

Co-Design, Co-Production, Co-Creation

We are the TEAM!

**Cancer patients can pillars of strength
for health care professionals**



社團
法人 台灣全癌症病友連線
Taiwan Association of Cancer Patients

Wei Chieh, Gloria, Lin



Gloria Lin

☐ **Cancer Experience:**

- ✓ Breast Cancer Survivor (1995~)

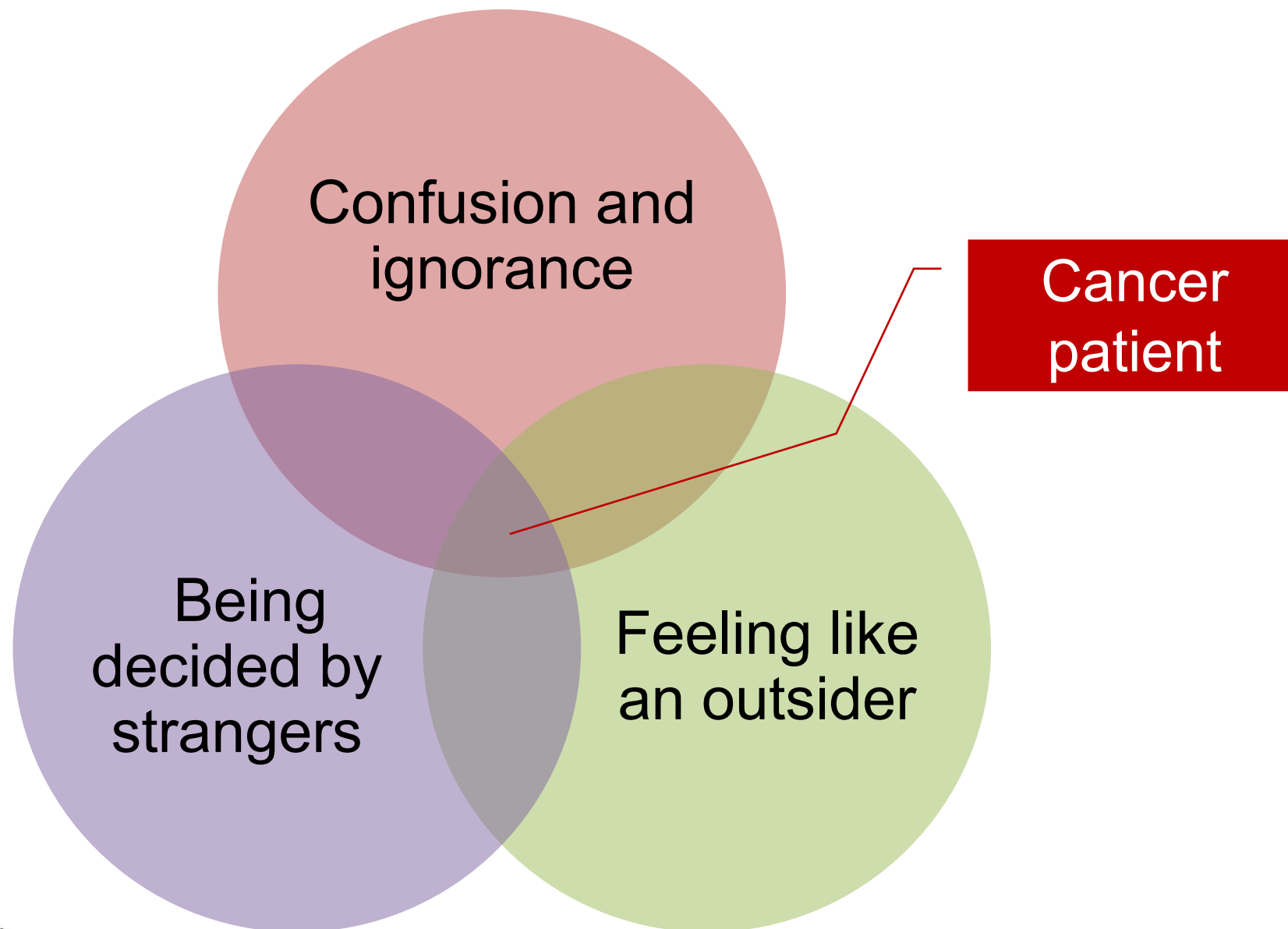
☐ **Working Experiences:**

- ✓ President, Taiwan Association of Cancer Patients (TACP) (2015~)
- ✓ Member of Cancer Research Steering Committee, Ministry of Health and Welfare, Taiwan (2013~)
- ✓ CEO/Founder, Taiwan Breast Cancer Alliance(TBCA) (2002~2018)

☐ **Awards:**

- ✓ Distinguished Achievement Award for Health Promotion, Taiwan (2015)
- ✓ UICC/RRI Teresa Lasser Award (2009)
- ✓ Medal of Honor from Department of Health, Executive Yuan, R.O.C. (2008)
- ✓ UICC/RRI Asia Pacific Volunteer Award (2006)

A look back to the past: 25 years ago



We believe in our strength

| Breast cancer stages | 5-year survival rate |
|----------------------|----------------------|
| Stage 0 | 97.5% |
| Stage I | 95.3% |
| Stage II | 88.7% |
| Stage III | 70.6% |
| Stage IV | 24.0% |

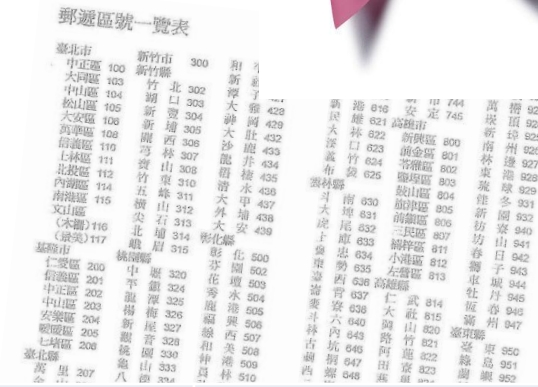
(資料取自國民健康署)

- ✓ To assist and support breast cancer patients
- ✓ To assist and support health care professionals

We believe in our strength



- ✓ List of communities at the back of envelope
- ✓ Hoping every woman in Taiwan can attend at least “one” breast cancer prevention workshop



The legend of 369 is created

| Year | Volunteers participated | Places visited | Number of people attended | Misconception corrected | Information about Health care policy improved | Willingness to have cancer screening increased |
|--------------|-------------------------|-----------------|---------------------------|-------------------------|---|--|
| 2009 | 184 | 52 | 5,167 | 10.90% | n/a | 2.80% |
| 2010 | 245 | 171 | 11,611 | 20.68% | 10.35% | 18.38% |
| 2011 | 118 | 146 | 9,917 | 19.90% | 10.10% | 18.28% |
| Total | 547 | 369/505場 | 26,695 | 51.48% | 20.45% | 39.46% |



We believe in our strength



The impact of the legend of 369

- ✓ **Implement new policy**
Free mammograms for women age 45-69
- ✓ **Mobile Mammography Service**

Mission impossible accomplished.



Breast cancer screening rate after the campaign

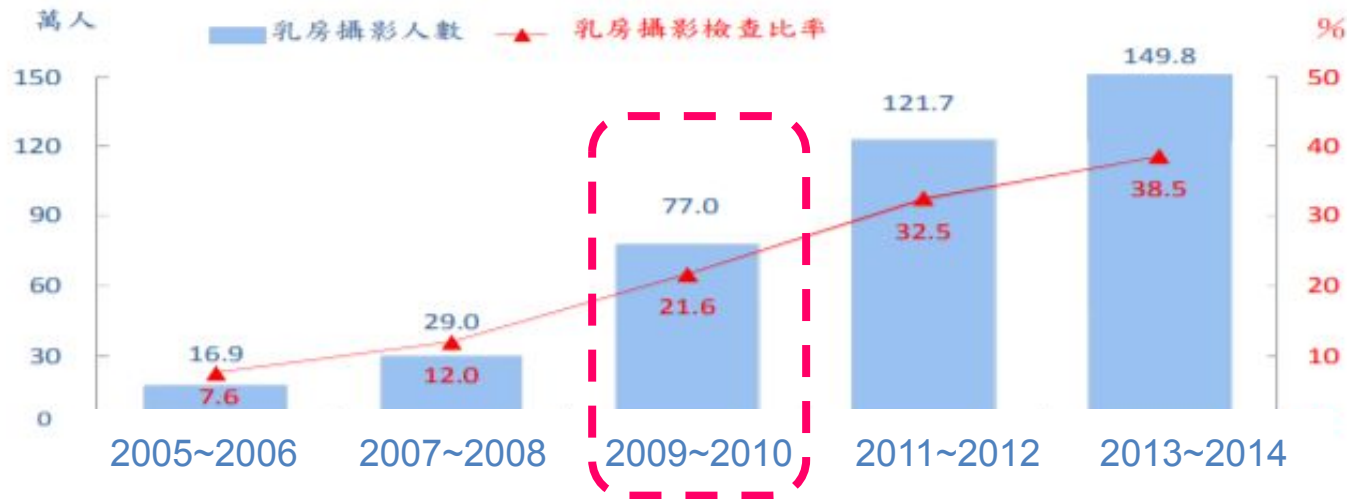


Only 38.5% of women aged 45-69 had mammograms from 2013 to 2014.

1. According to the cancer registry, the incidence rate of breast cancer ranks number one in 2012, and compared to ten years ago, there is an obvious increase. Even though the survival rate is high, the death rate is number four in cancers affected women, due to the low screening rate.

2. In order to lower the death rate, the government provides free mammograms for the groups of women with higher incidence rates. 1.498 million of women aged 45 to 69 had mammograms between 2013 to 2014 and the screening rate is 38.9%. Although the rate is still below 50%, it increases 30.9% compared to the rate from 2005 to 2006.

45-69 歲婦女 2 年內曾接受乳房 X 光攝影篩檢情形^②



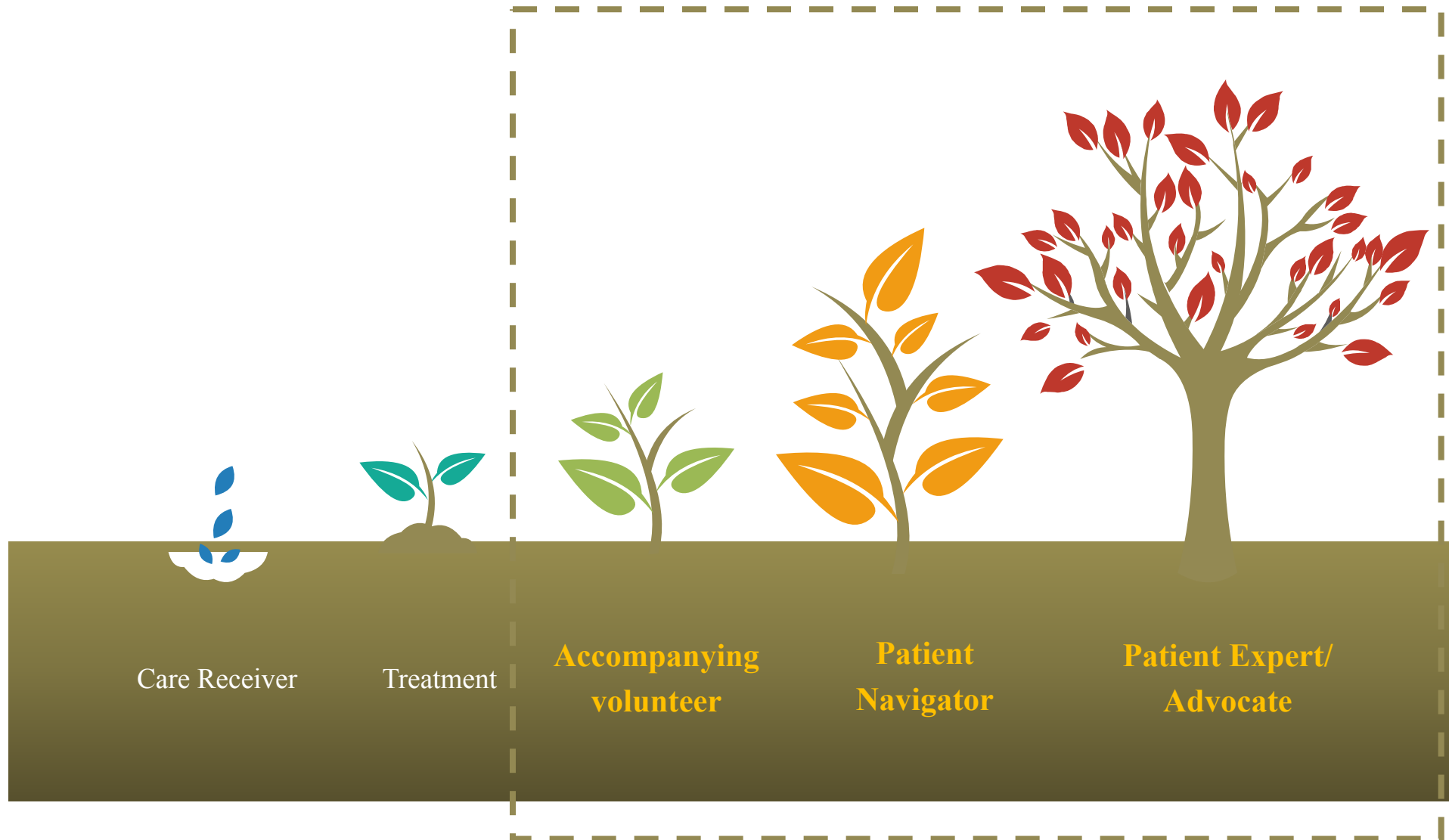
Source: Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Report 153

A vision for the next ten years

To be a gardener, waiting for the seeds to sprout and grow



Discovery the meaning of life, transfer the strength of life



The development of patient empowerment

Patient Navigator

Medical service and research helper

Treatment, Medicine development,
Research planning, Case management...

Accompanying Volunteer

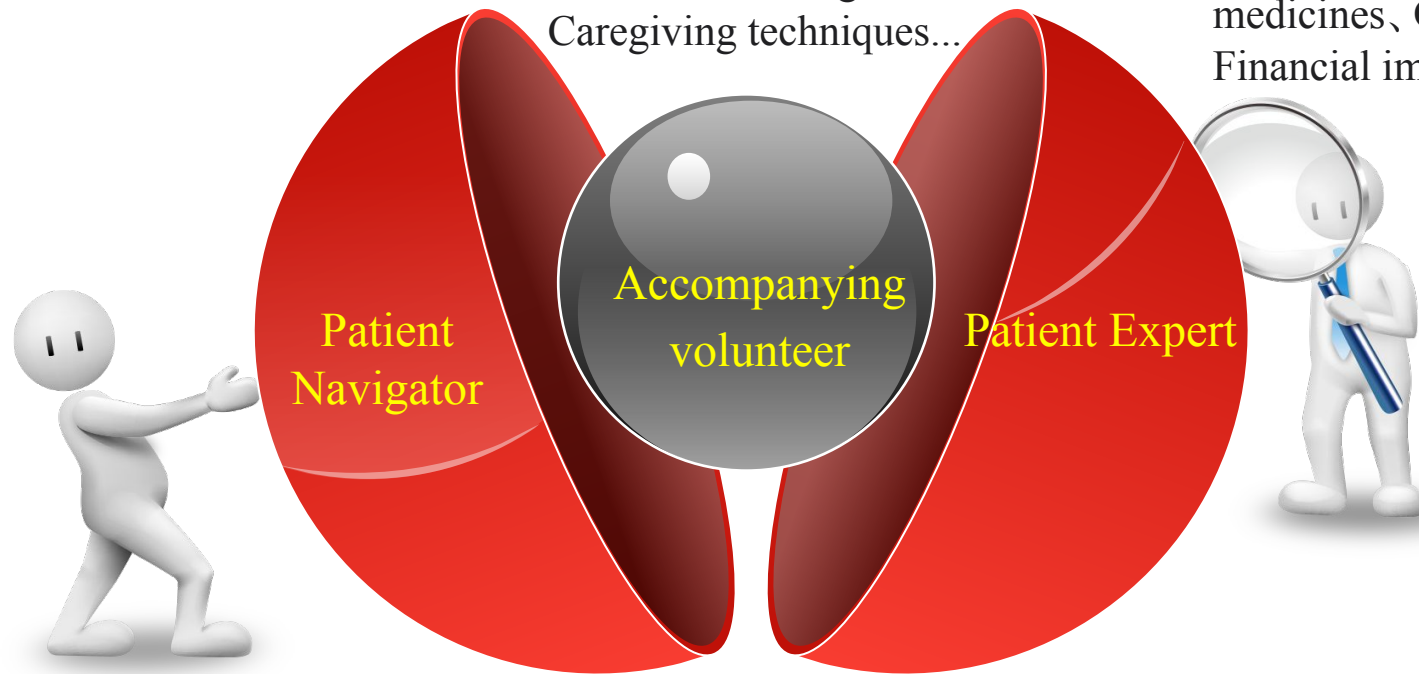
Peer support

Personal experience, the
change of roles,
Disease knowledge,
Caregiving techniques...

Patient Expert

Giving voice to patients

Patient needs, Regulation and
system,
Cost of disease, Efficacy of
medicines, Quality of life,
Financial impacts...



Patient Navigator

**Provide care with
warmth**



**Give counsel with
knowledge**

Empowerment Courses

(co-design/co-production/co-creation course, including medical and psychological training)

Relieve burdens for patients and health professionals, increase overall quality of care

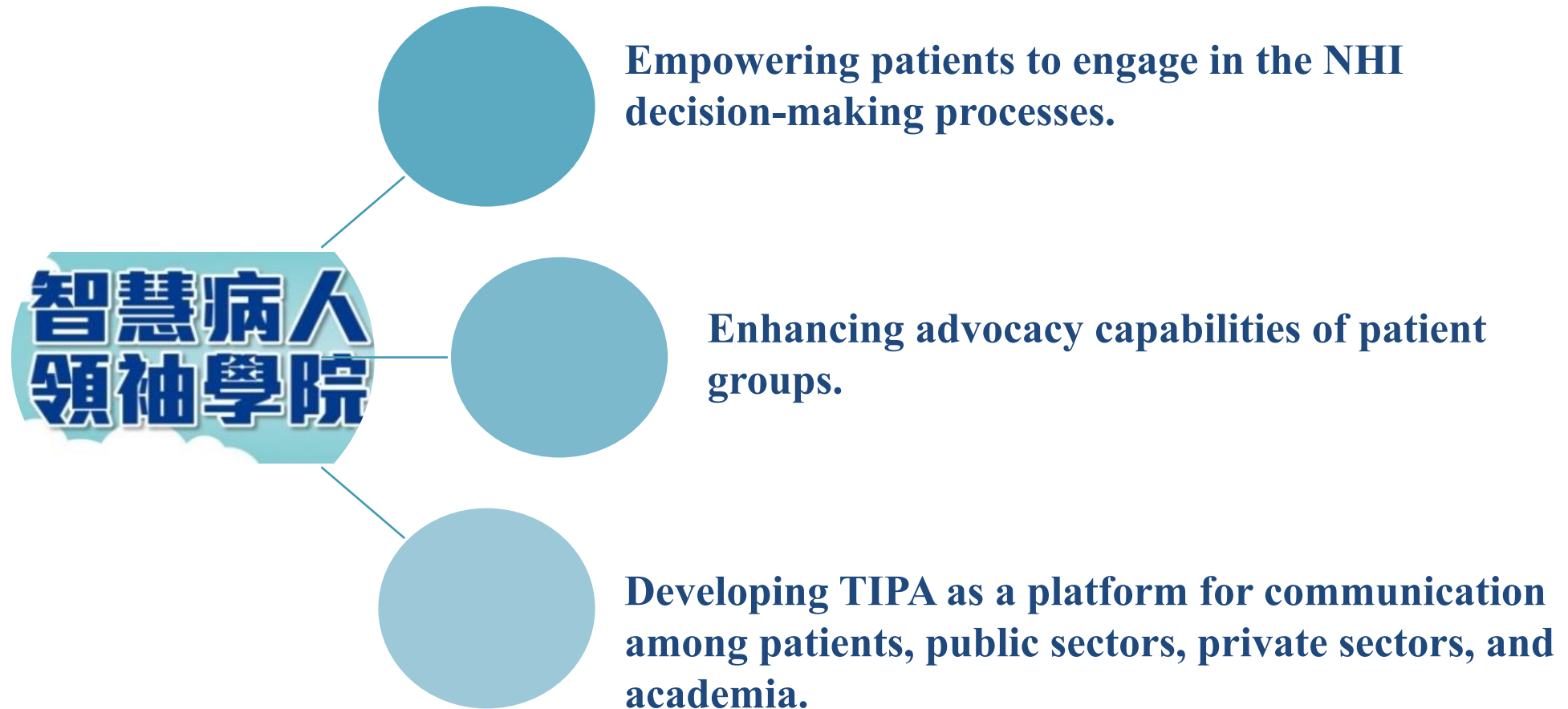
Share the workloads of case managers and physicians

- After entering medical service procedures, help patients in communication and connection
- Assist medical professionals with health education, patient communication, or administrative works.

Provide advanced and professional psychological supports



The Missions of TIPA



Patient Expert

Systematical Training for Patients to Become Patient Experts

Concentration on Patient Report Outcome and Patient Evidence

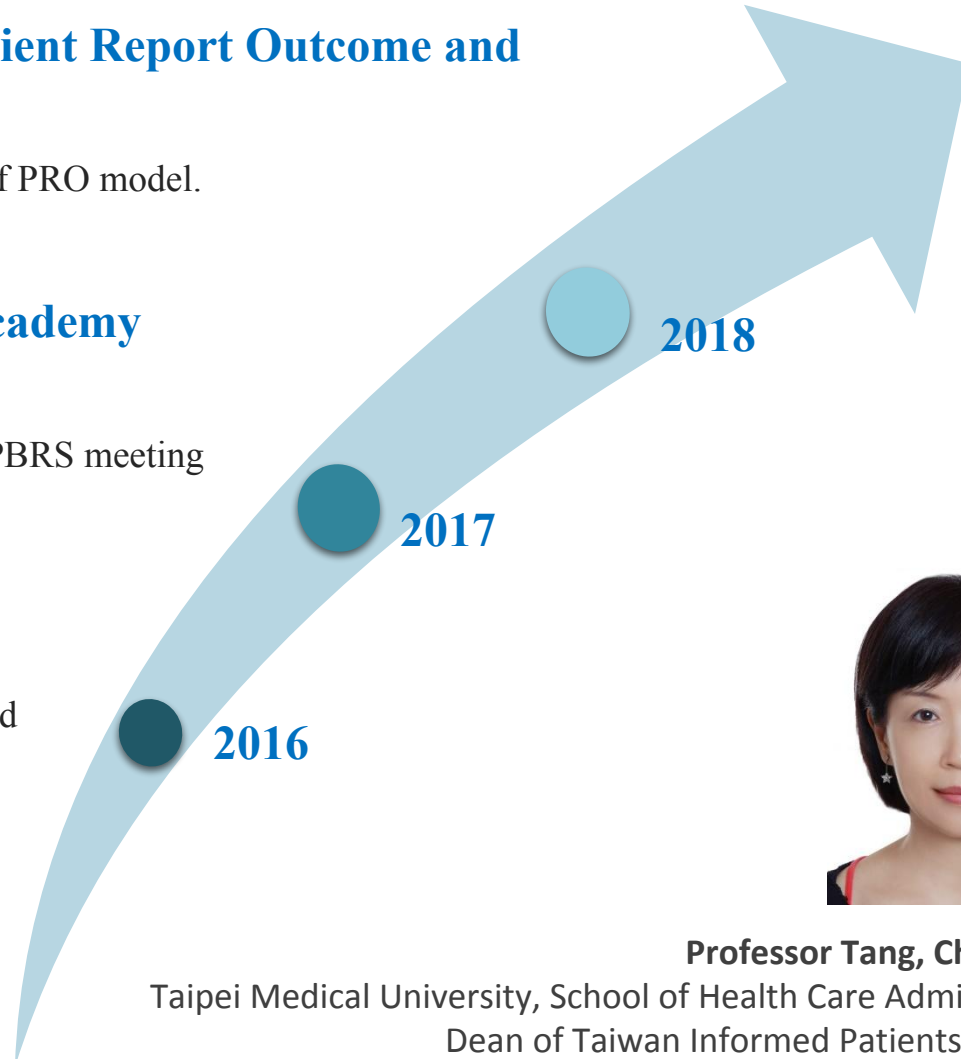
Workshops in development of PRO model.

Taiwan Informed Patients Academy (TIPA) founded

Periodical training courses and Model PBRS meeting

Two-day Lectures,

Fundamental knowledge in NHI system and HTA processes



Professor Tang, Chao-Hsiun

Taipei Medical University, School of Health Care Administration

Dean of Taiwan Informed Patients Academy

Taiwan Association of Cancer Patients

- Taiwan Alliance of Cancer Patients (TACP) was established on May 6th, 2015.
- It is an organization for patients of all kinds of cancers.
- With patients as the core of our organization, we aim to unite all cancer patients in Taiwan, to provide educational programs and workshops, and to advocate for patient rights in the areas of health care, national health insurance, social support, and even the legislative system.
- The motto of TACP is “Self-helping, Helping each other, and Helping others”. We want to help them not only to connect with social and financial resources, but also to uphold their patient rights.

Our Patient Services

- Patient empowerment for engagement in health policy decision-making.
- Patient perspective and Requirement Survey.



- Cancer Information.
- Patient Guideline.
- Information for a Healthy Lifestyle.
- Medical Lectures and online courses.

- Web Access to acquire information of clinical trial and patient support program.

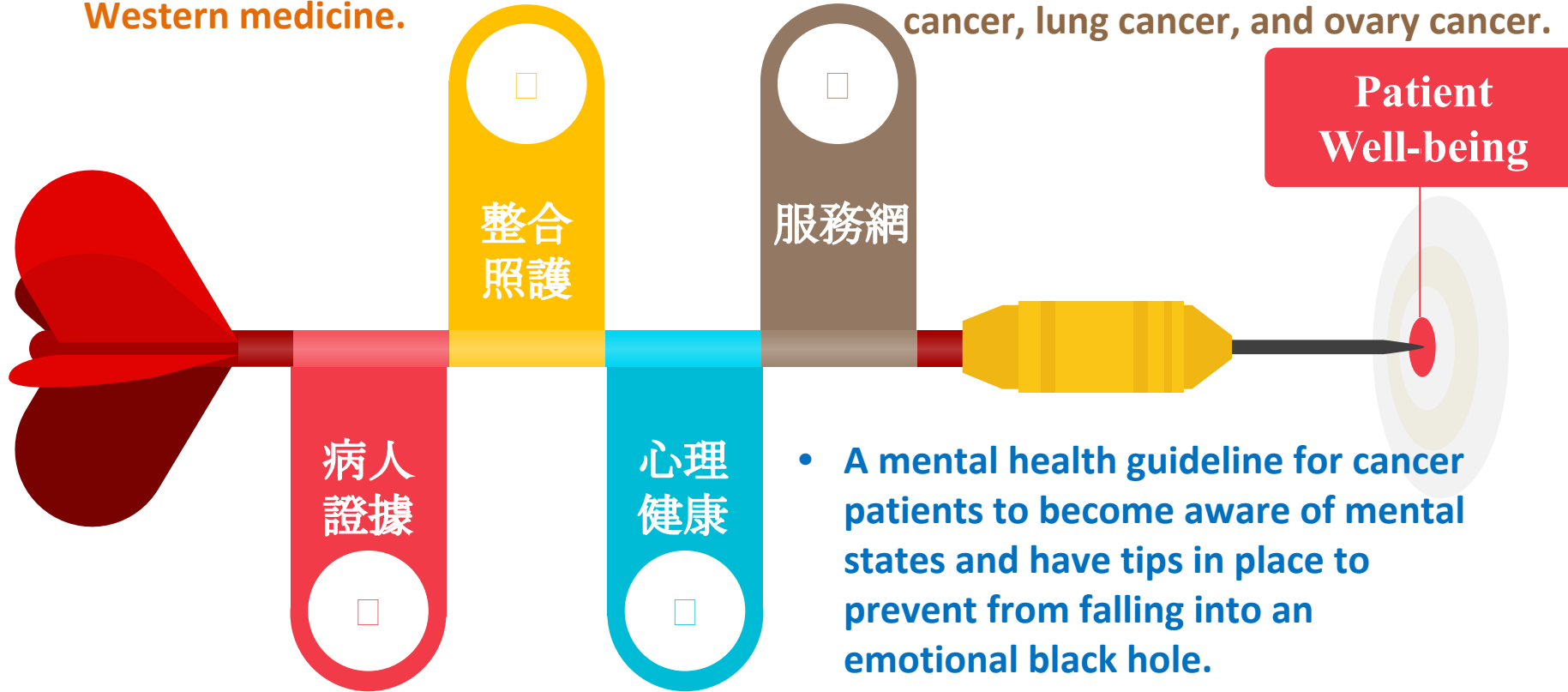


- Online communication via social media.
- Telephone counselling service.
- Patient Workshop.
- Internet Radio Station.

Our Blueprint

- A Comprehensive cancer care by integrating Traditional Chinese and Western medicine.

- Construction of a patient support network, especially focused on breast cancer, lung cancer, and ovary cancer.



- A model for collection, analysis, storage and retrieval of patient report outcome(PRO) data.
- A PRO database to generate an evidence-based patient information(EBPI).

- A mental health guideline for cancer patients to become aware of mental states and have tips in place to prevent from falling into an emotional black hole.

**“ As is a tale, so is life: not how long it is,
but how good it is, is what matters. ”**

-Lucius Annaeus Seneca

Thank you~

Taiwan Association of Patient Cancers (TACP)

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