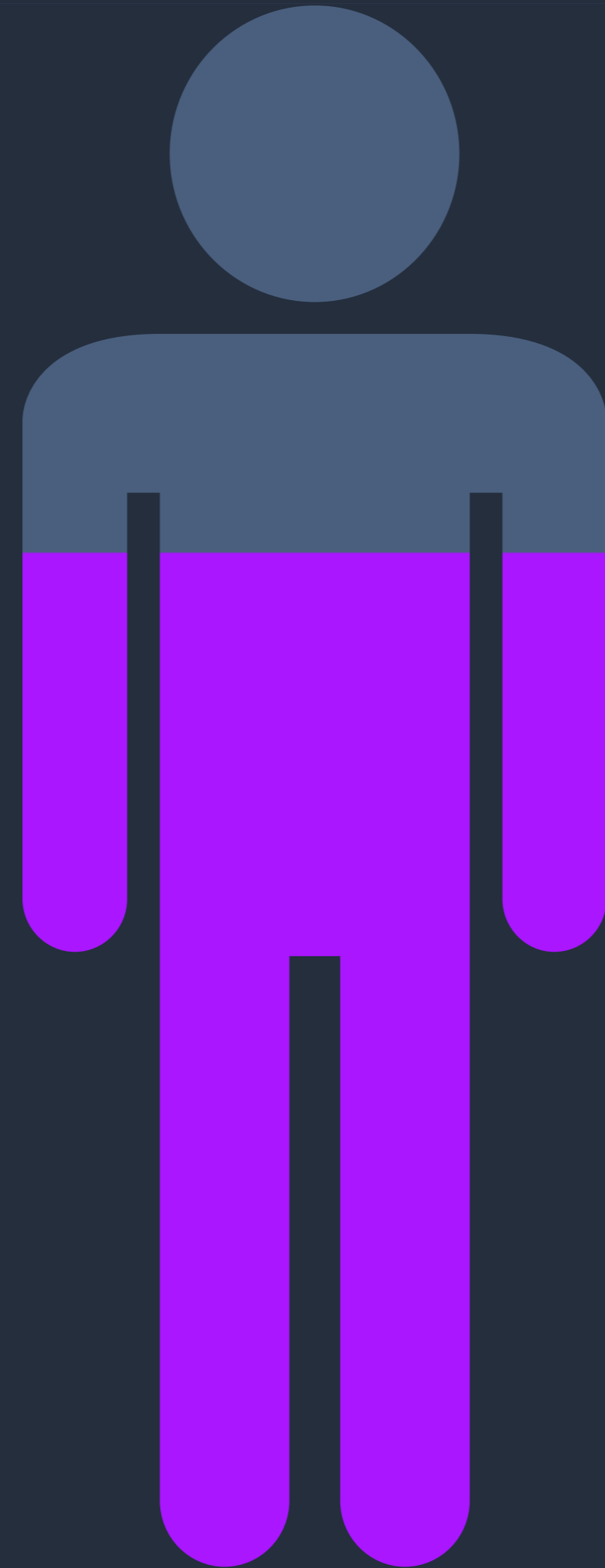
40 PATIENTS



MALE VS FEMALE CHART

57%
MALE

Male – 71 patients



43%
FEMALE

Female – 54 patients



The Importance of



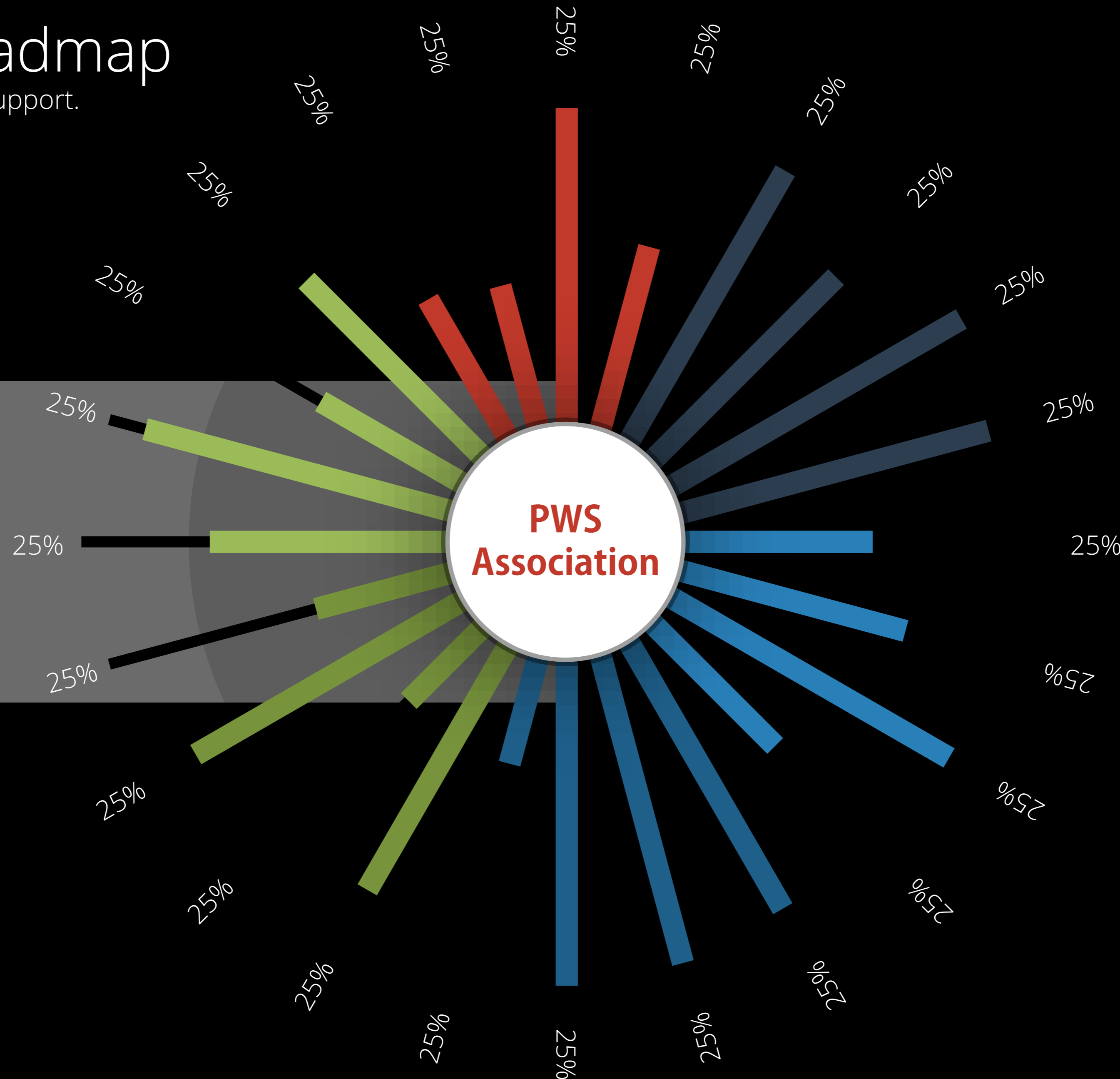
Strategic Roadmap

❖ Strategic Roadmap

o Professional Awareness and Support.

Professional Awareness and Support is vital for us,

- Ongoing Research, Education & Innovation.
- Multidisciplinary clinical & Caregiving Best Practise.
- Well Informed Families & Special Needs Educators.



Research University.

- ☐ To develop research based credentials.

Public and Private Hospital.

- ☐ Pioneering & Passionate Clinicians.

Allied Health Service Provider.

- ☐ To provide best practice Lifelong Intervention Program.

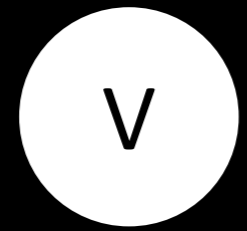
Child Development & Special Needs Educators.

- ☐ To develop their needs and prepare them for Independent Living.

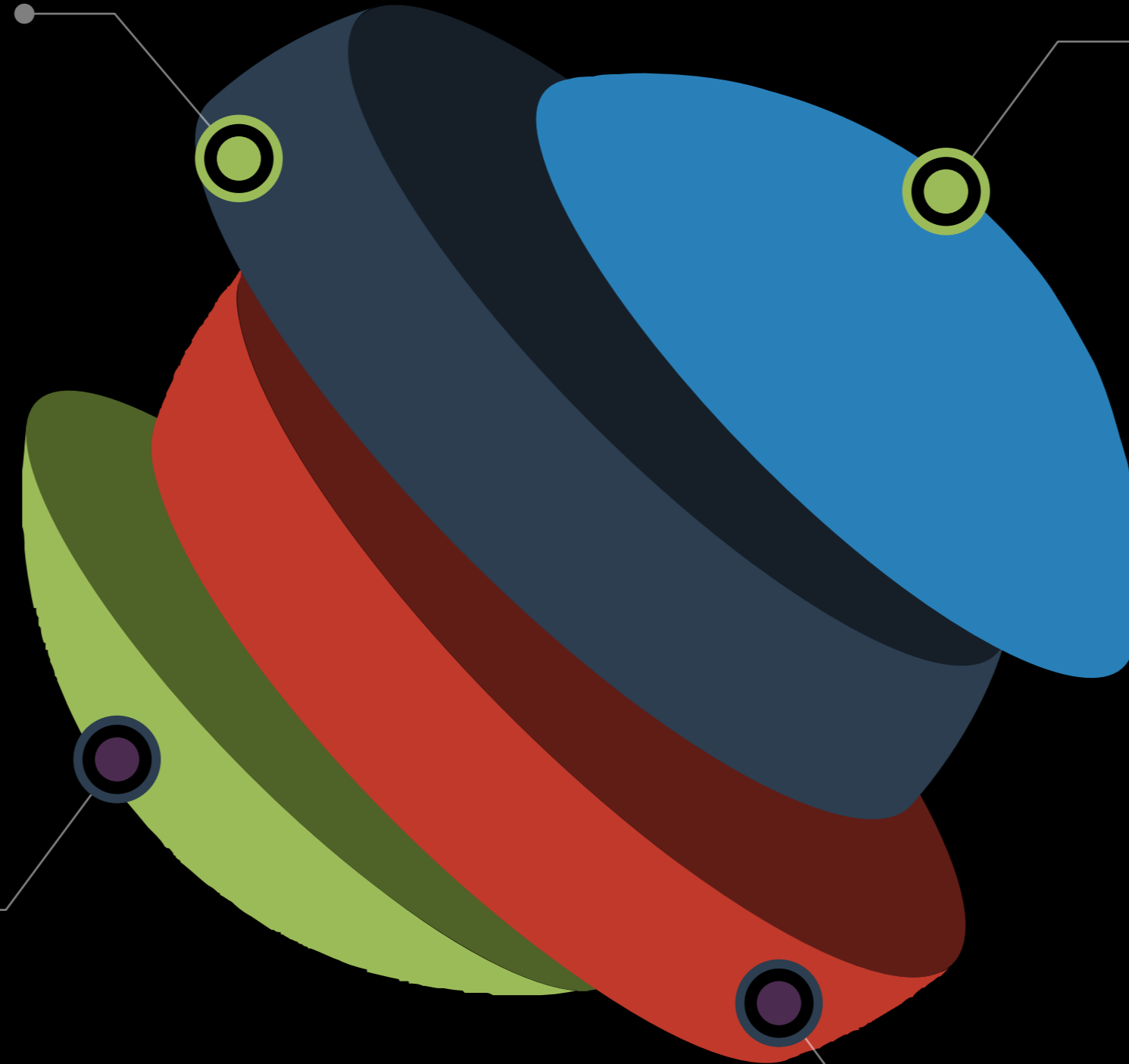
Strategic Roadmap

Professional Awareness and Support

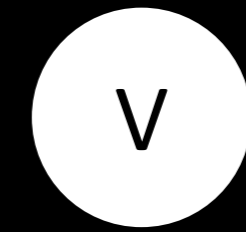
Public & Private Hospital
To develop Passionate Multidiscipline Clinician.



45%

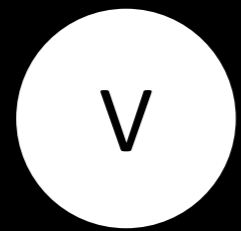


35%



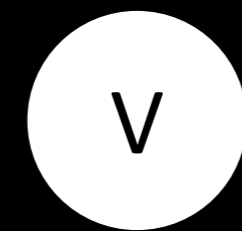
Child Development / Special Need Education Provider
To develop Independent Living Skills.

Research University
To develop Research Based Credentials.



25%

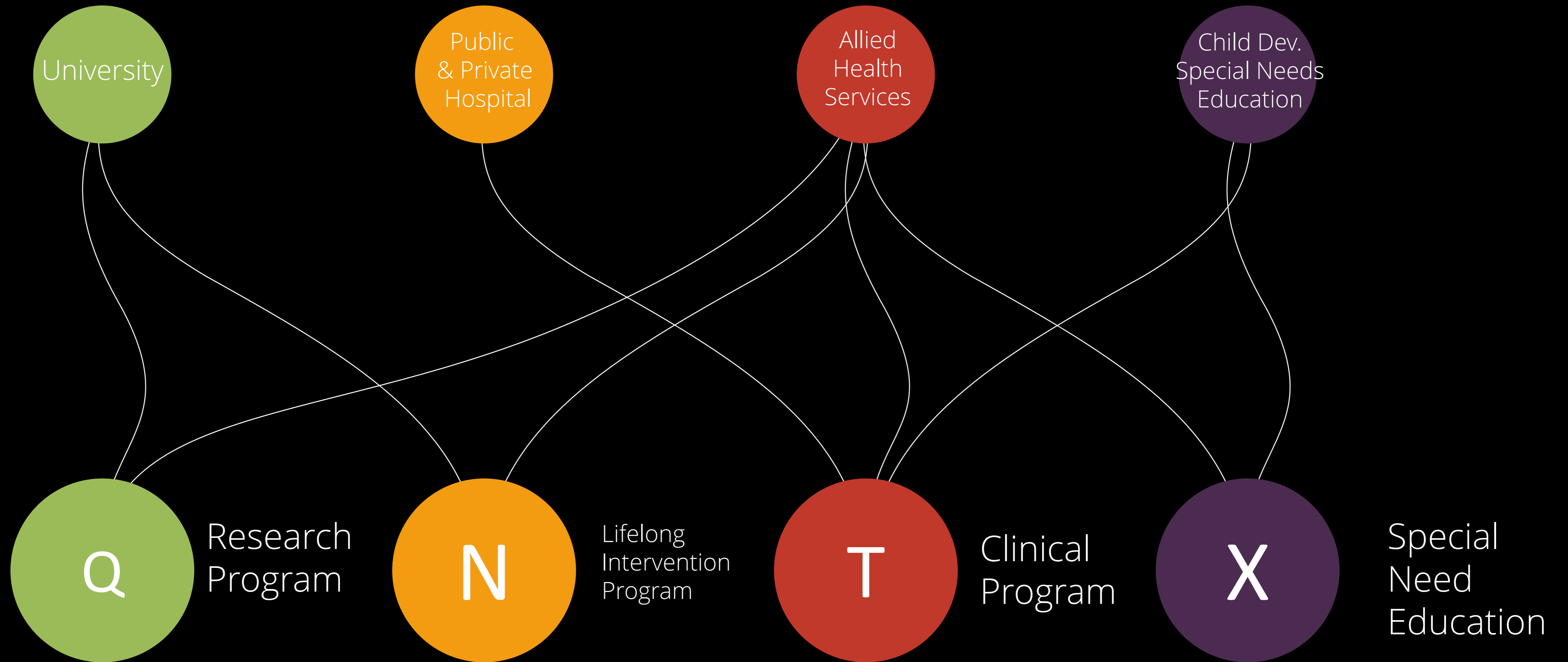
65%



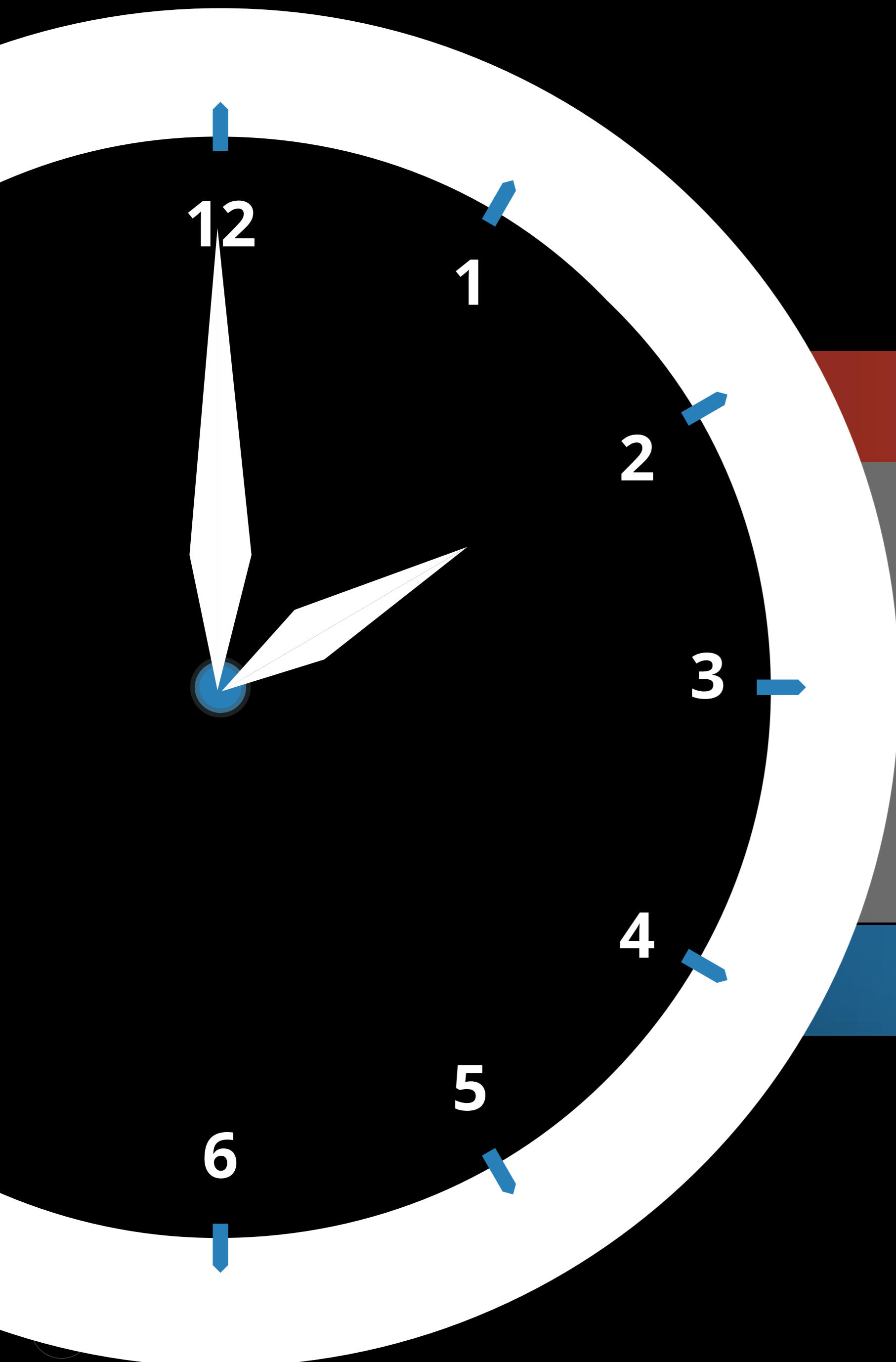
Allied Health Service Provider
To develop Multidisciplinary Caregiving Best Practices.

* The percentage is just the analogy to show the importance of the subject.

Investment Infographic Professional Awareness & Support



○ The most important element



Pharmaceutical Industry

P

Corporate Social Responsibility Program.

C

Government Policy

G

➤ PWS residence with rehab & certified Caregivers.

➤ Access to subsidized Treatment.

o The Game Changer.

❖ The important group.

- ❑ Impacting equitable coverage.
- ❑ Raise awareness and enhance visibility of PWS in all sectors including health, social, work, education and research.

P Pharmaceutical Industry

To advance and promote knowledge about medication and to ensure the availability and affordable of the drugs.

G Government Policy

To promote and enhance services in the healthcare, education, training, employment, welfare and other support services for patients and families.

C Corporate Social Responsibility Program.

To relieve financial hardship of patients and families affected with PWS.

Improve Person with PWS

Government /Policy

Pharmaceutical Industries
Clinical & Allied Health

Corporate CSR

C

Fund
To relieve financial hardship
& create empathy.

G

Governance & Policy
Will enhance and improve the life
of patients and families.

H

Pharmaceutical, Clinical &
Allied Health Service Provider
Important entities in preparing the person
with PWS towards their independent living.

ACTION **PWS** ***PLAN***

Governance & Policy Maker

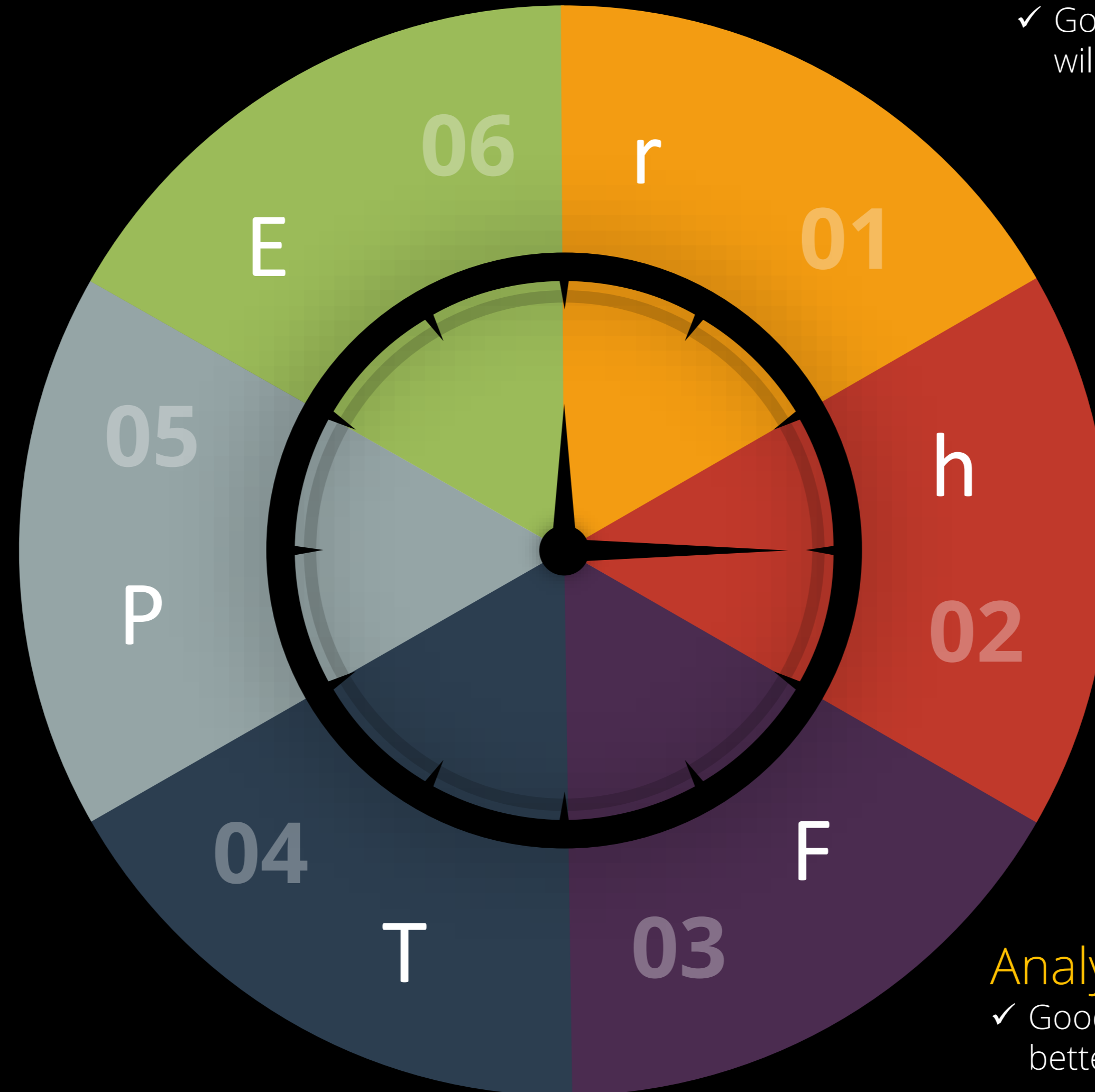
- ❑ To enhance services in the healthcare, education, training, employment, welfare and other support services for patients and families.

Contract

- ❑ Passionate Clinicians, Allied Health Services Provider, Child Development Centers and Special Needs Educators plays important roles.

Research

- ❑ To advance and promote knowledge and education by engaging in, encouraging and supporting research in PWS



Planning

- ✓ Good planning with clear direction will create a good result.

Communication

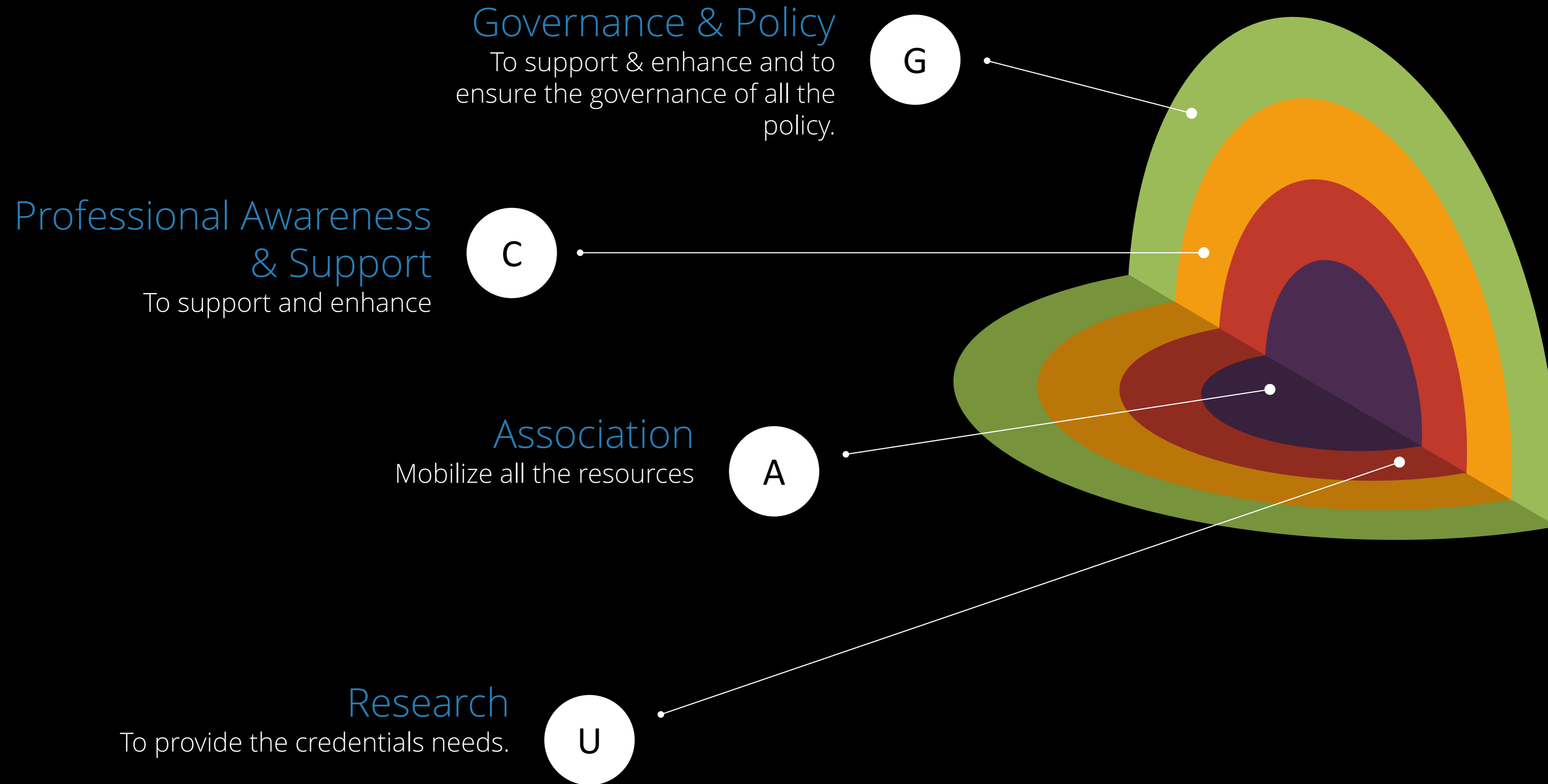
- ✓ Engagement with all parties / stake holders in the ecosystem with accurate information is vital.
- ✓ Awareness Program is on going process.

Analysis

- ✓ Good analysis will lead us to a better priorities.

To mobilize, empower **NETWORK** And build up

Mobilization & Empowerment



EMPOWERMENT

Communication
➤ Accurate information

20%

Planning
➤ To mobilize and empower the right person

50%

Analysis
➤ Priorities the needs.

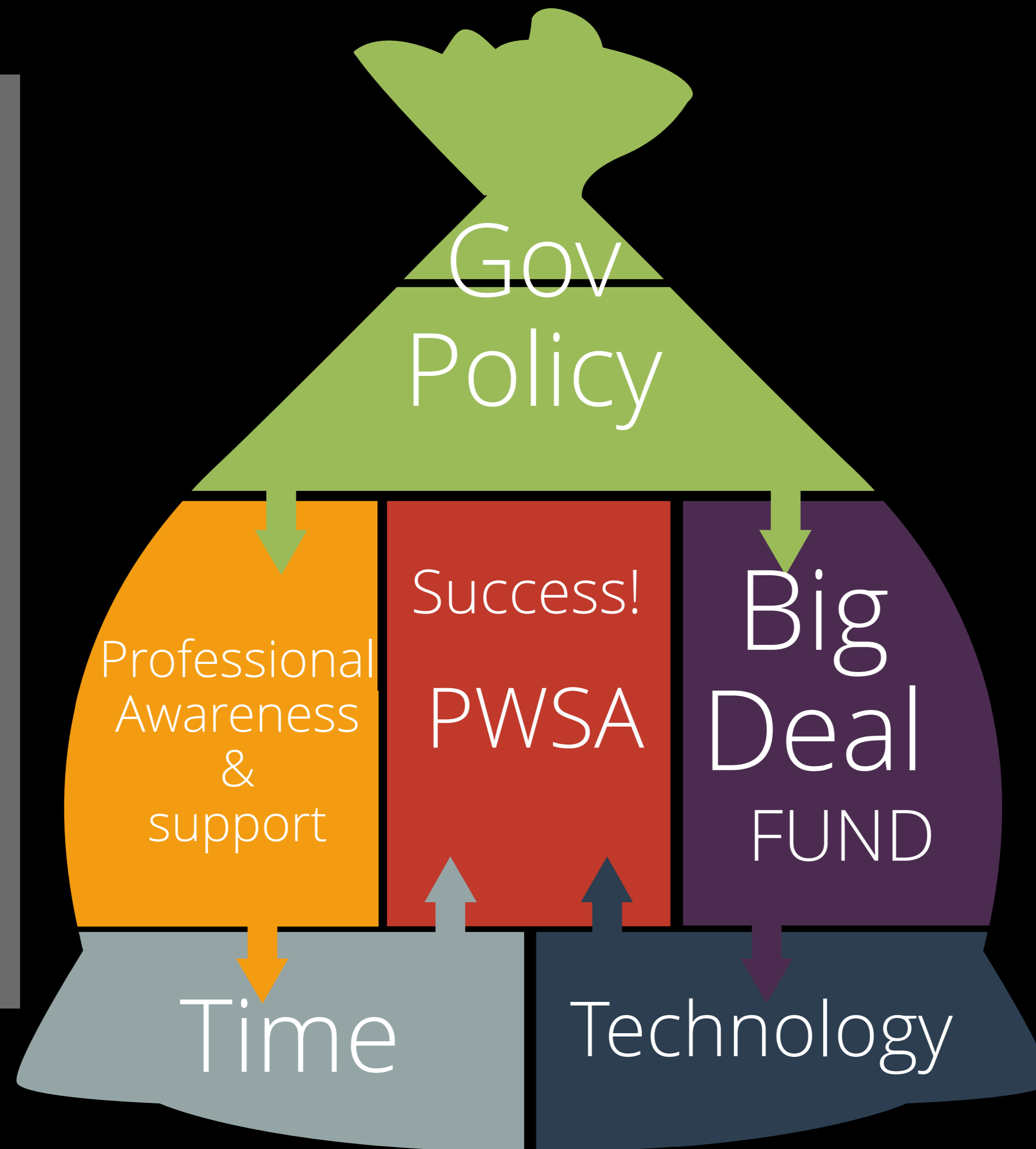
75%

* The percentage is just the analogy to show the importance of the subject.

Build up a Network

To reach out all the stakeholders in the ecosystem.

To establish network of association with organization, agencies and professionals involves in providing treatments, training and education to the patients and families.

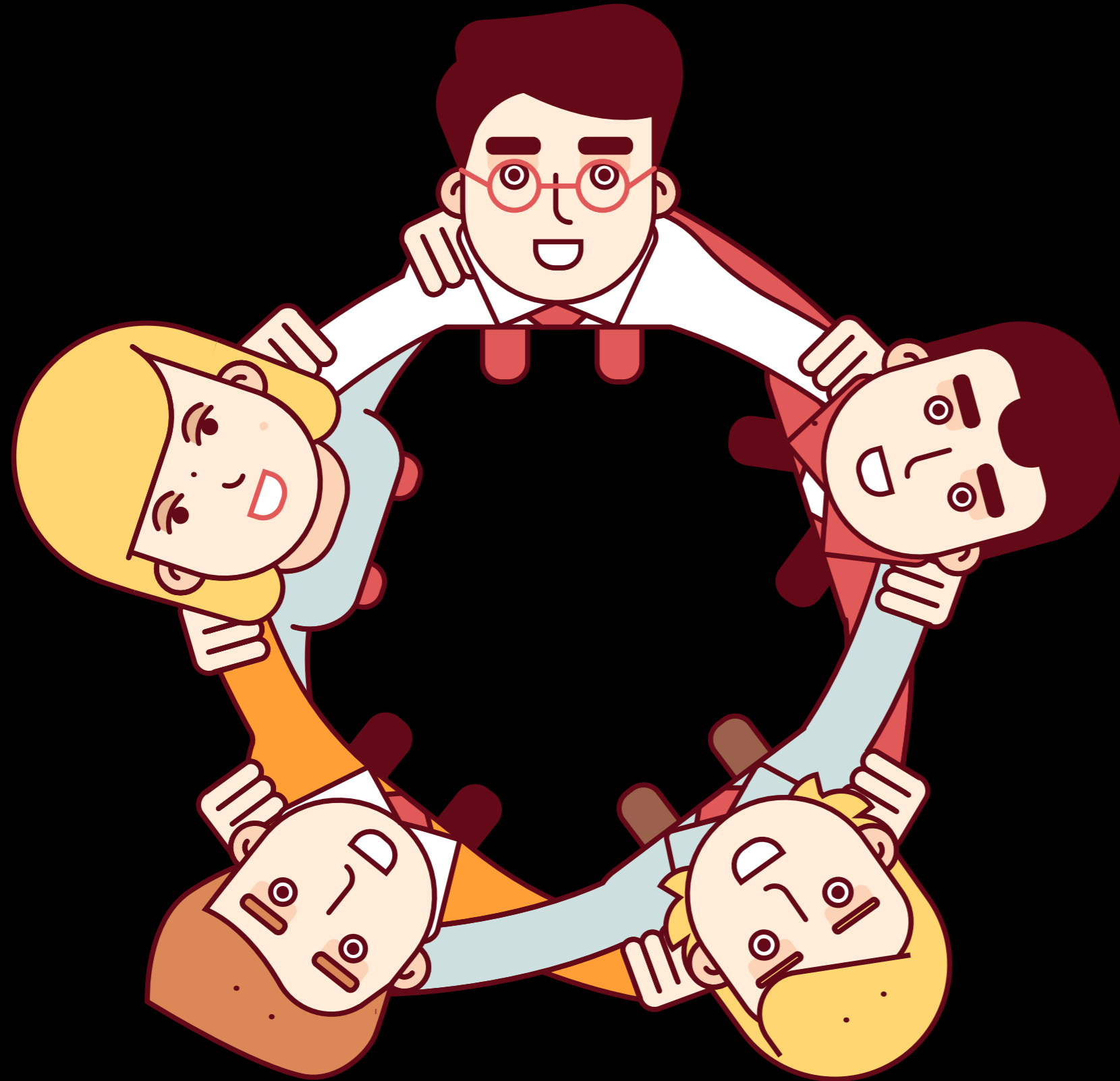


Government & Ministry.
▪ Policy maker.

Professional Awareness & Support.
▪ Important network in the Lifelong Journey.

Funds
▪ Ensure a good work-life balance and protection from loss of income for family members who are caregivers.

Time & Technology.
▪ To reach out with effective time.



Passionate & Advocacy

Good Mindset

- ❖ *We need to start first.*
- ❖ *Unite & togetherness make us stronger and resilient.*
- ❖ *Be focus*

**Working with
different
stakeholders
in the
ecosystem.**



Network around the
Globe.

Better Understanding
about PWS.
*Make the impactful & our
presence felt!!*

No One Left Behind

**We can
save PWS
community.**



IMPROVED

PWS Person Outcome

Enhance Cognition &
Independence

Family & Community
Social Economy
Benefits

Optimum Quality &
Purpose in Life

Meaningful
Employment



Strive Together WE can do it !!!



THANK YOU
PWSA