

**Confederation of Medical Associations in Asia and Oceania (CMAAO)**

2017.9.14 Hilton Tokyo Odaiba

# **End of Life Care**

President

Japan Association for Development of Community Medicine

Ex-President

The Japanese Association of Medical Sciences

**FUMIMARO TAKAKU**

# **Confederation of Medical Associations in Asia and Oceania (CMAAO)**

2017.9.14 Hilton Tokyo Odaiba

Fumimaro Takaku

I have no COI with regard to my  
presentation

# Chairman of Bioethics council of Japan Medical Association

2000～2002 (VII th)

2004～2018 (IX th～XV th)

Confederation of Medical Associations in Asia and Oceania (CMAAO)

2017.9.14 Hilton Tokyo Odaiba

# **End of Life Care for the Elderly**

President

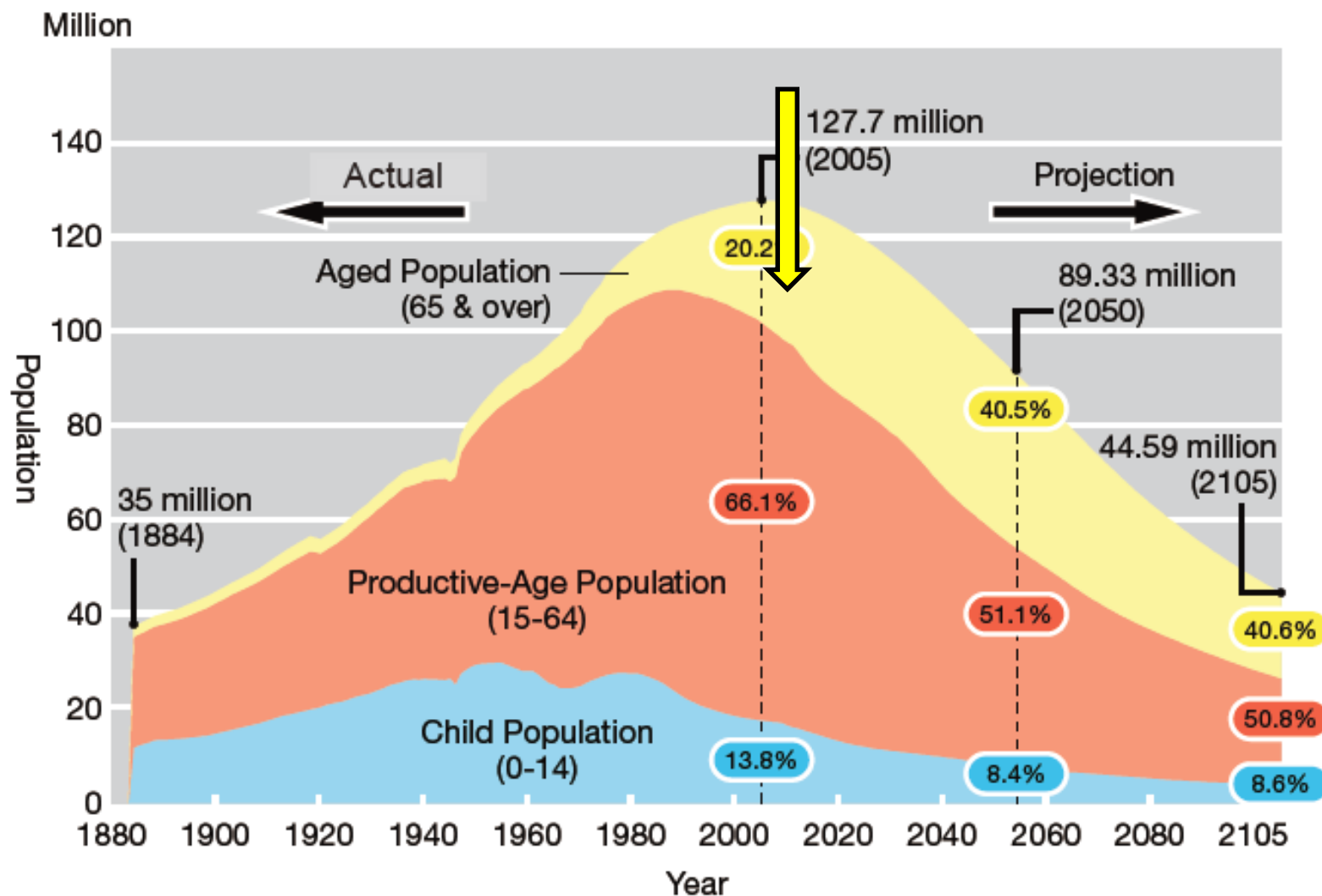
Japan Association for Development of Community Medicine

Ex-President

The Japanese Association of Medical Sciences

FUMIMARO TAKAKU

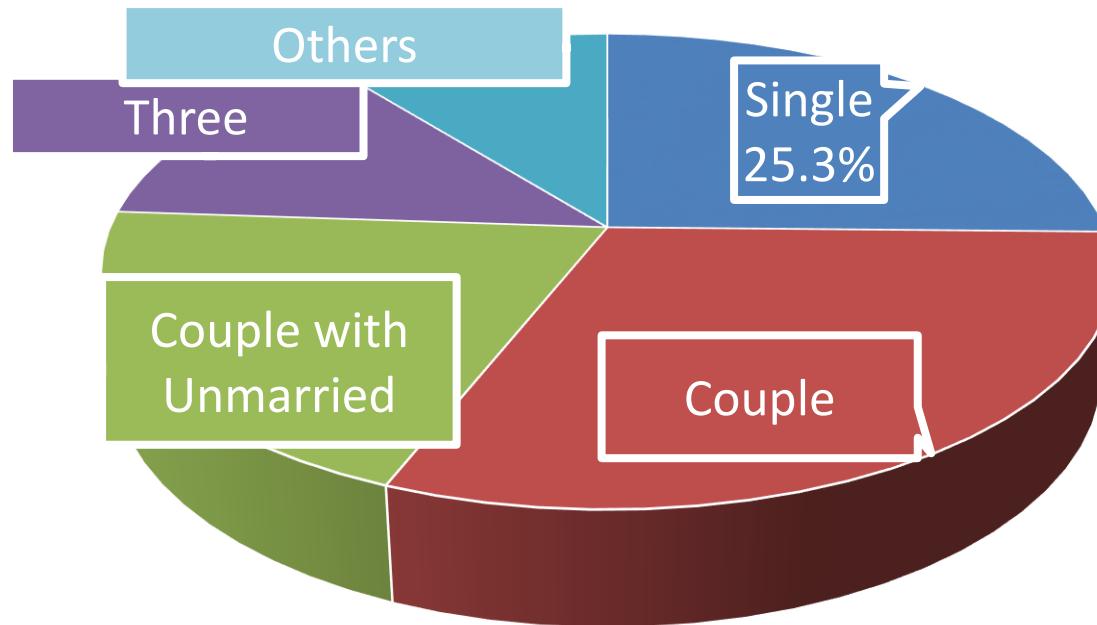
Population at age 65 and over are 34.6 millions as of Oct 2016, shares 27.3% of total Japanese.



Soichiro IWAO, Japanese Association for Dying with Dignity, Presented at WFRtD Meetings in Amsterdam 2016 Revised Aug 14 2017

## Households with heads aged over 65 years

Comprehensive Survey of Living Conditions, 2014 MHLW



Households with heads aged over 65 years: 23.6 Millions  
(46.7% of Total Number of Households: 50.4 Mil.)

## Prevalence of People with Dementia

People with Dementia who need support

2.8mil

People with Dementia who currently  
does not need support

1.6mil

People with Mild Cognitive  
Impairment

3.8mil

People without  
handicap

20.5mil

4.4mil : 15% of  
Total population  
over 65 yo

population over 65 years old : 28.7 mil

# Japan : An Aged Society in 2025

## 35 mil of People over 65 years

→Baby-boomers reach elderly population in 2015, and it becomes peak ten years after.

## 4.7 mil of People with Senile Dementia

→from 3.1 mil in 2010, which shares 10% of populations in 2015 and 13% in 2025.

## 6.8 mil of solitary life at age over 65 years

→40% (20 mil households) of total households with heads are single and shares 1/3.

## 1.6 mil of Total Death

→currently 1.2 mil of death per year. A number of death will skyrocketing.

## Rapid Ageing of the City Population

→extreme aging ongoing in some parts of suburban housing complexes



# 2006 Report

9<sup>th</sup>

Bioethics Council of Japan Medical Association

Concerning End of Life Care Again

“End of life care” is medical treatment in circumstances where you must keep in mind that “the time until death is limited.”

We believe that, for the patient, how much QOL is preserved is more important than prolonging life, and encourage a change in mentality such that the aims of treatment make both cure and care important .

While the evaluation of QOL is based on the patient’s sense of value, respect for the patient’s opinion is important.

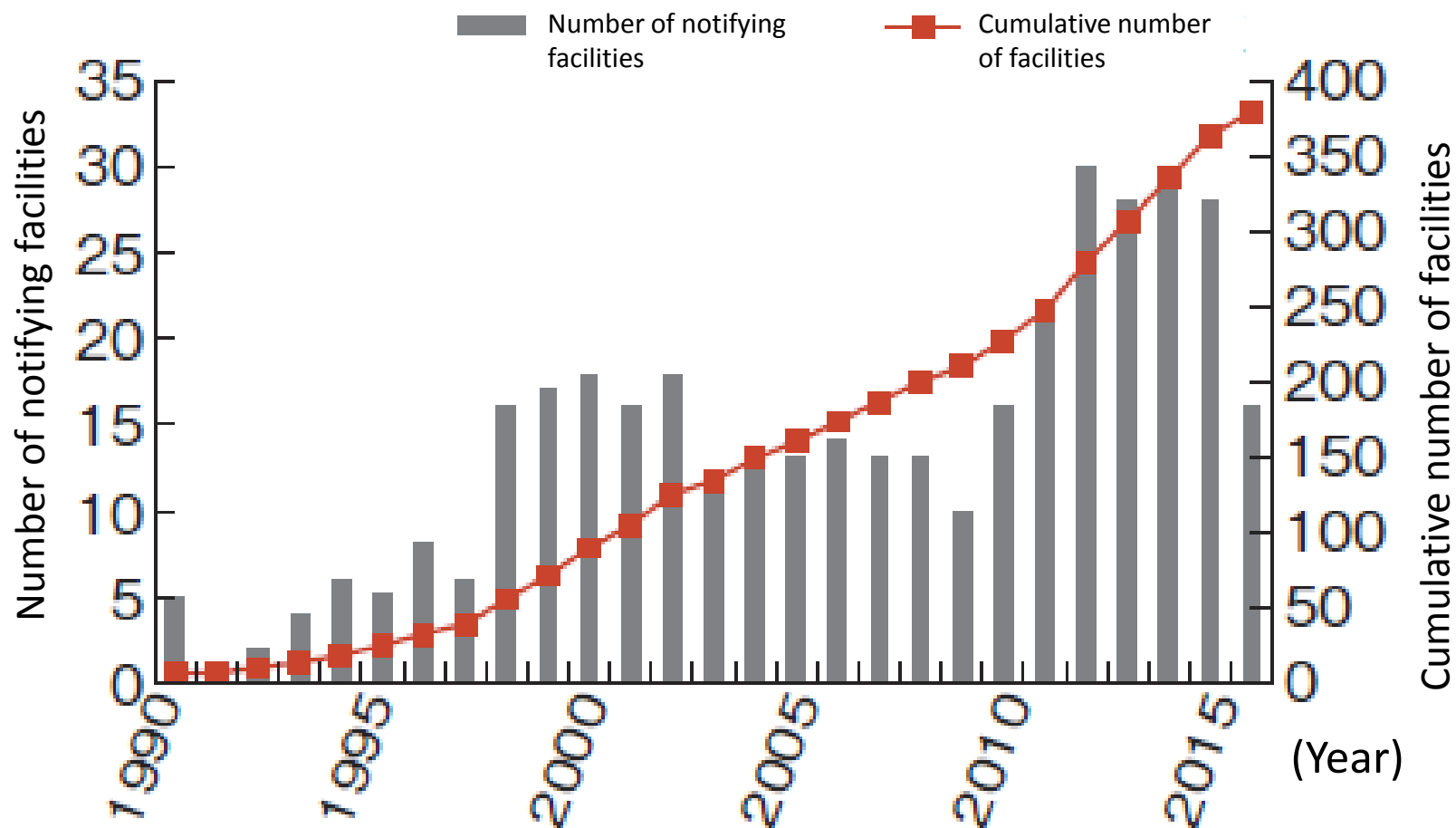
We also have to consider the presence of the family surrounding the patient. In light of this, we conclude that “a so-called joint self-determination based on full discussion with the family is preferable to self-determination by the patient alone.”

Palliative care became covered by the National Health Insurance in 1990 and it is pointed out that hospices and palliative care wards are currently increasing. Even so, compared to the UK and America, residential palliative care has still not spread.

In this report, we raise “palliative care for intractable pediatric diseases,” and assign pages to the points especially required with regard to the end of life period of newborn children and infants.

Malignancies and AIDS are wholly covered by NHS. But cardiovascular diseases and intractable disease are partially covered by NHS.

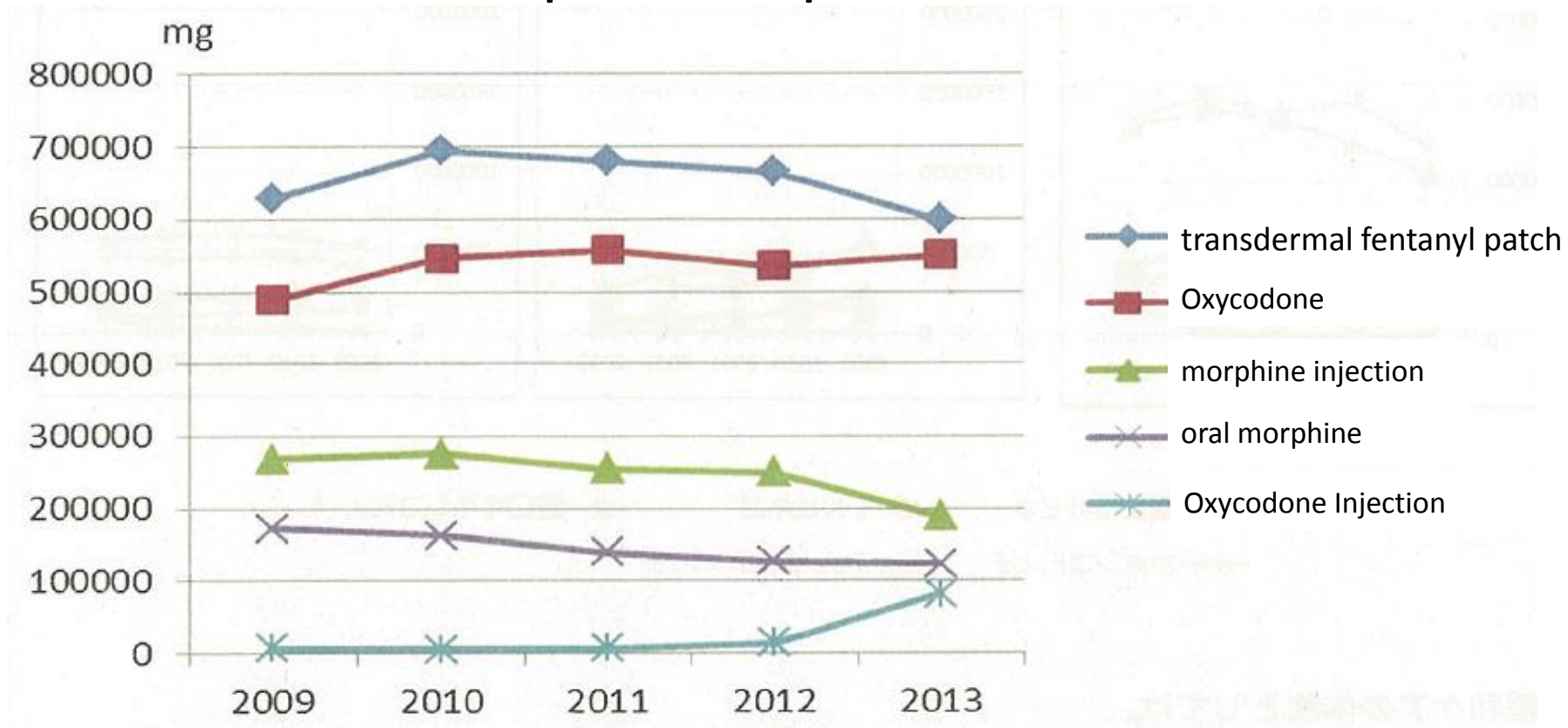
## Annual trend in the number of facilities with notifications received for hospitalization in palliative care wards



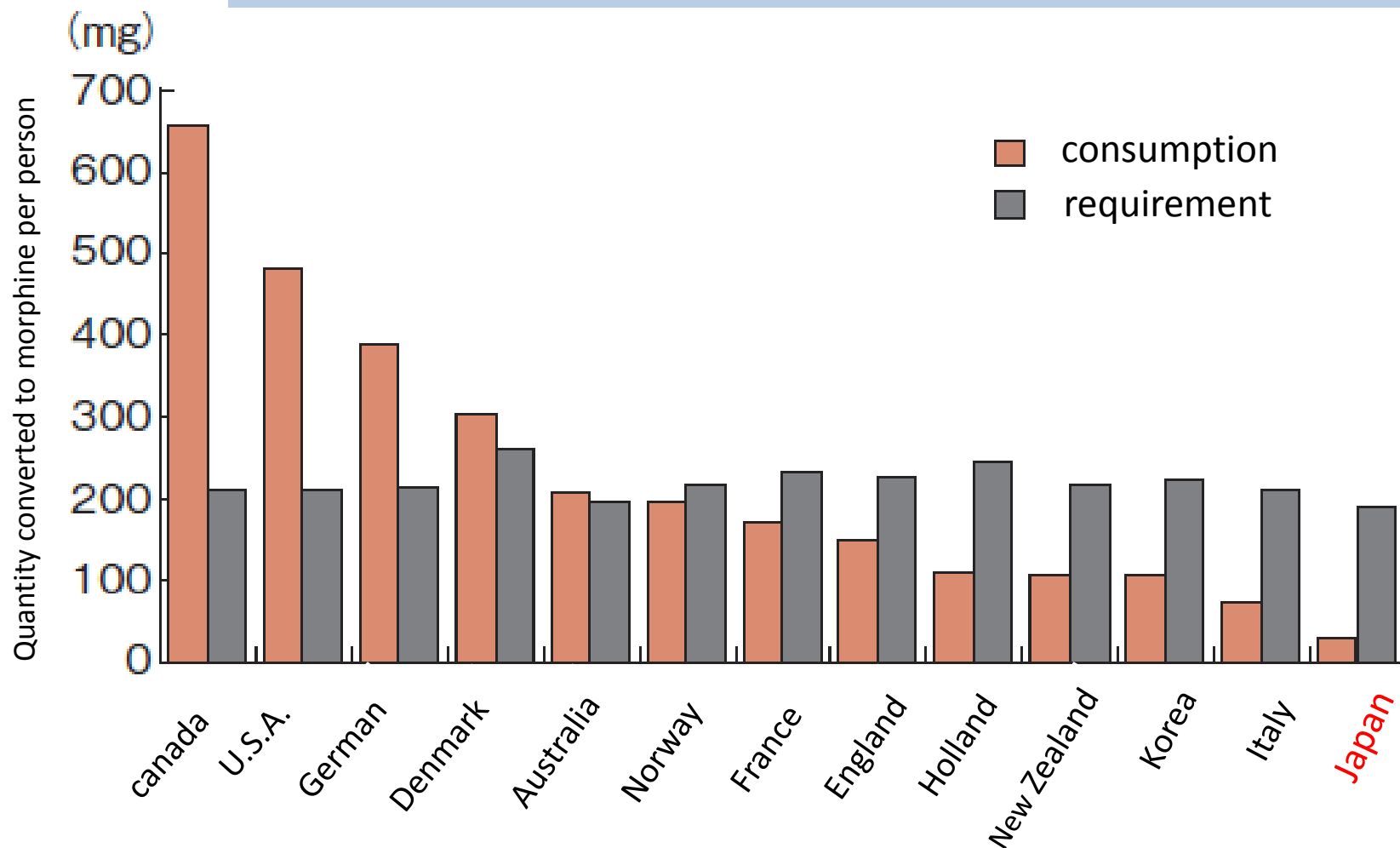
Akitoshi Hayashi, "Results for palliative care in Japan"

*The Journal of the Japan Medical Association*; 2017, 146(5), 917-920

## Trend in opioid consumption



## Required quantity and consumption of medical narcotics by country (2010)



Shigeki Yamaguchi et al.

"From the pain clinic doctors' perspective," *The Journal of the Japan Medical Association*; 2017, 146(5), 932-936, Quotation, modification

In the chapter of the report titled “Death with dignity,” it says that prolonging life with artificial respirators and tubal feeding, etc., conversely forces pain on the patient and creates a loss of dignity itself. Rather, ingenuity that realizes “peaceful death” is required.

Concretely, places for death in Japan are inclined towards hospitals.

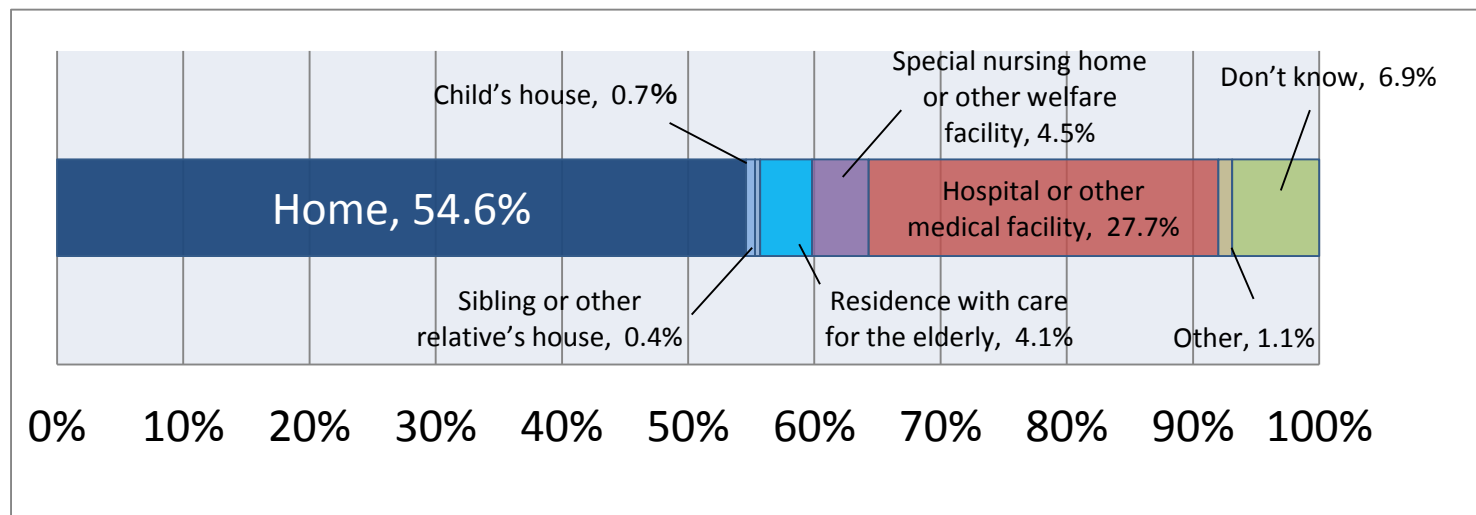
The preparation of social systems to enable death at home is highly required.

# Places where people want to spend their last moments

- With regard to places where people want to spend their last moments, **“Home” had the highest percentage at 54.6%**, with “Hospital or other medical facility” at 27.7% and “Special elderly nursing home or other welfare facility” at 4.5%.

## ■ Where would you like to spend your last moments if you had a disease with no prospect of cure?

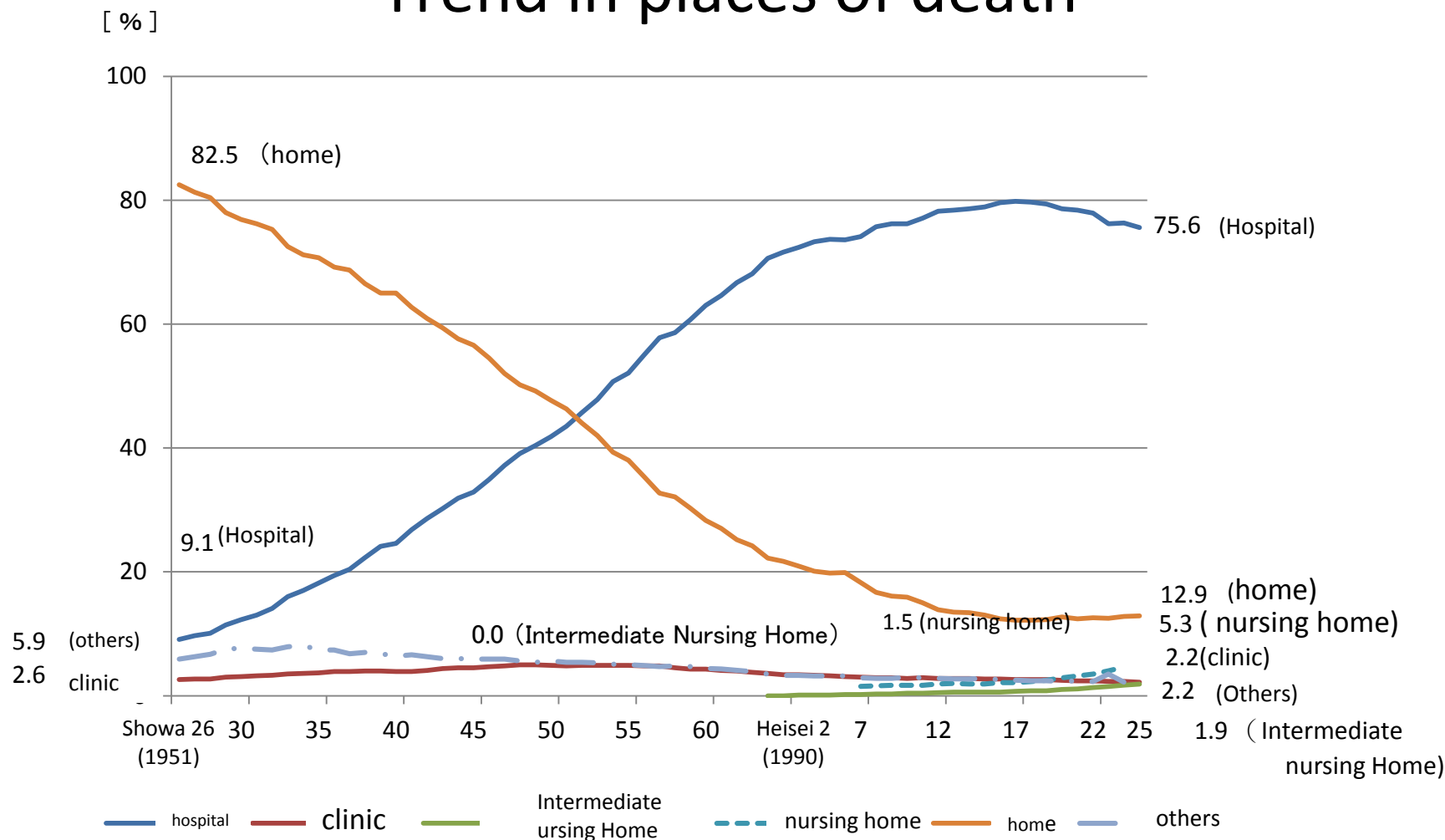
(n = 1,919 people)



Source: 2012 Awareness survey on elderly health (Cabinet)



# Trend in places of death



\* "Nursing home" means nursing homes for the elderly, special nursing homes for the elderly, low-cost nursing homes for the elderly and private nursing homes for the elderly. To 1994, deaths at nursing homes are included in deaths at home and others.

Material: Statistics and Information Department, Minister's Secretariat, Ministry of Health, Labour and Welfare, "Vital Statistics of Japan"

# 2008 Report

10<sup>th</sup>

Bioethics Council of Japan Medical Association

Guideline on End of Life Care

# Ideal end of life care

- (1) The decision that a patient is in the end of life state is made by a medical treatment and care team made up of multiple expert healthcare professionals centered on doctors.
- (2) Things in end of life care such as the start of treatment, its withholding, changes and discontinuation, etc., are judged carefully by the medical treatment and care team based on medical suitability and appropriateness, and based on the decision-making of the patient.
- (3) If the will of the patient cannot be confirmed and there is a document indicating the will of the patient prepared in advance, the medical treatment and care team presents that to the family, etc., and makes the judgment. Even if there is no such document but the will of the patient can be estimated by talking with the family, etc., the medical treatment and care team will, in principle, adopt a medical treatment policy respectful of that estimated will.

- (4) If agreement cannot be obtained in discussions with the family, a committee made up of multiple experts will be established separately and that committee will investigate and advise on the medical treatment policy, etc.
- (5) Comprehensive medical treatment and care is carried out to alleviate pain and other uncomfortable symptoms as much as possible, also including psychological and social support to the patient and family, etc.
- (6) Acts such as positive euthanasia and assisted suicide, etc., should not be carried out.

# 2014 Report

13<sup>th</sup>

Bioethics Council of Japan Medical Association

## Current Bioethics on Medical Treatment

– Especially End of Life Care and Genetic Testing / Treatment –

In 2012, a bipartisan group of parliamentarians put together a Death with Dignity bill. However, an excessive response to the law and the danger of abuse was afraid. Therefore, the Japan Medical Association recommends the guidelines on end of life care prepared by JMA and related organizations.

There was a strong opposition to make the law from groups which were supporting the disabled peoples.

There was a reminiscent of the killing the disabled people by Nazis Germany before and during the 2<sup>nd</sup> World War.

Consequently, the Death with Dignity bill has still not been established as law in Japan.

The Council put a high value on the guideline published by The Japan Geriatrics Society in 2012 with regard to end of life care for the elderly. Referring this guideline, our council's report concluded that life prolonging measures including artificial hydration and nutrition (AHN) and gastrostomy are a burden rather than help for patients and there are a lot of cases where they impair dignity. For elderly patients in particular, appropriate medical treatment that is neither insufficient nor excessive, and treatment and care that places importance on QOL in the remaining period of life are the best.

With regard to the perspective of medical economics too, our report said that “the problem of medical resources in end of life medical care is unavoidable.”

# 2017 Report

15<sup>th</sup>

Bioethics Council of Japan Medical Association

## Super aging society and end of life care



# The current state of Japanese society and end of life care

Japan has become a super aging society at unforeseen speed.

# Delays in changes of thinking among medical practitioners

Some medical practitioners believe that the only aim of medical care is “cure” and if that is not possible, prolonging life is medical care. In the background to such thinking are ideas beholden to old medical ethics. There has not been enough education (medical education) to the effect that assisting patients’ death (or life) with dignity is also a medical care. In the current situation, where as many as 80% of people die in hospital, if patient is taken to a hospital, excessive medical care can be carried out. Because there is no Death with Dignity Act, there is still a danger to medical practitioners being accused of murder or commissioned murder . Therefore there are some medical practitioners who think patient care as a method to avoid risk to themselves.

None of the above attitude is medical care for the patient, rather such care can be described as acts contrary to that. The excessive reactions of the Japanese mass media to the withdrawal of treatment like take off intubation are also a cause of excessive treatment.

Naturally, families do not have end of life experience and because there is no education on preparing for people to die, there are some family members who ask for medical care that actually impairs the dignity of the patient and places a physical burden on the patient while saying that it is for the patient's sake.

This is because there is a strong tendency to avoid talking about death among Japanese. There is also insufficient education among citizens about the fact that death is inevitable and having a peaceful death is exactly what is best for the patient.

In some cases, patient's family is living on patient's pension, and they want the patient live as long as possible disregarding the quality of life of the patient.

One member of the XVth Bioethics Council of Japan  
Medical Association

## Law and guidelines on the end of life period

There has still been no Death with Dignity Act (or Natural Death Act), laws that have been enacted in a considerable number of other countries.

Although a bipartisan group of parliamentarians prepared a Death with Dignity Bill (providing legal exemption from responsibility in cases where doctors withhold or discontinue life-prolonging medical treatment under certain conditions) in 2012, they did not even reach the stage of submitting it to the Diet.

In the background to their preparation of such a bill were the frequent cases which became big news stories in Japanese media announcing the start of investigations into doctors in clinical settings supposed to have committed acts such as removing patients from artificial respirators.

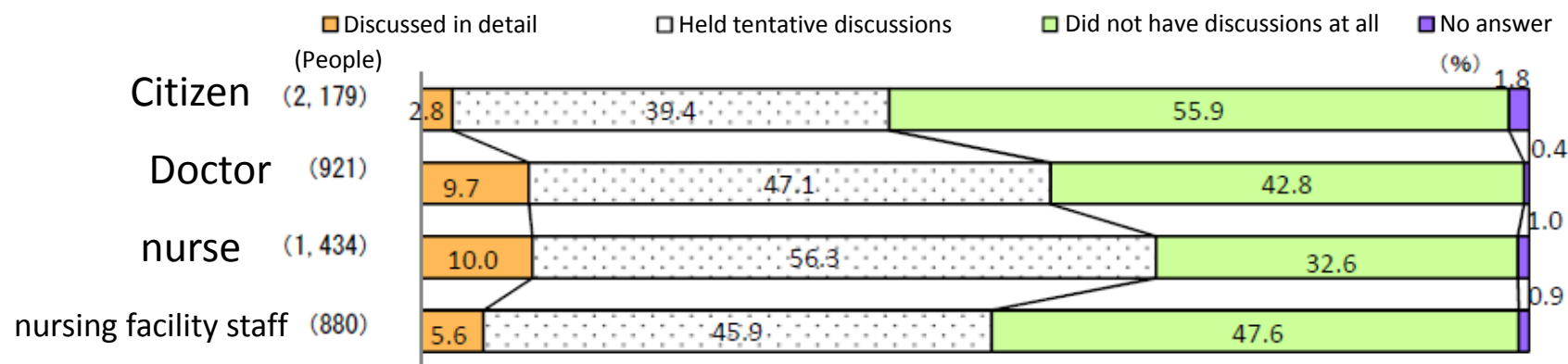
In Japan, many guidelines have been prepared and published by medically-related academic societies and expert groups.

The 2008 guideline prepared by the Japan Medical Association is one of those. There are also ones by the Japanese Society for Palliative Medicine (2010 Guideline on Pain Alleviation and many others), The Japan Geriatrics Society (2012), a joint guideline by 3 societies: The Japanese Society of Intensive Care Medicine, Japanese Association for Acute Medicine, and The Japanese Circulation Society (2014), and the All Japan Hospital Association (2016), etc.

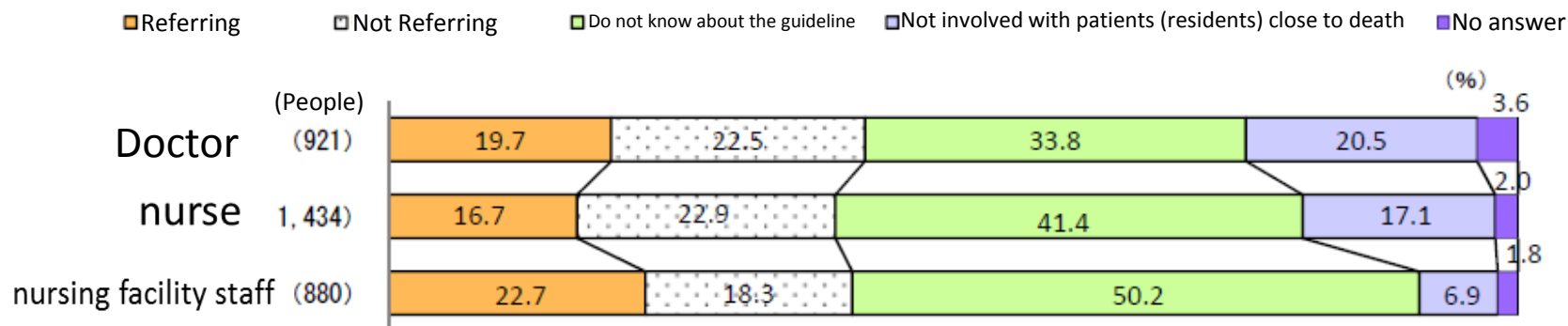
A big feature of Japan is that certain rules have been established on end of life care in guidelines rather than as law .

**Column:** From the results of the “Awareness survey on medical treatment in the last stage of life” (March 2013)

◆ **Proportion of people who have had discussions with family members on medical treatment in the last stage of life**  
**(Medical treatment that you want to receive and do not want to receive as your own death approaches)**



◆ **State of use of the “Guideline on the medical care determination process in the last stage of life”**



## The current situation in clinical settings in Japan

The situation in Japan is that the elderly are dying in unprecedented numbers. The most important and urgent issue is realizing the arrival of a peaceful and appropriate death for each individual elderly person in Japan.

It is thought that in clinical settings and also among citizens understanding of the significance of living wills and ending notes is expanding gradually. People have also started to become aware of the importance of ACP (advance care planning) which has already been discussed in a number of other countries.



## Issues at present

**From the above described reports, it is possible to organize the current issues concerning end of life care in Japan under the following points.**

**First, how should we devise systems, etc., to support decision-making to realize ways of end of life living and peaceful death based on the decision-making of patients?**

**Second, what are the specific measures to prevent undesired life prolongation at home and in facilities and hospitals?**

**Third, how will Japan respond to the new movement of PAS (PAD), which is increasing overseas?**

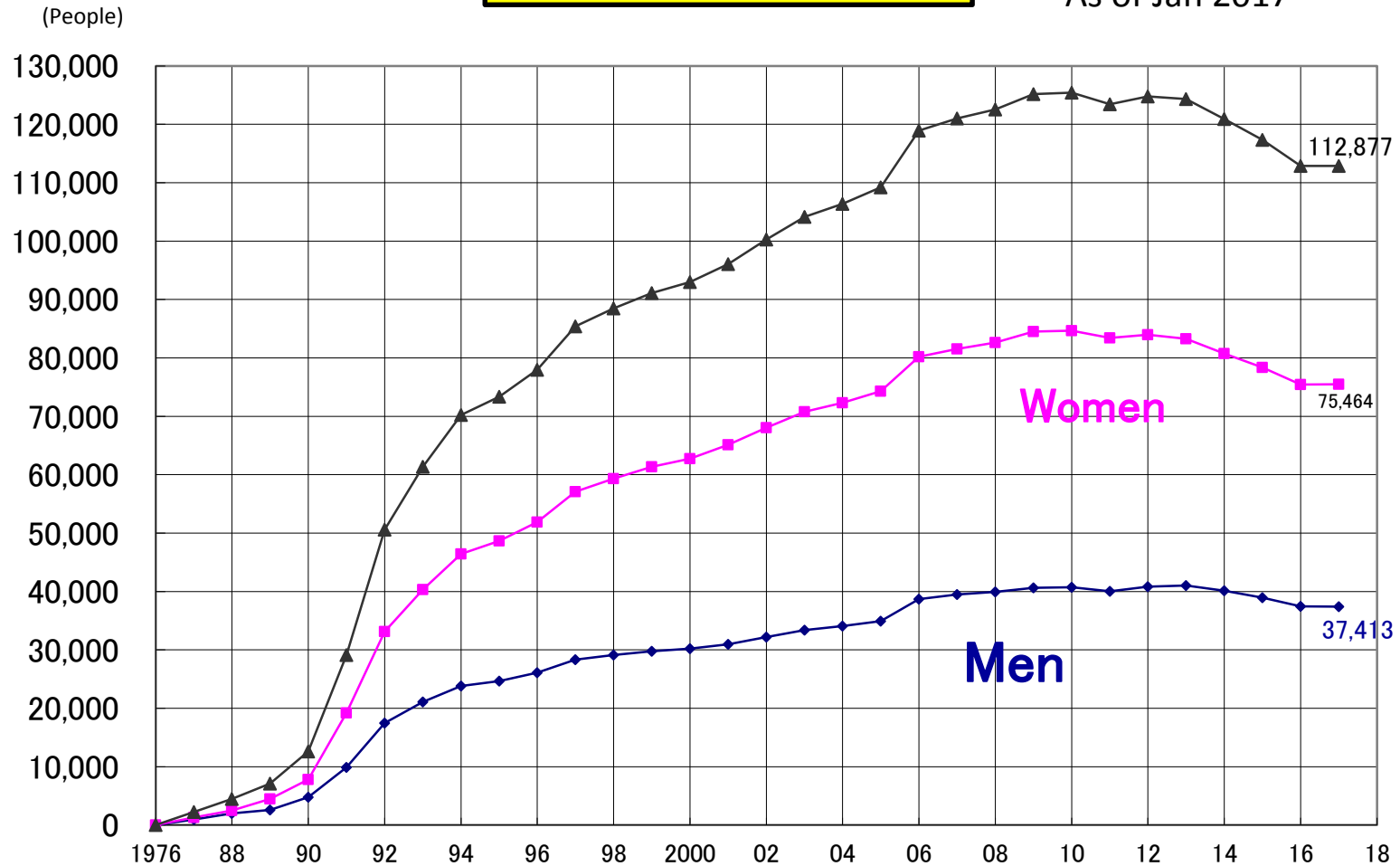
**All of these are difficult issues, but they are unavoidable ones in Japan, where aging taking us beyond a super aging society is advancing.**

# Japanese Society of Dying with Dignity

- Established in 1976
- Issued Japan's first Living Will
- 120,000 members (as of March 2017)
- Protect one's right to live a healthy life and die a peaceful death
- Living Will (advance directive)
  - Refuse life-prolonging measures that will postpone the moment of death.
  - Maximize use of all measures to alleviate pain
  - Refuse life-prolonging measures in case of a comatose state over a span of several months

# JSDD Population Trends

As of Jan 2017



# JSDD Members as of Dec 2016

Living Total	112,876
Men	37,413
Women	75,464

Average Age	77.9
Men	77.8
Women	77.9

## Newly Joined Members (Latest 5 years)

Total	34,359	Age	71.9
Men	13,489	Men	72.2
Women	20,870	Women	71.6

## Withdrawn Members (Latest 5 years)

Total	13,245	Age	84.3
Men	6,618	Men	83.1
Women	6,627	Women	85.6

## Active Periods of Withdrawn Members (Months)

Total	143.1
Men	129.8
Women	156.5

# Contributions made by the JSDD LW

a survey with cooperation from the surviving families 2016

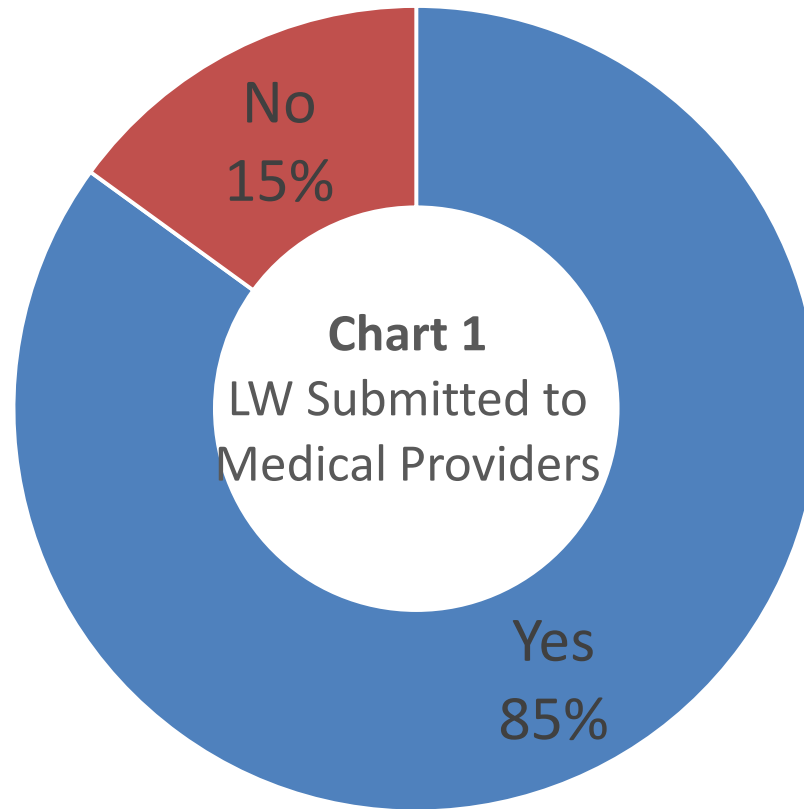


Chart 1: 773 patients (85%) submitted their LWs to the doctor.

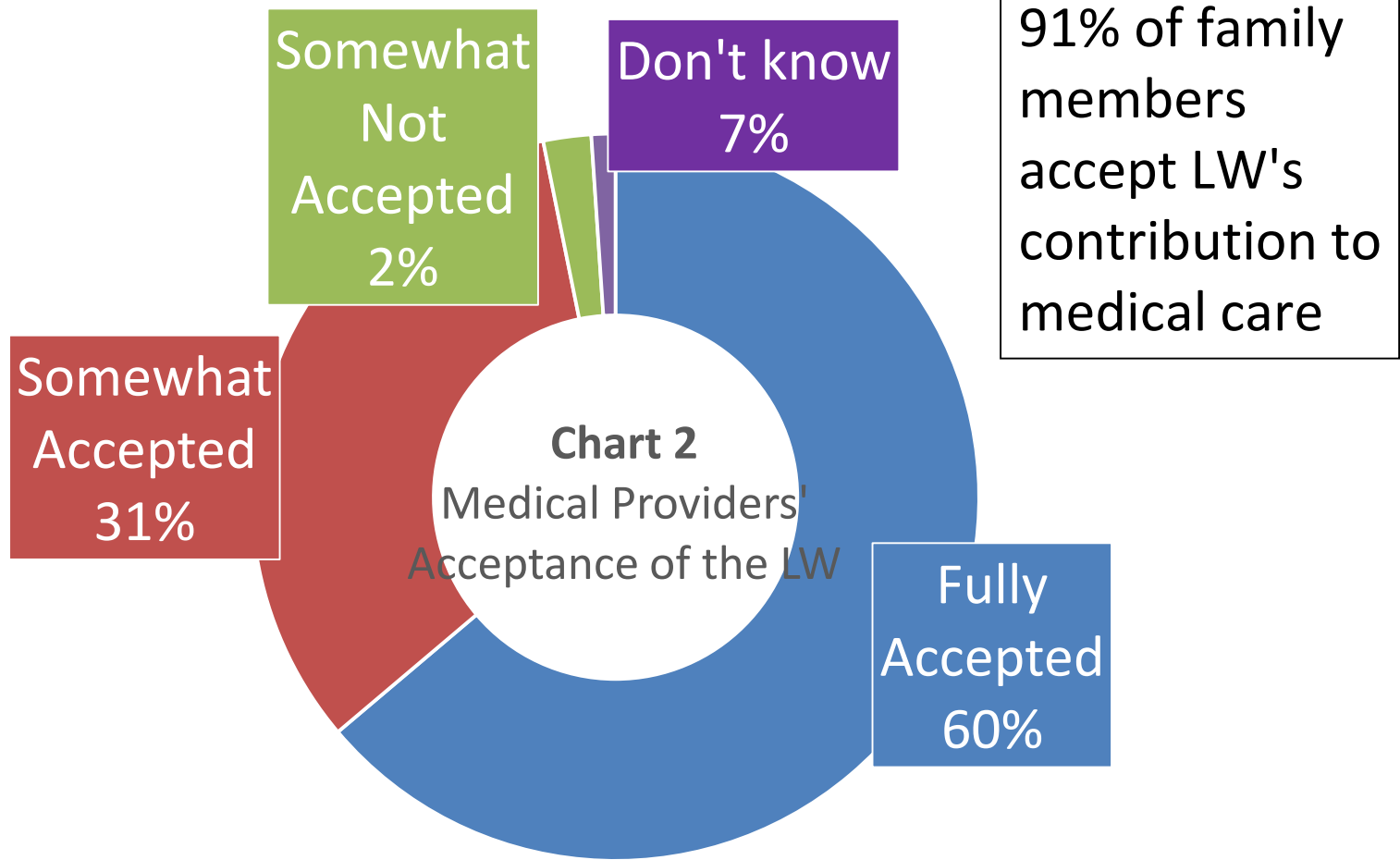
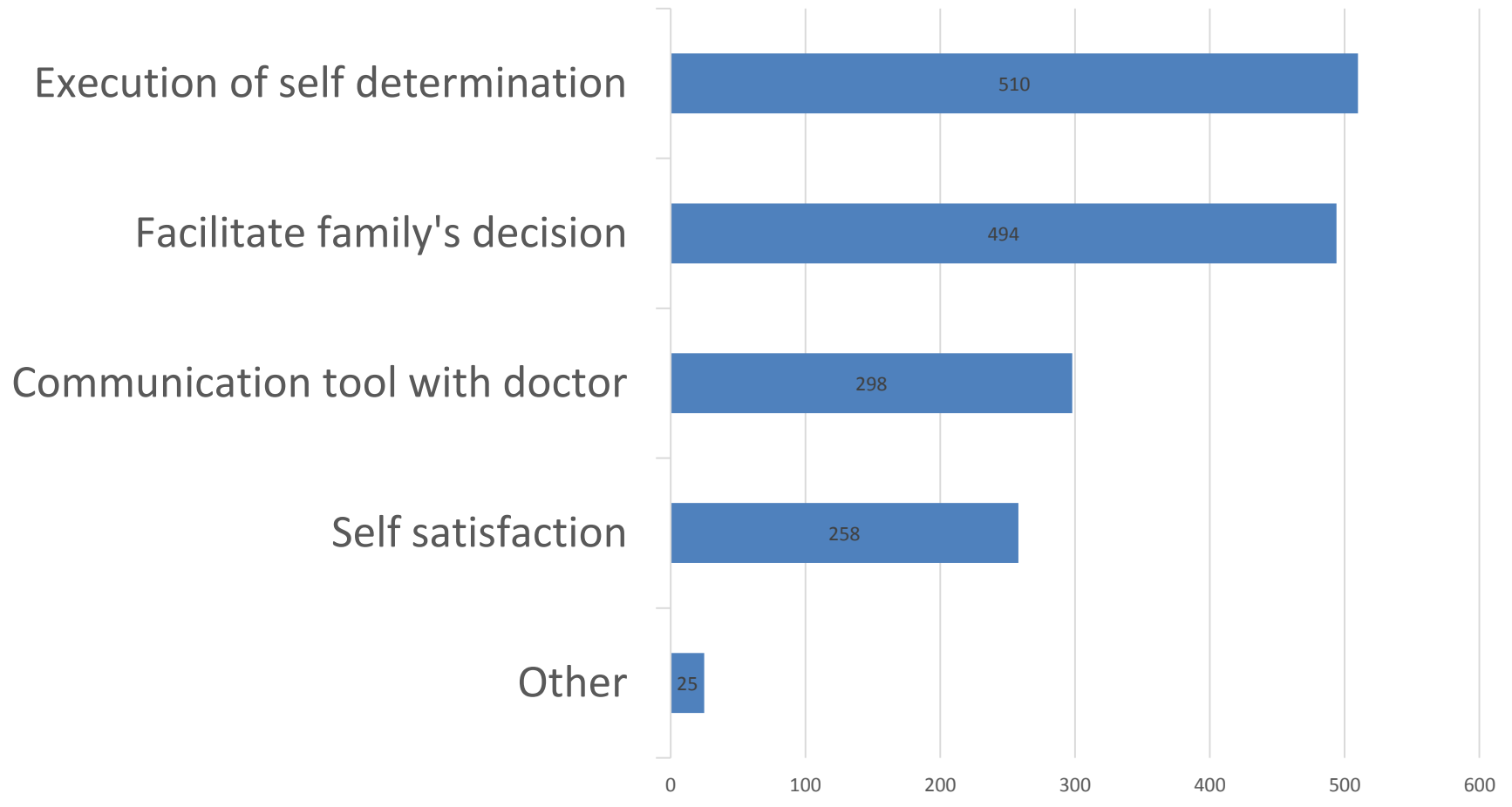
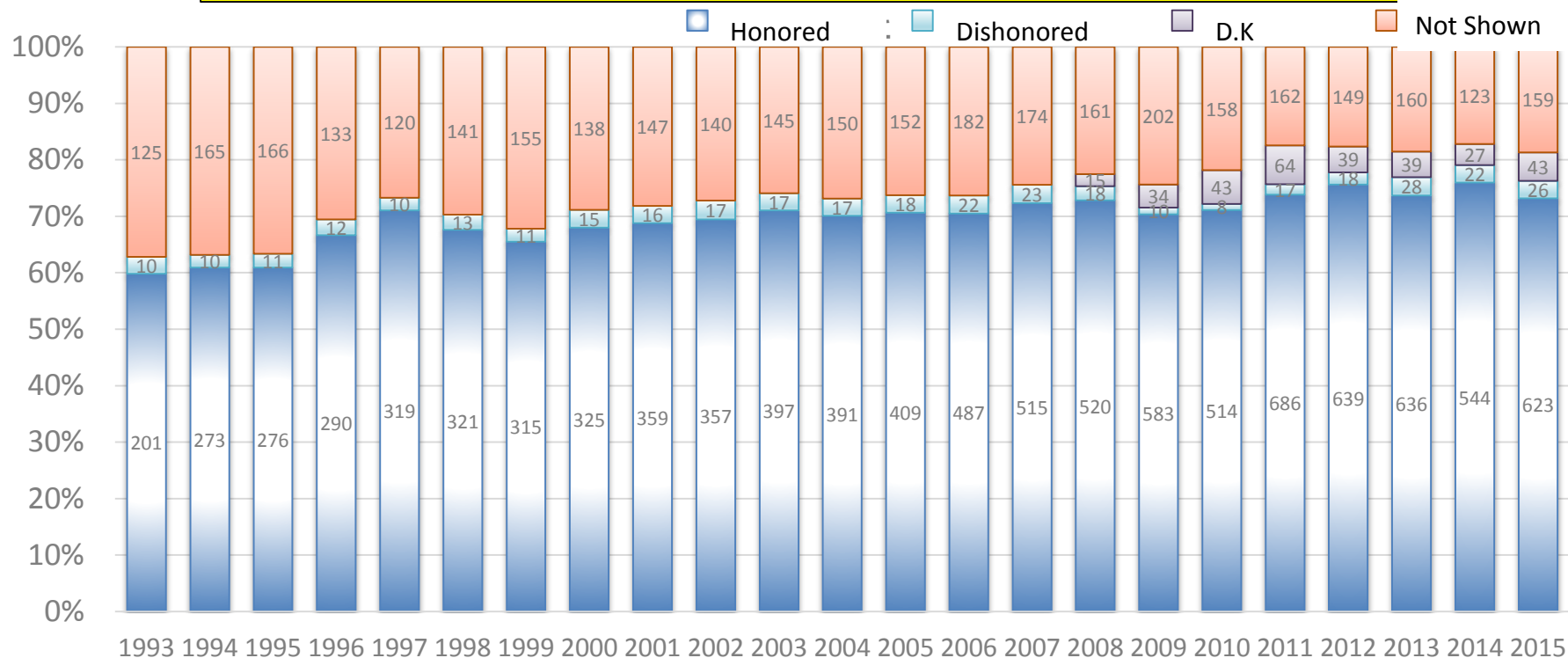


Chart 2: Medical Providers' Acceptance of the LW  
91% of the respondents admit the LW's contribution to patients' medical care.

## Chart 3 The meaning of the Living Will



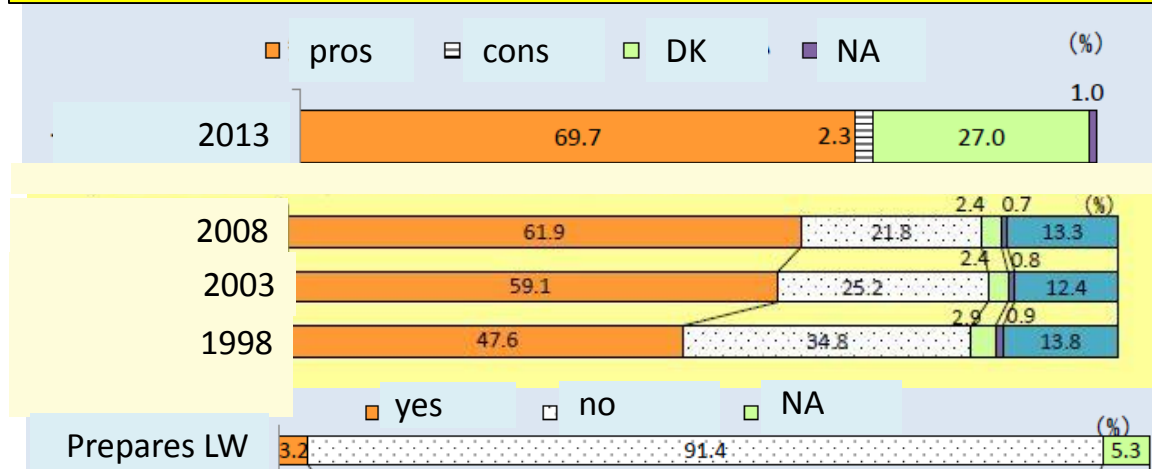
## Trends of JSDD Living will Acceptance by Physicians





# LW

69.7% Positive to prepare, but only 3.2% already signed



Results from the population survey conducted by MHLW every 5 years

# RELIGION AND END OF LIFE CARE SALVATION OF THE SPIRIT AT THE END OF LIFE

15<sup>TH</sup> BIOETHICS COUNCIL OF THE JAPAN MEDICAL ASSOCIATION

MAY 26, 2017

Naoki Nabeshima,  
Professor of Humanities, Ryukoku University  
Chaplain Training Head



Naoki Nabeshima : Presented at fifteenth time fourth meeting, 2017.5.26,  
Bioethics Council of Japan Medical Association.

The background is a deep blue gradient with a subtle pattern of white dots. Overlaid on this are several white geometric elements: a large circular scale on the left with markings from 150 to 260, and several concentric circles of varying sizes, some with arrows indicating a clockwise direction. The title text is positioned in the lower right area of the slide.

# **Interfaith Chaplains in Palliative Care Wards**

Naoki Nabeshima : Presented at fifteenth time fourth meeting, 2017.5.26,  
Bioethics Council of Japan Medical Association.

# THE CREATION OF INTERFAITH CHAPLAINS

Based on the support activities of religious people following the grief of the Great East Japan Earthquake of 2011, and the results of hospice and vihara activities since 1982, interfaith chaplain training:

Started in 2012 on the Practical Religion Course offered by the Graduate School of Arts and Letters, Tohoku University; and

Started in 2014 in the Ryukoku University Graduate School of Practical Shin Buddhist Studies .

In 2016, the Society for Interfaith Chaplaincy in Japan was established.

2014 Chaplain training:  
Tohoku University and Ryukoku  
University joint memorial service  
at Ishinomaki



Naoki Nabeshima : Presented at fifteenth time fourth meeting, 2017.5.26,  
Bioethics Council of Japan Medical Association.

# THE ROLE OF THE INTERFAITH CHAPLAIN “SIGNPOSTS TO PEOPLE FALLING INTO THE DARKNESS OF DEATH”

PROPOSAL OF DR. KEN OKABE, 2012

- **Interfaith chaplains are religious people who draw near to distress, respect others' outlooks on life and beliefs, and foster the power to live in public spaces such as medical welfare facilities, regional society and disaster affected areas, etc. without engaging in missionary work or religious solicitation.**
- **Interfaith partnership**



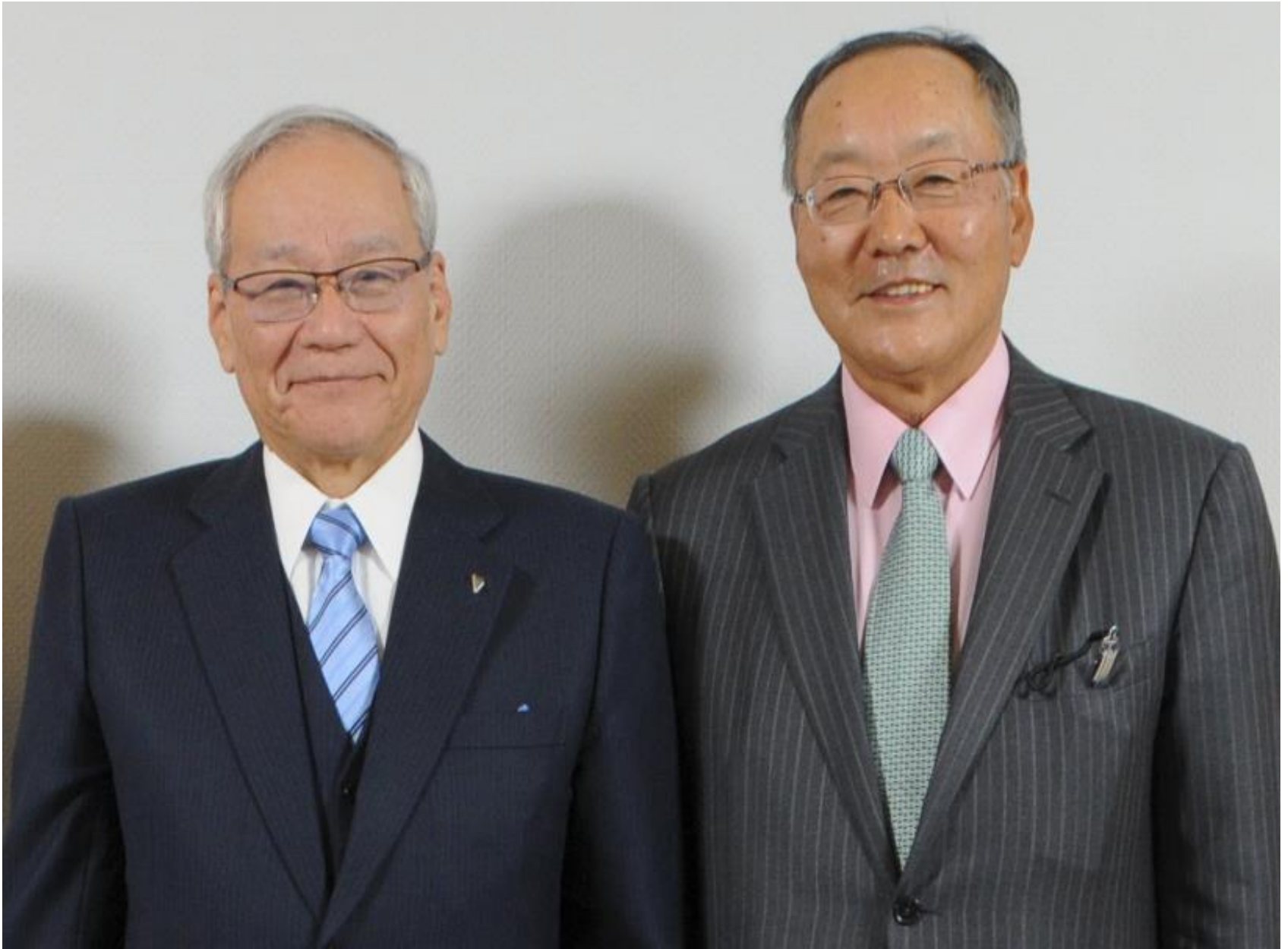
2014 Interfaith chaplain  
training

Ishinomaki assembly hall  
in temporary housing

Café de Monk

Naoki Nabeshima : Presented at fifteenth time fourth meeting, 2017.5.26,  
Bioethics Council of Japan Medical Association.





Yoshitake Yokokura ,  
President Japan Medical Association

Soichiro Iwao, President Japan  
Society for Dying with Dignity

YOSHITAKE YOKOKURA, PRESIDENT, JAPAN MEDICAL ASSOCIATION  
“LIVING WILLS IN THE SUPER AGING ERA” YOMIURI SHIMBUN 2017  
DIALOGUE WITH SOICHIRO IWAO, PRESIDENT,  
JAPANESE ASSOCIATION FOR DYING WITH DIGNITY

- “How to spend one’s last moments is a question not only for the person concerned, but also for the family left behind. The feeling that “I should have done such and such at that time” will occur with certainty in family members. If a person has left a living will, family members can feel repose at such times. Because of that, I think that the role of the attending physician will become more important from now on.
- “At some point, the time will come when your own life will end. To meet a peaceful end is the wish of many people and to that end, We think it is important to leave a proper record of your own will. Please make sure to leave a living will.”