



kidney Health for all.  
Optimal care for people  
with kidney disease.

*IFKF-WKA Connect*

*April 2021*

*Official Newsletter of IFKF-WKA*

**Supplement 1:**

Patient Engagement - What matters to patients

by Dr. SF Lui



11 March 2021

# LIVING WELL WITH KIDNEY DISEASE



World Kidney Day is a joint initiative of ISN IFKF-WKA

ISN & IFKF-WKA Webinar

World Kidney Day 2021

Living well with kidney disease

11 March 2020, 11 am and 10 pm CET

# Patient engagement: What matters to patients

## Siu-Fai Lui BBS MH JP

- President, International Federation of Kidney Foundations-World Kidney Alliance.
- Co-Program Director, World Kidney Day Steering Committee
- Chairman, Hong Kong Kidney Foundation.



# Living well with kidney disease

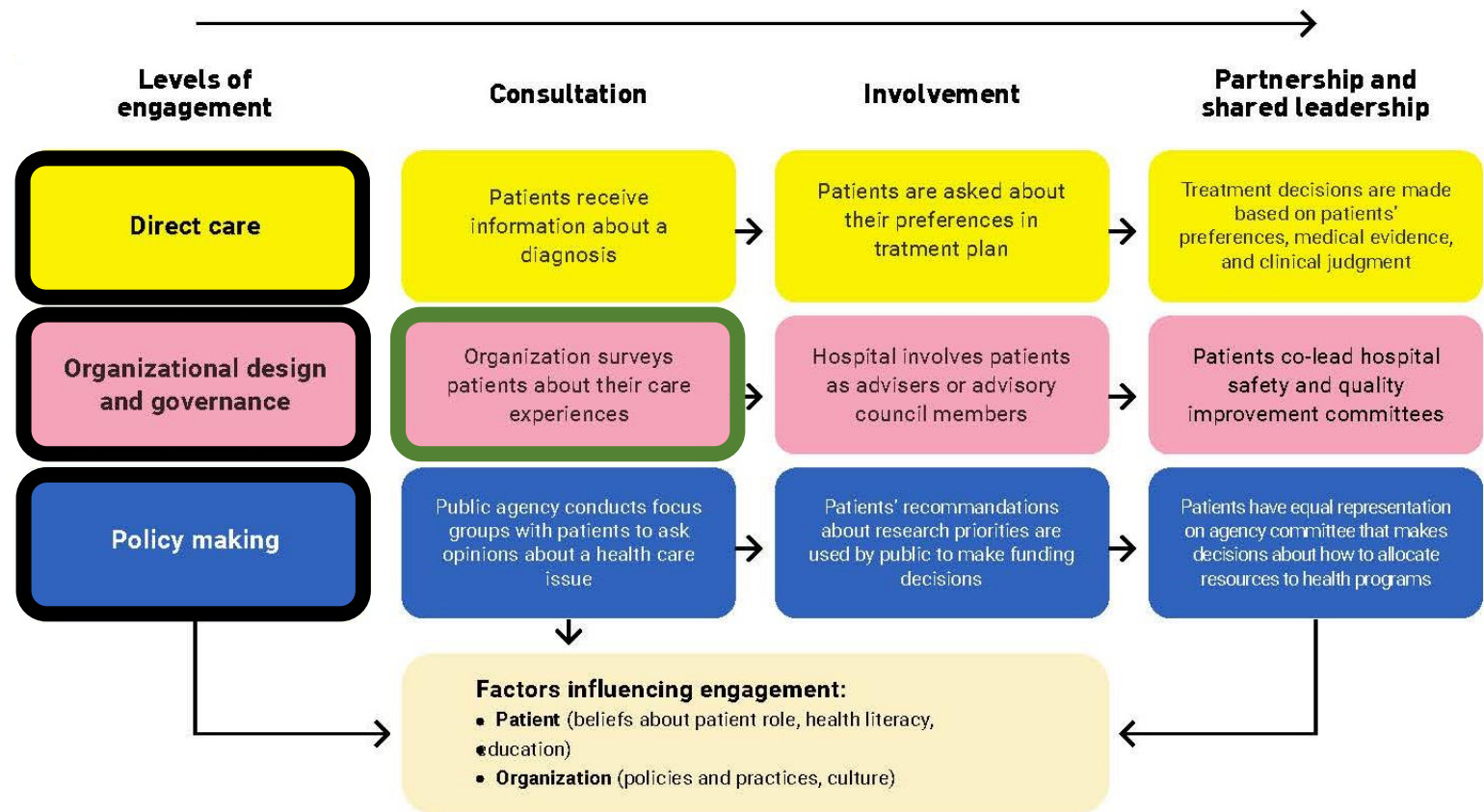
TOWARDS PATIENT-CENTERED CARE  
FOR PEOPLE LIVING WITH KIDNEY DISEASE



World Kidney Day is a joint initiative of

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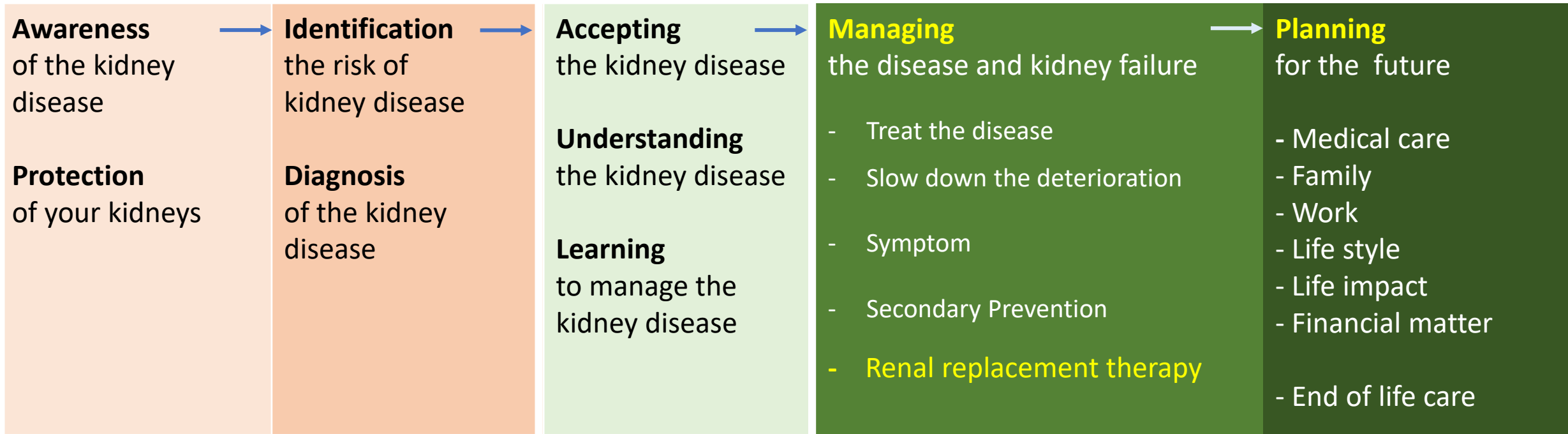
## Continuum of engagement



Source: Carmen, et. al., 2013

Yet engagement is not a quick fix. Many patients and clinicians are still operating in an older paradigm of a paternalistic clinician and system. Efforts need to be made not only to raise patients' awareness about the benefits of engagement but also to encourage and support their increasing responsibility and leadership. (Carman, et al., 2013)

# Kidney disease - a “Life” journey



**Engagement**

**Active participation**

**Empowerment**

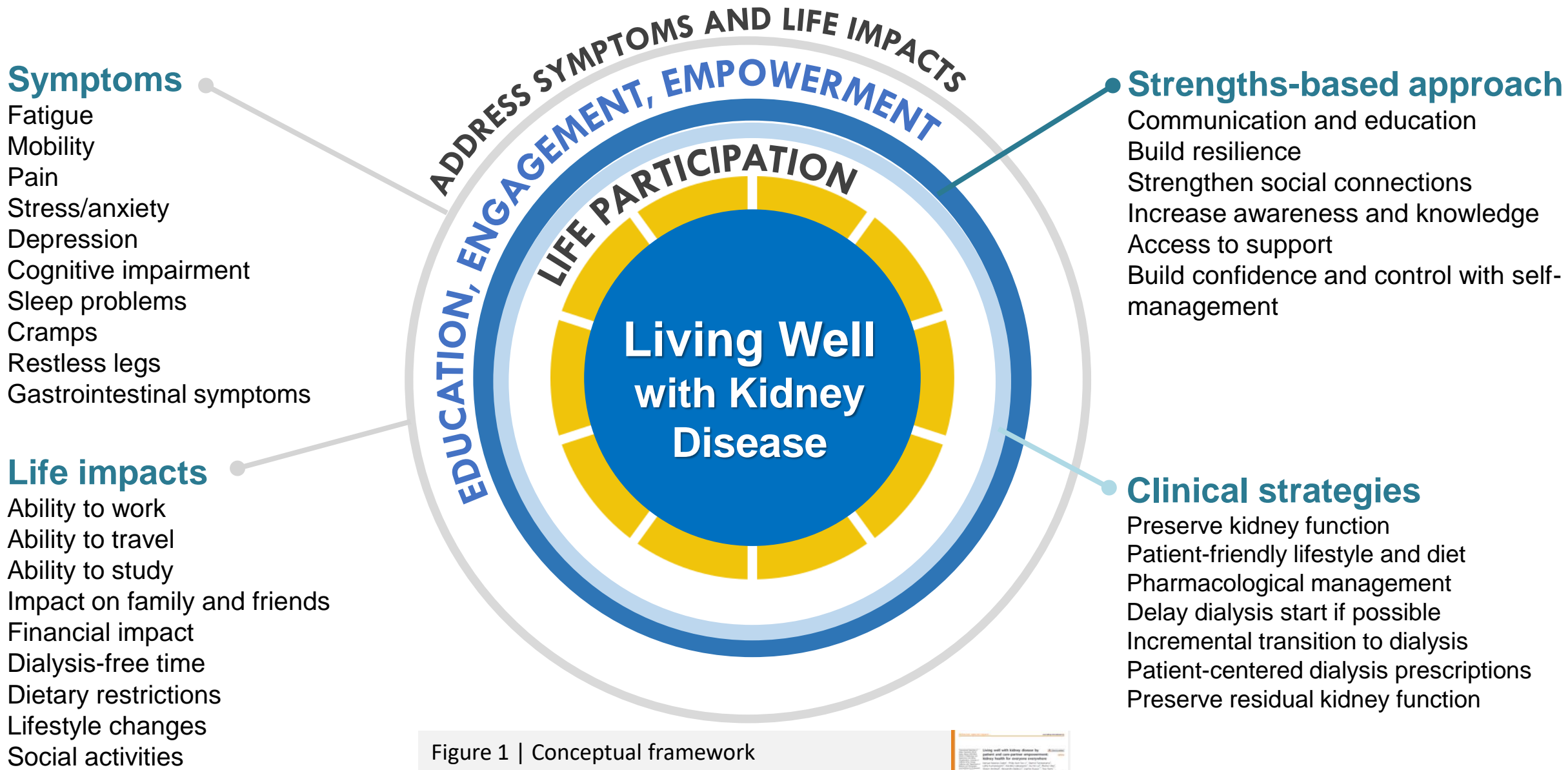


Figure 1 | Conceptual framework “Living Well with Kidney Disease” based on **patient centeredness** and **empowering patient**, with a focus on **effective symptom management** and **life participation**.



## Symptoms

- Fatigue
- Mobility
- Pain
- Stress/anxiety
- Depression
- Cognitive impairment
- Sleep problems
- Cramps
- Restless legs
- Gastrointestinal symptoms

## Life impacts

- Ability to work
- Ability to travel
- Ability to study
- Impact on family and friends
- Financial impact
- Dialysis-free time
- Dietary restrictions
- Lifestyle changes
- Social activities

# From Framework to Action

# Living Well with Kidney Disease

## Patient engagement for Patient-centred care.

## Strengths-based approach

- Communication and education
- Build resilience
- Strengthen social connections
- Increase awareness and knowledge
- Access to support
- Build confidence and control with self-management

## Management strategies

- Preserve kidney function
- Patient-friendly lifestyle and diet
- Pharmacological management
- Delay dialysis start if possible
- Incremental transition to dialysis
- Optimised dialysis prescriptions
- Preserve residual kidney function

Figure 1 | Conceptual framework  
“Living Well with Kidney Disease” based on  
patient centeredness and empowering patient,  
with a focus on effective symptom management  
and life participation.





# LIVING WELL WITH KIDNEY DISEASE

**(1) A questionnaire for patient**  
for a self-assessment and a reflection on living well.

**(2) A patient survey**  
to assess how our patients are doing with living well

Developed by Dr. SF Lui and Dr. YL Cheng  
for Hong Kong Kidney Foundation &  
Hong Kong Society of Nephrology



## 6 questions

1. I am on renal replacement therapy (type) ....
2. My **self-assessment** of living well with kidney disease (score 1-10).
3. What is preventing me from living well with kidney disease?  
(**physical, psychological, life impacts**)
4. Of these, **what matters most to me?** (list the top 3)
5. **What others (healthcare system/professionals, family and friends) can do to help/support me or options I would like to have?**
6. **What I can do for myself?**



**Q3. I have the following problems/ concerns which is affecting me from living well with kidney disease?** *(can select more than one item)*

**A. Physical**

- a1. Fatigue [ ]
  - a2. Mobility [ ]
  - a3. Pain [ ]
  - a4. Shortness of breath\* [ ]
  - a5. Poor appetite\*/  
Gastrointestinal symptoms [ ]
  - a6. Thirsty/ fluid restriction\* [ ]
  - a7. Cramp [ ]
  - a8. Restless legs [ ]
  - a9. Pruritus (itchiness)\* [ ]
  - a10. Sleep problem [ ]
  - a11. Cognitive Impairment [ ]
  - a12. Others (please describe) [ ]
- 

**B. Psychological**

- b1. Stress [ ]
  - b2. Anxiety [ ]
  - b3. Depression [ ]
  - b4. Concern about when I  
will need to start dialysis  
(pre-dialysis)\* [ ]
  - b5. Concern about rejection  
of the transplanted kidney  
(Tx patient)\* [ ]
  - b6. Concern about the future\* [ ]
  - b7. Others (please describe) [ ]
- 

**C. Life impacts**

- c1. Ability to work [ ]
  - c2. Ability to study [ ]
  - c3. Ability to travel [ ]
  - c4. Impact on family  
and friends [ ]
  - c5. Financial impact [ ]
  - c6. Dialysis-free-time [ ]
  - c7. Diet restriction [ ]
  - c8. Lifestyle changes [ ]
  - c9. Social activities. [ ]
  - c10. Others (please describe) [ ]
- 

*(\*not listed in the Conceptual Framework)*

**Q4. Of the items I have chosen for Question 3, the top 3 items that matters most to me to live well with kidney disease are?**

\_\_\_\_\_

**Q5. What I can do for myself to live well with kidney disease?**

*(can select more than one item)*

- a. Take better care of myself: manage the underlying disease (such as hypertension, diabetes) to prevent complications [ ]
- b. Comply with medical advice, including medication [ ]
- c. Comply with dialysis treatment as instructed [ ]
- d. Understand my illness and treatment, take part in self-care. [ ]
- e. Willing to be empowered for self-care [ ]
- f. Keep fit with exercise [ ]
- g. Eat smart, eat well [ ]
- h. Watch body weight (not overweight, or underweight) [ ]
- i. Self-reflection and sharing with others (family, friends) [ ]
- j. Make plan for the future days [ ]
- k. Others (please describe) \_\_\_\_\_ [ ]

**Q6. What others can do to help me &/or what options I wish I could have to live well with kidney disease?** (list up to 3 items)

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_



## LIVING WELL WITH KIDNEY DISEASE

\*Required

Q1. I am a patient \*

- With chronic kidney disease, not on renal replacement therapy
- On In-centre Haemodialysis
- On Home Haemodialysis
- On Continuous Ambulatory peritoneal dialysis (CAPD)
- On Automated peritoneal dialysis (APD)
- With kidney transplantation

Q2. My own assessment of I am living well with kidney disease? 1= not well, 10 (very well) \*

1 2 3 4 5 6 7 8 9 10

Not well            Very well

Next

# On-line goggle-form Hard copy

Q3(a) I have (or concerned with) the following problems which are affecting me from living well with kidney disease? \*Physical (can choose more than one item)

- a1. Fatigue
- a2. Mobility
- a3. Pain
- a4. Shortness of breath
- a5. Poor appetite/Gastrointestinal symptoms
- a6. Thirsty/fluid restriction
- a7. Cramp
- a8. Restless legs
- a9. Pruritus (itchiness)
- a10. Sleep problems
- a11. Cognitive impairment

a12. Other (please describe) \*Physical

Q3(b) I have (or concerned with) the following problems which are affecting me from living well with kidney disease? \*Psychological (can choose more than one item)

- b1. Stress
- b2. Anxiety
- b3. Depression
- b4. Concern about when will need to start dialysis
- b5. Concern rejection of the transplanted kidney
- b6. Concern about the future

b7. Other (please describe) \*Psychological

Q3(c). I have (or concerned with) the following problems which are affecting me from living well with kidney disease? \*Life impact (can choose more than one item)

- c1. Ability to work
- c2. Ability to study
- c3. Ability to travel
- c4. Impact on family and friends
- c5. Financial impact
- c6. Dialysis-free-time
- c7. Diet restriction
- c8. Lifestyle changes
- c9. Social activities

c10. Other (please describe) \*Rehabilitation/Financial/Social

Q4. Of the items, I have chosen for Question 3 a-c, the top 3 items that matter most to me to live well with kidney disease are? \*

- a1. Fatigue
- a2. Mobility
- a3. Pain
- a4. Shortness of breath
- a5. Poor appetite/Gastrointestinal symptoms
- a6. Thirsty/fluid restriction
- a7. Cramp
- a8. Restless legs
- a9. Pruritus (itchiness)
- a10. Sleep problems
- a11. Cognitive impairment
- a12. Others \* Physical
  - b1. Stress
  - b2. Anxiety
  - b3. Depression
  - b4. Concern about when will need to start dialysis
  - b5. Concern rejection of the transplanted kidney
  - b6. Concern about the future
  - b7. Others \*Psychological
    - c1. Ability to work
    - c2. Ability to study
    - c3. Ability to travel
    - c4. Impact on family and friends
    - c5. Financial impact
    - c6. Dialysis -free-time
    - c7. Diet restriction
    - c8. Lifestyle changes
    - c9. Social activities
    - c10. Others \*Life impact

! This is a required question

Q5. What I can do for myself to live well with kidney disease? (can choose more than one item)

- a. Take better care of myself: manage the underlying disease (such as hypertension, diabetes) to prevent complications
- b. Comply with medical advice, including medication
- c. Comply with dialysis treatment as instructed
- d. Understand my illness and treatment, take part in self-care.
- e. Willing to be empowered for self-care
- f. Keep fit with exercise
- g. Eat smart, eat well
- h. Watch body weight (not overweight, or underweight)
- i. Self-reflection and sharing with others (family, friends)
- j. Make plan for the future days
- k. Others (please describe in the below)
- Other: \_\_\_\_\_

Q6. What others can do to help me &/or what options I wish I could have to live well with kidney disease? (list up to 3 items)

Your answer \_\_\_\_\_

Back

Submit



## Living well with kidney disease

Hong Kong Kidney Foundation, Hong Kong Society of Nephrology  
And Hong Kong Association of Renal Nurses jointly hosting

### A patient survey with a questionnaire

- Are you living well?
- What may be troubling or preventing you from living well?
  - What you may do for yourself to live well?
- What you may wish others to do for you to enable you to live well?

The survey can help you to conduct a self evaluation and reflection.

We would like to know how you are doing?

What may be troubling you?

What we can do for you?

11 Jan 2021– 11 February 2021

Please take 5 minutes to complete the on-line survey



Scan the barcode to go to the on-line survey  
or use this link <https://cutt.ly/wjpGqn4>

## WKD 2021 @ Hong Kong

## LIVING WELL WITH KIDNEY DISEASE

An on-line patient survey for  
all Hong Kong patients on  
renal replacement therapy

11 Jan 2021 – 11 February 2021.

**1138 patients**

The finding was announced  
at the WKD event held in  
Hong Kong on 7 March 2021



## Living well with kidney disease

Hong Kong Kidney Foundation, Hong Kong Society of Nephrology  
And Hong Kong Association of Renal Nurses jointly hosting

### A patient survey with a questionnaire

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## Pilot study 7 members of IFKF-WKA (6 countries)

Bangladesh

Hungary

Italy

India Tanker Foundation

India Renal Foundation

Hong Kong

Malaysia

Jan – February 2021

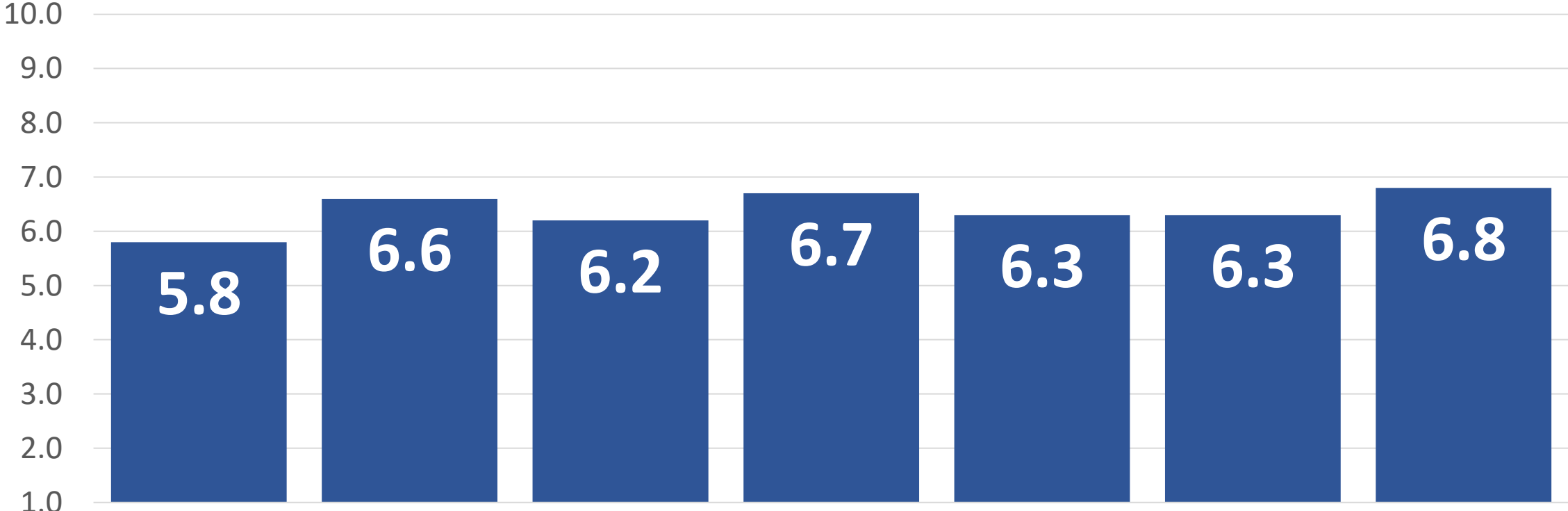
n=4807 from 7 members

# Presentation of the findings from 7 organizations

- The top 5 items (symptoms, concerns, option) for each of the questions reported by the patients from each organization.
- The prevalence of the top 5 items.
- Variation between the countries.

# Overall score (1-10)

N=4807



	Bangladesh	Hungary	Italy	INDIA Tanker Foundation	India Renal Foundation	Hong Kong	Malaysia
Number	<b>350</b>	<b>256</b>	<b>905</b>	<b>618</b>	<b>285</b>	<b>1138</b>	<b>1255</b>

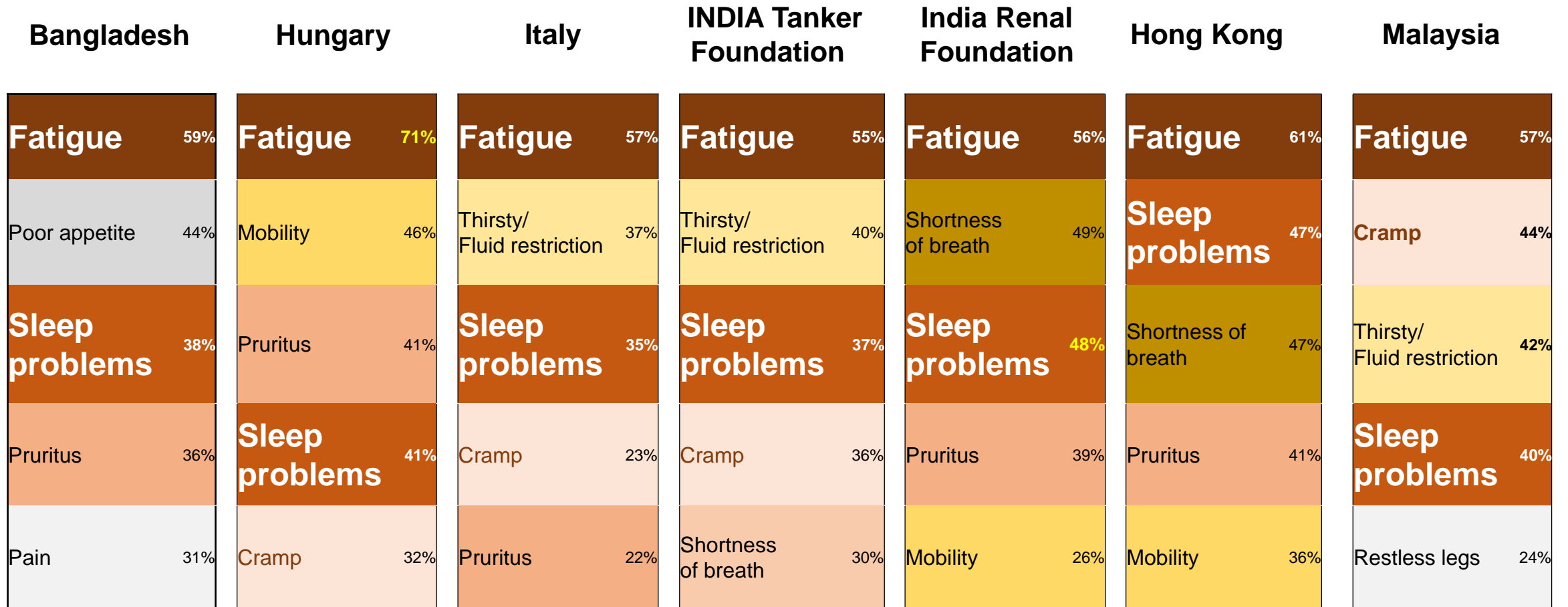


**I have the following physical problem/ concern  
which is affecting me from living well with kidney disease?**

The number of center reporting the item as one of the top 5 items

<b>Fatigue</b>	<b>7</b>
<b>Sleep problems</b>	<b>7</b>
Pruritus	5
Cramp	4
Thirsty/ Fluid restriction	3
Mobility	3

# I have the following physical problem/ concern which is affecting me from living well with kidney disease?



**I have the following psychological problem/ concern  
which is affecting me from living well with kidney disease?**

The number of center reporting the item as one of the top 5 items

<b>Concern about the future</b>	<b>7</b>
<b>Anxiety</b>	<b>7</b>
<b>Stress</b>	<b>7</b>
<b>Depression</b>	<b>7</b>

# I have the following psychological problem/ concern which is affecting me from living well with kidney disease?

Bangladesh	Hungary	Italy	INDIA Tanker Foundation	India Renal Foundation	Hong Kong	Malaysia
Anxiety 39%	Concern about the future 66%	Concern about the future 58%	Anxiety 55%	Concern about the future 67%	Concern about the future 57%	Concern about the future 45%
Depression 23%	Anxiety 39%	Anxiety 34%	Concern about the future 50%	Anxiety 57%	Anxiety 42%	Stress 27%
Stress 16%	Stress 31%	Stress 29%	Stress 36%	Depression 33%	Stress 38%	Anxiety 19%
Concern about the future 5%	Depression 17%	Depression 19%	Depression 28%	Stress 24%	Depression 17%	Depression 9%

**I have the following life impact problem/ concern  
which is affecting me from living well with kidney disease?**

The number of center reporting the item as one of the top 5 items

Financial impact	6
Ability to work	6
Ability to travel	6
Lifestyle changes	6
Diet restriction	5

## I have the following life impact problem/ concern which is affecting me from living well with kidney disease?

Bangladesh	Hungary	Italy	INDIA Tanker Foundation	India Renal Foundation	Hong Kong	Malaysia
<b>Financial impact</b> 59%	Lifestyle changes 44%	Lifestyle changes 54%	<b>Financial impact</b> 64%	<b>Ability to work</b> 68%	<b>Financial impact</b> 50%	<b>Financial impact</b> 51%
<b>Ability to work</b> 40%	<b>Ability to work</b> 40%	Impact on family and friends 41%	<b>Ability to work</b> 47%	<b>Financial impact</b> 57%	Diet restriction 39%	Lifestyle changes 48%
Impact on family and friends 36%	<b>Financial impact</b> 38%	Ability to travel 39%	Diet restriction 43%	Lifestyle changes 35%	Impact on family and friends 38%	Diet restriction 40%
Lifestyle changes 13%	Ability to travel 35%	<b>Ability to work</b> 36%	Ability to travel 33%	Ability to travel 32%	<b>Ability to work</b> 38%	Social activities. 31%
Social activities 13%	Impact on family and friends 33%	Diet restriction 35%	Lifestyle changes 23%	Diet restriction 24%	Ability to travel 35%	Ability to travel 31%

**Of the items I have chosen for Question 3,  
the top 3 items that matters most to me  
to live well with kidney disease are?**

The number of center reporting the item as one of the top 5 items

Fatigue	7
Concern about the future	6
Financial impact	5
Sleep problems	5
Thirsty/Fluid restriction	3



## What I can do for myself to live well with kidney disease?

The number of center reporting the item as one of the top 5 items

Comply with medical advice, including medication	7
Take better care of myself: manage the underlying disease	7
Eat smart, eat well	7
Comply with dialysis treatment as instructed	5
Understand my illness and treatment, take part in self-care	4



# Summary

The top 5 problems/ concerns reported by the patients

Fatigue	7
Concern about the future	6
Financial impact	5
Sleep problems	5
Thirsty/Fluid restriction	3



## Way forward: A call for action

- **Engage patient**  
Aware of what is troubling/concerning them?  
Understand what matters most to them?
- **Engagement, Partnership, Empowerment**
- **A call for**
  - identify and manage the symptoms
  - research on the symptoms (fatigue)
  - optimize treatment
  - address psychological element
  - reduce the impact on life.





## Way forward: A call for action

### An individual patient's self-assessment

A self-evaluation tool (Apps, hard copy)

- To facilitate effective communication with healthcare work
- To share their problems and concerns with others (healthcare workers, family, friends)

### Self-action to live well with kidney disease

- To be engaged, to be empowered
  - To plan for future.
- 