



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

*IFKF-WKA Connect*  
*1 April 2022*

*Appendix 2: To connect, Be connected*

*PowerPoint Presentation by SF Lui for the World Kidney Day  
International Webinar on 10 March 2022*



**ISN & IFKF-WKA Webinar:  
World Kidney Day 2022:  
Bridge the knowledge gap  
to better kidney care -  
Bringing Together the  
Community for Kidney  
Health**

**Robyn Langham - Session 1**  
WKD Steering Committee co-chair,  
University of Melbourne,  
Melbourne, Victoria, Australia

**Kam Kalantar Zadeh - Session 2**  
WKD Steering Committee co-chair,  
The International Federation of Kidney  
Foundation – World Kidney Alliance (IFKF-WKA),  
Division of Nephrology and Hypertension and  
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University of California Irvine, Orange, California,  
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**SF Lui**  
President,  
The International Federation of Kidney  
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President,  
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**Verónica Martínez**  
Member of the ISN's Patient Liaison  
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**Ann Bonner**  
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Griffith University, Southport, Queensland,  
Australia

**Beatrice Titilola Segun-Agboola**  
Nephrology Nurse Educator,  
School of Postbasic Nursing,  
University of Ilorin Teaching Hospital, Ilorin,  
Nigeria

**Paul Laffin**  
Advocacy Director,  
The International Society of Nephrology,  
France

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Webinar 1 11 a.m. CET for Europe/Africa /Asia	Webinar 2 10 p.m. CET for North/South America/Australia
<b>Welcome remarks from President IFKF-WKA (SF Lui) and ISN (Agnes Fogo)</b>	
<b>Patients' Experience</b> <b>Manvir Victor, Malaysia</b> IFKF member and Chair of the ISN Patient Liaison Advisory Group.	<b>Patients' Experience</b> <b>Verónica Martínez, Mexico</b> Member of the ISN's Patient Liaison Advisory Group
<b>Health Literacy</b> Anne Bonner, Australia	
<b>To Connect, Be Connected</b> <b>SF Lui, IFKF-WKA</b>	
<b>Engaging Healthcare Professionals</b> Beatrice Titilola Segun-Agboola, Nephrology Nurse Educator, Nigeria.	
<b>Advocating for Better Kidney Health</b> Paul Laffin, Northern Ireland.	
Moderated Q&A (live)	



The link to the recording of the presentation on “To Connect, Be Connected”

[https://www.dropbox.com/s/z4odim0sqg7qsf/WKD22\\_Webinar%20IFKFWKA%20ISN\\_Lui%20SF%20v220308.pdf?dl=0](https://www.dropbox.com/s/z4odim0sqg7qsf/WKD22_Webinar%20IFKFWKA%20ISN_Lui%20SF%20v220308.pdf?dl=0)



# To connect, Be connected.

**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.



## Kidney health for all: bridging the gap in kidney health education and literacy

Robyn G. Langham<sup>1</sup>, Kamyar Kalantar-Zadeh<sup>2</sup>, Ann Bonner<sup>3</sup>, Alessandro Balducci<sup>4</sup>, Li-Li Hsiao<sup>5</sup>, Latha A. Kumaraswami<sup>6</sup>, Paul Laffin<sup>7</sup>, Vassilios Liakopoulos<sup>8</sup>, Gamal Saadi<sup>9</sup>, Ekamol Tantisattamo<sup>2</sup>, Ifeoma Ulasi<sup>10</sup> and Siu-Fai Lui<sup>11</sup> for the World Kidney Day Joint Steering Committee<sup>12</sup>

Health literacy is the degree to which **persons** and **organizations** have or equitably enable individuals to have the ability to **find, understand, and use** information and services to inform health-related decisions and actions for themselves and others.

# UPDATING HEALTH LITERACY FOR HEALTHY PEOPLE 2030

Defining Its Importance for a New Decade in Public Health

For the first time in 20 years, and with the launch of Healthy People 2030 (HP2030), the Healthy People initiative has expanded its definition of health literacy.

## EVOLUTION OF THE DEFINITION OF HEALTH LITERACY



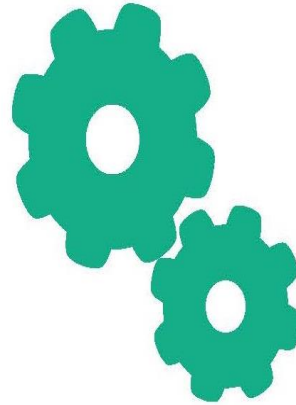
The HP2010 definition of health literacy solely focused on the individual's capacity to comprehend basic health information. HP 2030 expands the definition to include a focus on both personal and organizational health literacy, recognizing health literacy in a systems context with interventions at all levels.

## PERSONAL HEALTH LITERACY

Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. Changes from the previous definition include (1) an emphasis on the use of health information and services, (2) a shift from appropriate decisions to *informed* decisions and actions, and (3) inclusion of a public health perspective whereby personal health literacy can be used to promote the health of others.



## ORGANIZATIONAL HEALTH LITERACY



The adoption of a definition for organizational health literacy signals that personal health literacy is contextual and that organizations play a critical role by making health information and services easy to understand and access. The definition also points out that organizations must be equitable in how they address health literacy.

## BENEFITS OF BOTH PERSONAL AND ORGANIZATIONAL HEALTH LITERACY

The HP2030's updated health literacy definition builds on Healthy People's previous health literacy contributions to public health. Both personal and organizational health literacy can have a powerful effect on an individual's health. It can make the difference in understanding a diagnosis, treatment, or recommended lifestyle changes to lead active, healthy lives.



Source: Stephanie Santana; Cindy Brach; Linda Harris; Emmeline Ochiai; Carter Blakey; Frances Bevington; Dushanka Kleinman; Nico Pronk. Updating Health Literacy for Healthy People 2030. *J Public Health Manage Pract*. Published ahead of print, Mar. 12, 2021. doi: 10.1097/PHH.0000000000001324

**JPHMP** Direct

The companion site of the *Journal of Public Health Management and Practice*

# The 5 “rights” of provision of healthcare information

The right **information** (content/ context),  
at the right **time** (stage),  
by the right **source** (trustworthy, factual),  
in the right **format** (understandable),  
via the right **channel / platform** (most accessible) .

# A “Life” journey with your Kidneys

<p><b>Know</b> your kidneys (function)</p>	<p><b>Aware</b> who are at high risk of kidney disease</p>	<p><b>Understand</b> kidney diseases</p>	<p><b>Manage kidney failure</b></p>	<p><b>Plan for the future</b></p>
<p><b>Protect</b> your kidneys</p>	<p><b>Aware</b> of the symptoms of kidney disease</p> <p><b>Know</b> how to get tested for kidney disease to make a diagnosis</p>	<p><b>Manage</b> kidney diseases</p> <ul style="list-style-type: none"> <li>- treatment</li> <li>- prevent / slow down the deterioration of Kidney failure</li> <li>- prevent complications</li> </ul>	<ul style="list-style-type: none"> <li>- Accept the kidney failure</li> <li>- Slow down the deterioration</li> <li>- Manage symptoms</li> <li>- Secondary Prevention</li> <li>- Renal replacement therapy: Dialysis, transplantation                             <ul style="list-style-type: none"> <li>&gt; Preparation</li> <li>&gt; Start dialysis at appropriate time</li> <li>&gt; Care for oneself</li> </ul> </li> <li>- Rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>- Medical care</li> <li>- Family</li> <li>- Work</li> <li>- Life style</li> <li>- Life impact</li> <li>- Financial matter</li> <li>- End of life care</li> </ul>

**Different health and healthcare information is required  
for different people/patients at different time**

General public.....A patient with kidney disease... With end stage kidney failure.....

# A pilot survey by IFKF-WKA

## **Access to healthcare information by the kidney patients**

- **Do you have enough healthcare/ medical information**  
about your kidneys and kidney disease to care for yourself?
- **What kind of healthcare/medical information on**
  - (i) kidney and kidney diseases
  - (ii) treatment of kidney disease/failure
  - (iii) living well with kidney disease you want to know?
- **Where you have obtained**  
**Where would you prefer to obtain**  
the best healthcare/ medical information on kidney disease and treatment?





Bridge the knowledge gap to better kidney care



International Federation of Kidney Foundations - World Kidney Alliance

A WORLD KIDNEY PATIENTS SURVEY

"Access of healthcare information for patients with kidney disease/ kidney failure"

conducted by .....

Serial No: \_\_\_\_\_

1 You are (or the carer of)

Tick one

a	Someone with kidney Disease	
b	Someone with kidney failure (not yet on dialysis)	
c	Someone on peritoneal dialysis	
d	Someone on haemodialysis	
e	Someone with a kidney transplant	

2 Your age

Enter age (in number)

3 Your Education level

Tick one

a	High school level / Grade 10 or above / Higher education institution	
b	Junior school level / Secondary school / Grade 7-9	
c	Primary school level / Grade 1-6	
d	No formal school education	

4 Do you have enough healthcare/medical information about your kidneys and kidney disease to care for yourself?

Please give 1-10 point  
(1 =not enough, 10 =very adequate)

5 What kind of healthcare/medical information on kidney and kidney diseases you want to know?

Tick one (can be many)

a	About the kidney and kidney function	
b	The common causes of kidney disease and failure	
c	Symptoms of kidney disease	
d	Am I at risk of kidney disease/ kidney failure?	
e	How can I protect my kidneys?	
f	Are my kidneys working OK? (the status of my kidney function)	
g	Other (please list)	

6 What kind of healthcare/medical information on the treatment of kidney disease/failure you want to know?

Tick one (can be many)

a	Treatment of kidney disease	
b	When will I need dialysis (for those with kidney failure)	
c	What are my options for dialysis treatment (for those with kidney failure)	
d	Information on peritoneal dialysis	
e	Information on haemodialysis	
f	Information on kidney transplant	
g	Information on palliative care	
h	Information on complications of kidney disease	
i	Can alternative medicine help me?	
j	Other (please list)	

7 What kind of healthcare/medical information on living well with kidney disease you want to know?

Tick one (can be many)

a	How to live well with kidney disease? (work, daily life, travel)	
b	How to eat well with kidney disease?	
c	How to keep fit with kidney disease?	
d	How to manage psychological stress?	
e	How can I enhance the care for myself?	
f	The social support for patient?	
g	How to reduce the impact on family and friends?	
h	How can I continue or return to work or study?	
i	Other (please list)	

8 List up to three places where you have obtained the best healthcare/medical information on kidney disease and kidney treatment

List in order  
(1=first choice, 2=second choice, 3=third choice)

a	Hospital & clinic (e.g. visit, education class, printed patient education materials)	
b	Print media (e.g. open public sources - newspapers, magazine, book, booklets)	
c	Electronic media (e.g. TV, radio)	
d	Social media (e.g. Facebook, YouTube, IG)	
e	Website (reliable, easy to find and access anytime, any where)	
f	Other patients	
g	Other source (please list)	

9 List up to three places where you would prefer to obtain the best healthcare/medical information on kidney disease and kidney treatment

List in order  
(1=first choice, 2=second choice, 3=third choice)

a	Hospital & clinic (e.g. visit, education class, printed patient education materials)	
b	Print media (e.g. open public sources - newspapers, magazine, book, booklets)	
c	Electronic media (e.g. TV, radio)	
d	Social media (e.g. Facebook, YouTube, IG)	
e	Website (reliable, easy to find and access anytime, any where)	
f	Other patients	
g	Other source (please list)	

10 Please list any other suggestion

International Federation of Kidney Foundations - World Kidney  
Alliance  
A WORLD KIDNEY PATIENTS SURVEY

"Access of healthcare information for patients with kidney disease/  
kidney failure"

\* 1. You are (or Carer of)

- ☐ Someone with kidney disease
- ☐ Someone with kidney failure (not yet on dialysis)
- ☐ Someone on peritoneal dialysis
- ☐ Someone on haemodialysis
- ☐ Someone with a kidney transplant

\* 2. You Age

1 50 100

\* 3. Your Education level

- ☐ High school level / Grade 10 or above / Higher education institution
- ☐ Junior school level / Secondary school / Grade 7-9
- ☐ Primary school level / Grade 1-6
- ☐ No formal school education

\* 4. Do you have enough medical information about your kidneys and kidney disease to care for yourself? Please give 1-10 point (1 point = not enough, 10 points = very adequate).

1 = not enough 5 10 = very adequate

\* 5. What kind of healthcare/medical information on kidney and kidney disease do you want to know? (can be many)

- ☐ About the kidney and kidney function
- ☐ The common causes of kidney disease and failure
- ☐ Symptom of kidney disease
- ☐ Am I at risk of kidney disease/kidney failure?

☐ How can I protect my kidneys?

☐ Are my kidneys working OK? (the status of my kidney function)

☐ Other (please list)

\* 1. 你是 \* 或照顧者(請只選一項)

- ☐ 腎臟病患者
- ☐ 有腎功能衰竭(腎功能不健全但未需要洗腎)
- ☐ 接受腹膜透析治療(洗肚) 的病人
- ☐ 接受血液透析治療(洗血) 的病人
- ☐ 腎臟移植的病人

\* 2. 你的年齡

1 50 100

\* 11. You are from

- ☐ Bangladesh
- ☐ Barbados
- ☐ Egypt
- ☐ Ethiopia
- ☐ Hong Kong
- ☐ Hungary
- ☐ India (Tanker Foundation)
- ☐ India (Pondicherry Kidney Foundation)
- ☐ Malaysia
- ☐ Turkiye
- ☐ Mexico
- ☐ US (Hawaii).

Federación Internacional de Fundaciones del Riñón - Alianza  
Mundial del Riñón  
ENCUESTA MUNDIAL DE PACIENTES CON ENFERMEDAD RENAL

"Acceso a la información para pacientes con enfermedad renal"

ASOCIACIÓN ALE, I.A.P.

\* 1. Eres paciente o cuidador de: (Marque una)

- ☐ Alguien con pre-diálisis
- ☐ Alguien en diálisis peritoneal (manual, automatizada)
- ☐ Alguien en hemodiálisis
- ☐ Alguien con trasplante de riñón

\* 2. Edad \*Ingrese la edad (en número)

1 50 100

\* 3. Tu nivel de educación (Marque una)

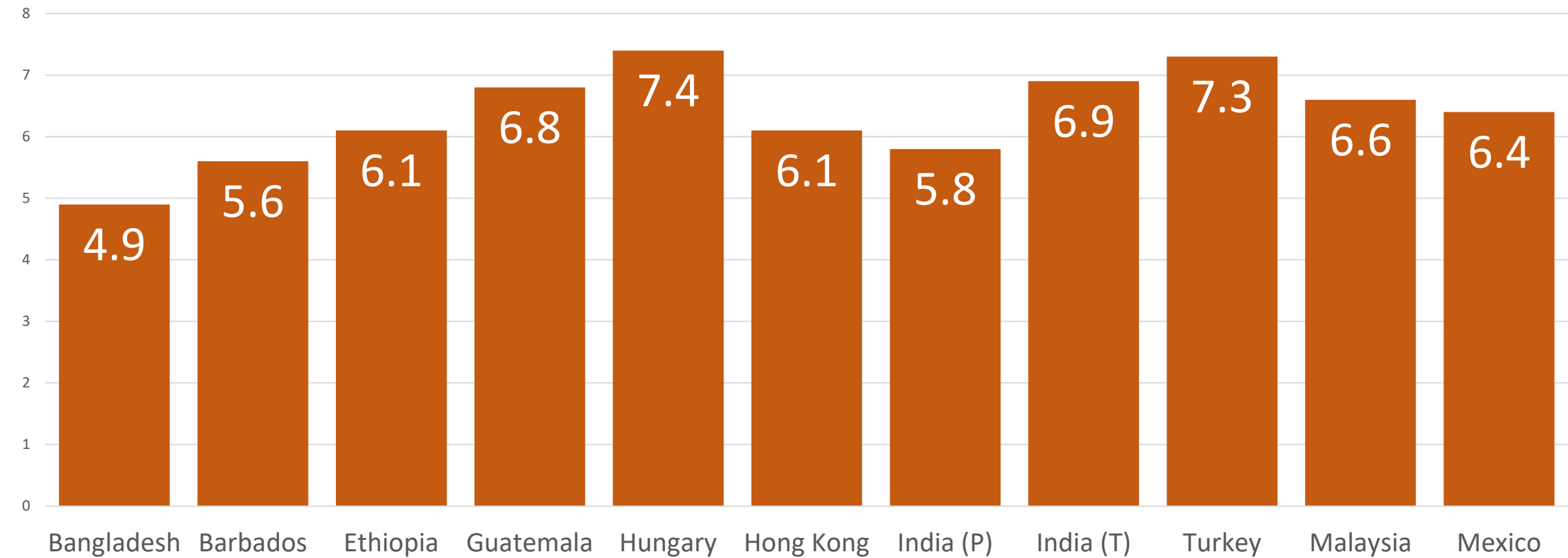
# Pilot survey conducted Jan – Feb 2022

	Place	N
1	Bangladesh	350
2	Barbados	14
3	Ethiopia	55
4	Guatemala	91
5	Hungary	51
6	Hong Kong	1090
7	India	633
8	Turkey	23
9	Malaysia	652
10	Mexico	31
	<b>TOTAL</b>	<b>3001</b>

You are (or the carer of)		
a	With kidney disease	<b>13%</b>
b	With kidney failure (not yet on dialysis)	<b>2%</b>
c	On peritoneal dialysis	<b>21%</b>
d	On haemodialysis	<b>57%</b>
e	With a kidney transplant	<b>7%</b>

Do you have enough healthcare/medical information about your kidneys and kidney disease to care for yourself?

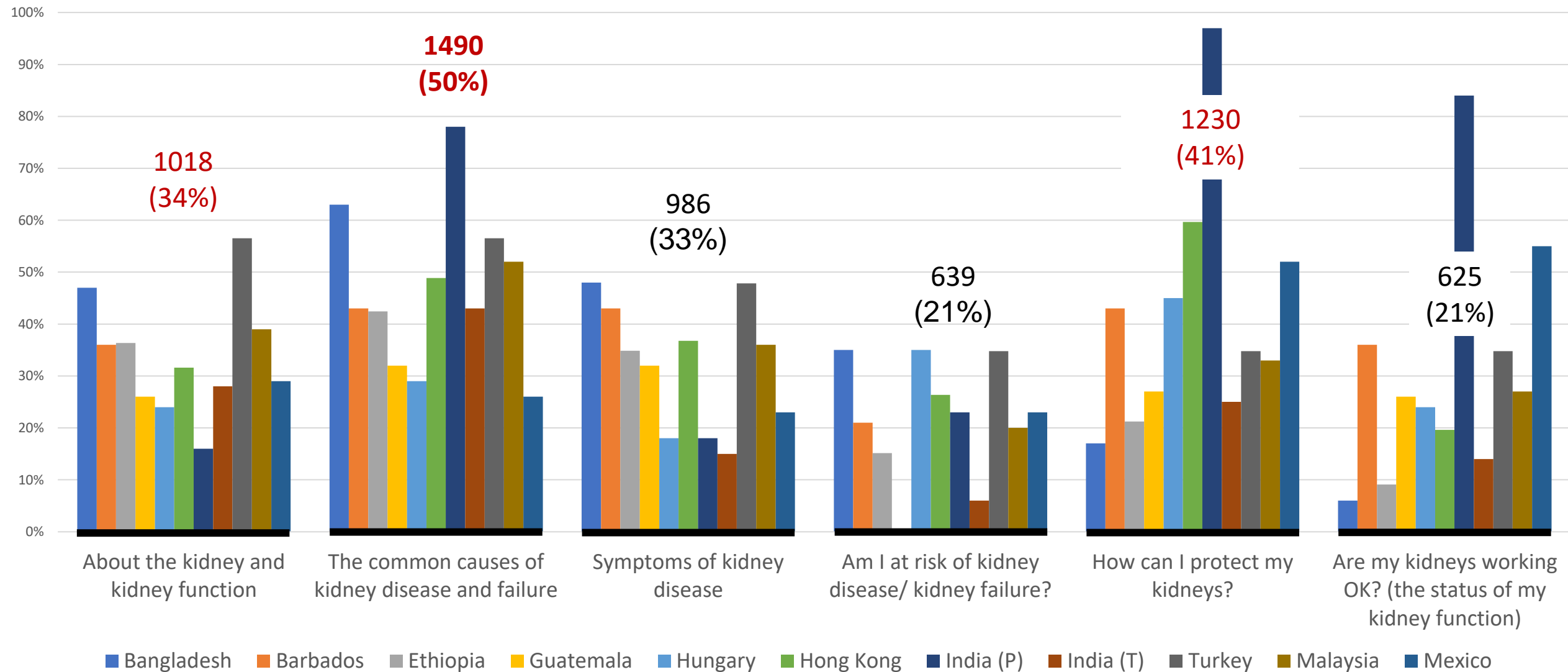
Mean Score (out of 10) = 6.4



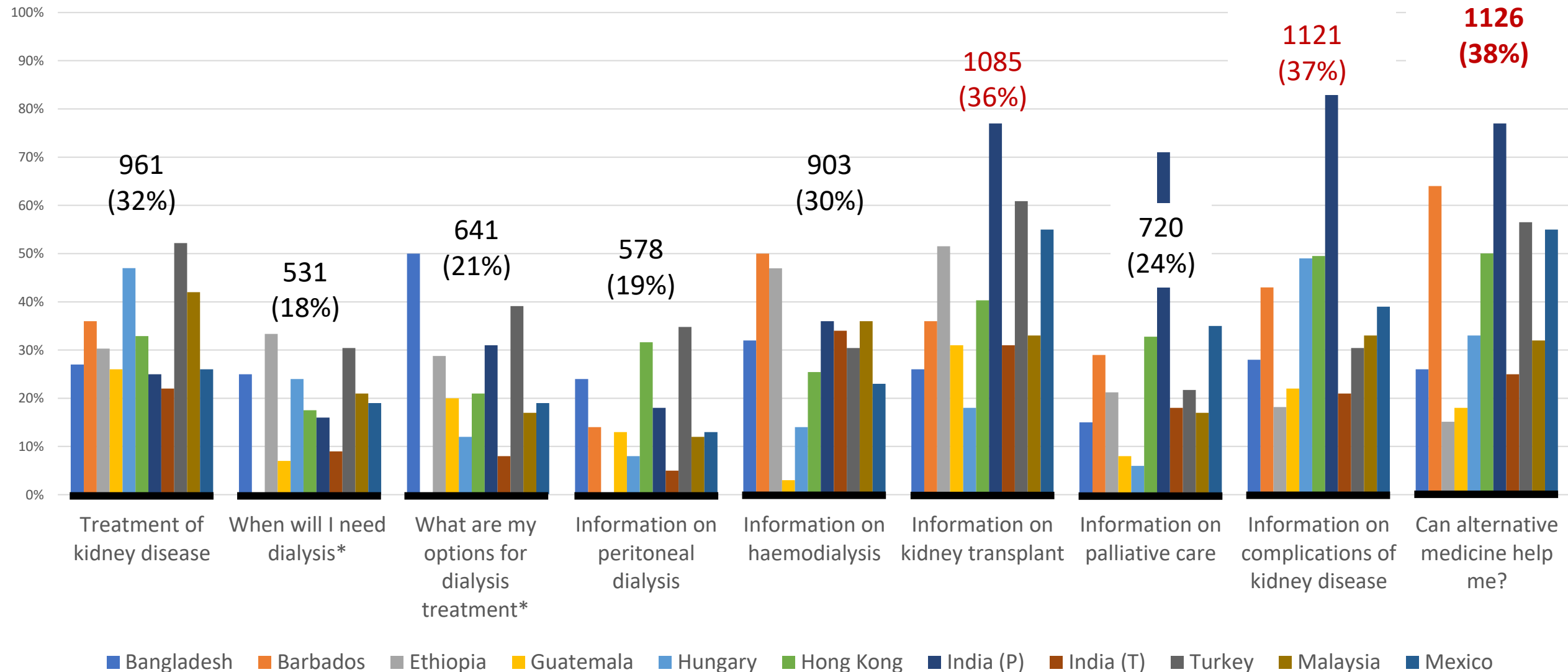
	Bangladesh	Barbados	Ethiopia	Guatemala	Hungary	Hong Kong	India (P)	India (T)	Turkey	Malaysia	Mexico
No.	350	14	66	91	51	1090	77	556	23	652	31



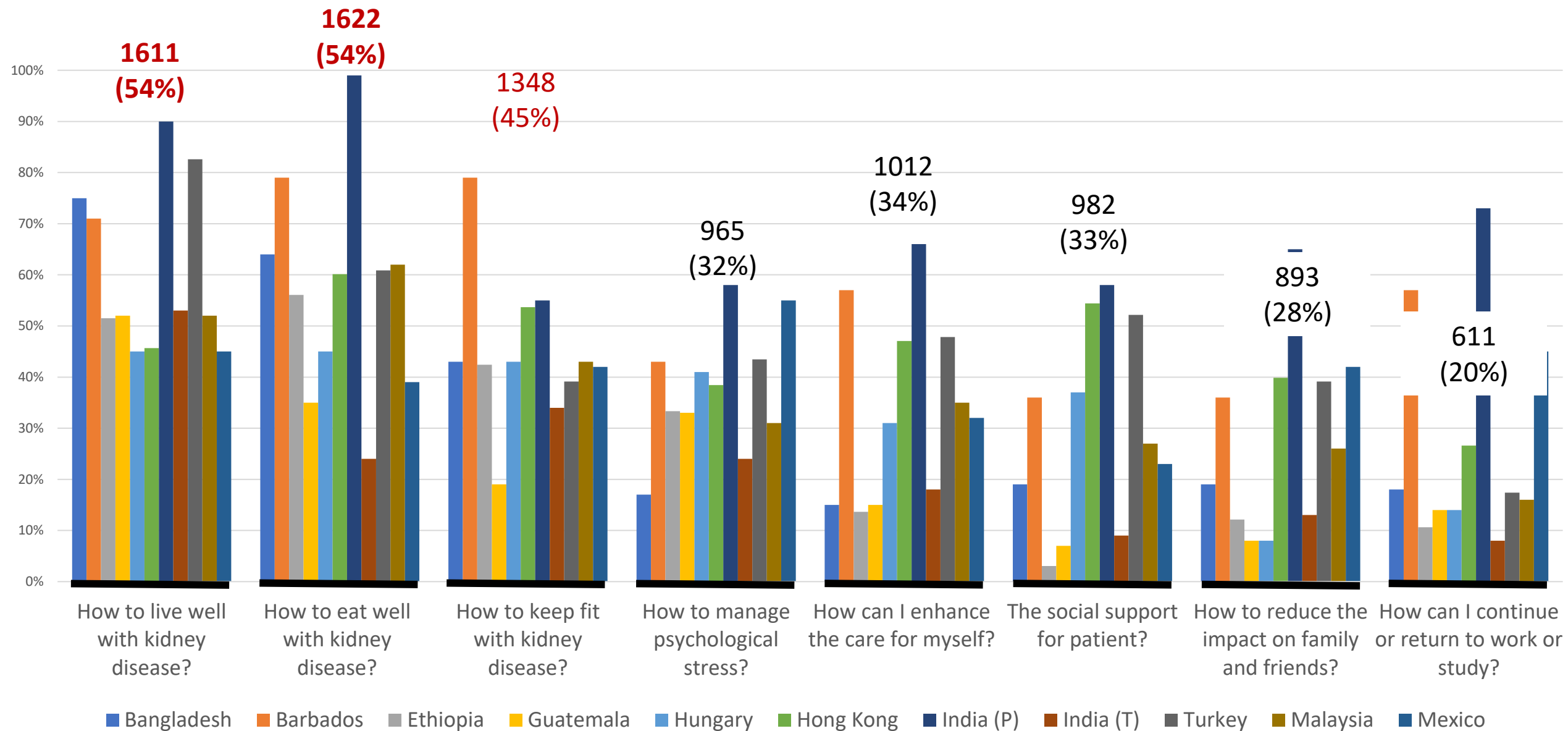
# What kind of healthcare/medical information on kidney and kidney diseases you want to know?



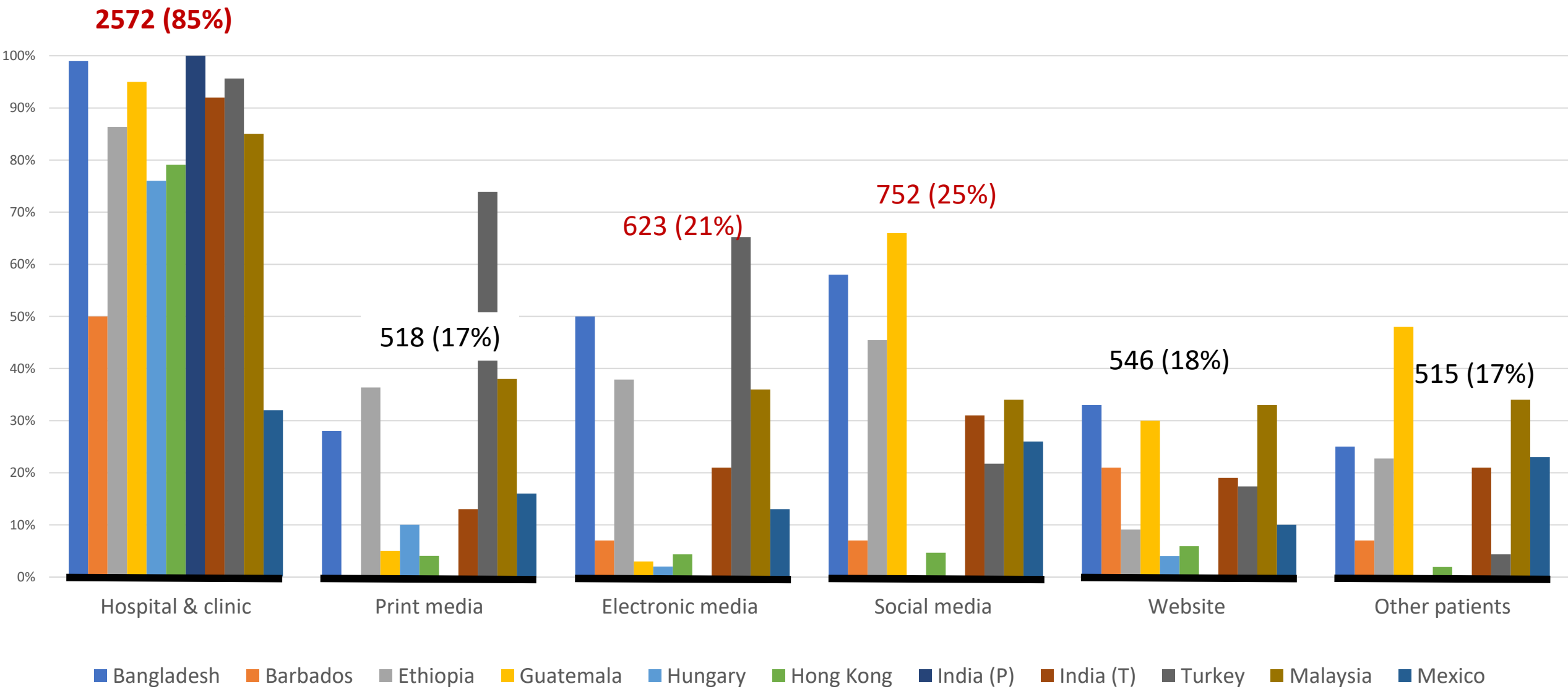
# What kind of healthcare/medical information on the treatment of kidney disease/failure you want to know?



# What kind of healthcare/medical information on living well with kidney disease you want to know?

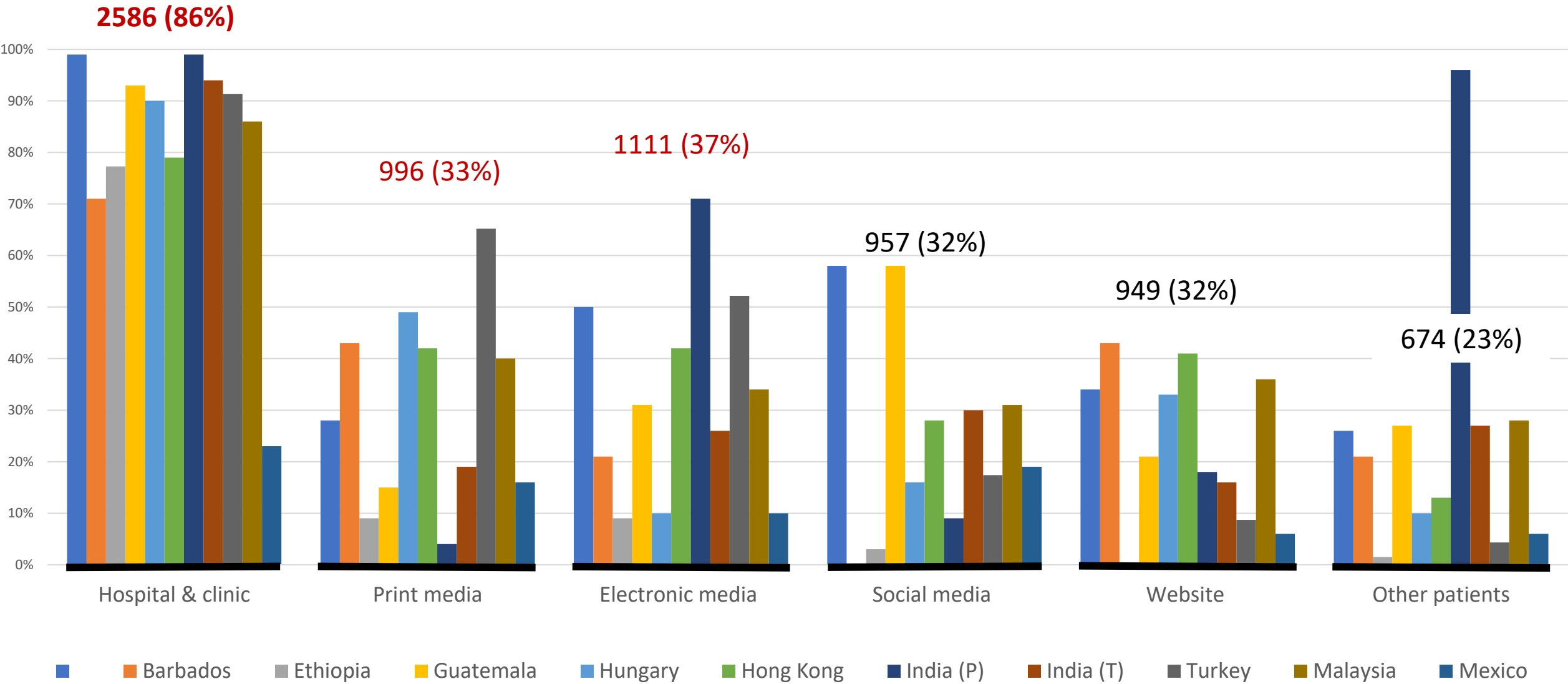


List up to three places **where you have obtained**  
the best healthcare/medical information on kidney disease and kidney treatment





List up to three places **where you would prefer to obtain**  
the best healthcare/medical information on kidney disease and kidney treatment



# Findings (overall, need subgroup analysis)

- **Patients want to know:**

- How to protect kidneys
- Common causes
- Kidney function
- Complications
- Alternative medicine
- Transplantation
- Living well
- Eat well
- Keep fit

- **Patients wish to get the information**

- From healthcare professionals (86%)
- Electronic media (37%)
- Website (32%)
- Social media (32%)
- Printed matters (33%)
- Other patients (23%)

# Way forward

- Enhance the skill of healthcare professionals to transfer knowledge.
- A more effective and efficient way for healthcare professionals to provide the health and healthcare information (mass transfer)
- **Promote online webinar and website**
  - Pros: - Delivered by healthcare professionals (what patients want)
  - Factual and trusted information (social media cannot be control)
  - Webinar recordings posted on website.
  - Information can be accessed anytime (24hr x 7)
  - Information can be accessed any where (in the world)
  - Content in the format the receivers can understand
  - Co-design with patients, sharing by patients, can be interactive.

*(Use social media to promote the site but not source of information)*

**Kidney informative  
social media**

Education and awareness

**People with  
kidney disease**

**Update with  
accurate data**

Identify and remove misinformation

**Kidney Health  
for All  
Collaborative  
Social Media  
Platforms**

**Kidney  
Consumer  
Advocacy**

**Kidney  
Healthcare  
Workers**

**Kidney support networks  
Guided by healthcare  
workers**



[www.worldkidneyday.org](http://www.worldkidneyday.org)





# Kidney Talks

Hong Kong Kidney Foundation  
Hong Kong Society of Nephrology  
Hong Kong Association of Renal Nurses

**Series 1 – 9 episodes (5 Oct 2021 - 25 Jan 2022)**

Online webinar alternative Tuesday night

Live via Zoom, Facebook, YouTube

Recording posted on HKKF website.

Posting on newspaper's website (4m hits)



**腎智台 KIDNEYS TALK**



**知多腎好**

**The Launching of the "Kidneys Talk"**  
**A Live Channel on Kidney Care for Everyone**

**你講 我講 與腎同行**  
From 5 October 2021  
fortnightly on Tuesday evening 8:00 - 8:45  
**LIVE ONLINE** and to view recording



Dr. Lui Siu Fai  
Chairman,  
Hong Kong Society of Nephrology



Dr. Chow Kai Hong  
Chairman,  
Hong Kong Kidney Foundation



Dr. Lee Koi Fai  
President,  
Hong Kong Association of Renal Nurses



Dr. Lui Siu Fai, Chairman of the HKKF, serves as one of the speakers in the first series.



Representatives of the HKKF, co-organiser of the "Kidneys Talk" Channel.



Representatives of the HKSN, co-organiser of the "Kidneys Talk" Channel.

The burden of kidney diseases is substantial that the disease affects about 10% of global population and its prevalence continues to increase. Essentially, kidney diseases are associated with various comorbidities including cardiovascular diseases (CVD) and diabetes mellitus (DM) as well as a wide spectrum of psychosocial problems. Thus, measures for preventing kidney diseases and timely management upon disease onset are vital to combat the increase in cases of kidney diseases in our society as well as to control the worsening of kidney health for patients.

Organised by the Hong Kong Kidney Foundation (HKKF), with the Hong Kong Society of Nephrology (HKSN) and the Hong Kong Association of Renal Nurses (HKARN) as the co-organisers, the "Kidneys Talk" Live Channel has been launched on the 5th October, 2021. The channel aims not only to provide information on management of kidney diseases, but also to serve as a platform for patients with kidney diseases to share their experiences and inquiries on living with this disease.



The "Kidneys Talk" Channel broadcasts fortnightly on Tuesday evening at 8:00 - 8:45 since 5th October 2021. The first series of the live channel consists of 9 episodes covering the whole journey of living with kidney diseases, from knowing the kidney and prevention of kidney disease to management of kidney diseases and treatment options for end-stage kidney diseases. Specialists in nephrology and other healthcare professionals, including nurses and dietitians, as well as patients will be invited to share their expertise and experience in managing kidney diseases in each episode. In the second series, the association between diet and kidney health will be discussed.



Dr. Lui Siu Fai, Dr. Chow Kai Hong, Dr. Lee Koi Fai, Dr. Wong Siu Ho, Dr. Sunny, Dr. Lee, William shared the diagnosis of kidney diseases in episode 2.



腎病的檢查和診斷 (4)

想知更多 腎臟資訊

請向詳情 網上重溫

直播連結



**腎智台 KIDNEYS TALK**

**你講 我講 與腎同行**  
**網上 LIVE 講座**

**專業醫護人員 與你關注腎臟健康每一步**  
• 醫護專題講解 • 腎臟健康貼士 • 腎友同路人分享

**知多腎好**  
2021年10月5日起  
每隔一周  
星期二晚上八點播出

**9 伴你同行**  
25.1.2022

**8 精靈飲食 輕鬆生活**  
11.1.2022

**7 洗腎無障礙**  
28.12.2021

**6 腎臟移植 新的開始**  
14.12.2021

**5 「洗血」的疑惑**  
30.11.2021

**4 洗肚：真相與誤解！**  
16.11.2021

**3 洗腎的十字路口 何去何從**  
2.11.2021

**2 腎病了 你需知**  
19.10.2021

**1 點解腎會病？**  
5.10.2021

**想知更多 腎臟資訊**



講座詳情及網上重溫  
香港腎臟基金會網址  
hkkf.org.hk



直播連結  
香港腎臟基金會  
https://bit.ly/3JSUeGz

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# Online series 1

## “Kidneys Talk” for Everyone

	Fortnightly 8:00-8:45 pm	Topic	Title of the talk	Guest speakers	Hosts
1	5 October 2021	<b>Kidney and you</b>	Kidney and Kidney disease	Dr. SL Lui Dr. Vincent Chow	Ms. Maggie Ng Dr. KF Chau
2	19 October 2021	<b>Kidney disease and you</b>	Your kidneys are not well, you need to know!	Dr. Sunny Wong Dr. William Lee	Ms. Candy Chea Dr. Samuel Fung
3	2 November 2021	<b>Kidney failure and you</b>	At the crossroad of kidney replacement therapy.	Dr. SF Lui Dr. YL Cheng	Dr. KF Chau Ms. Windy Lee
4	14 November 2021	Kidney Replacement therapy <b>1: Peritoneal dialysis</b>	The myth of peritoneal dialysis	Dr. CK Chan Ms. Sandy Hui (nurse)	Ms. Maggie Ng Ms. Windy Lee
5	30 November 2021	Kidney Replacement therapy <b>2. Haemodialysis</b>	The concerns on haemodialysis	Dr. Maggie Mok Ms. Janet Li (nurse)	Dr. Samuel Fung Ms. Maggie Lee
6	14 December 2021	Kidney Replacement therapy <b>3. Kidney Transplantation</b>	Kidney Transplant – a new beginning	Dr. Maggie Ma Dr. Winston Fung	Ms. Candy Chea Prof Sydney Tang
7	28 December 2021	<b>Rehabilitation 1</b>	Barrier free renal replacement therapy	Dr. Lorraine Kwan Dr. Jack Ng	Dr. KF Chau Dr. YL Cheng
8	11 January 2022	<b>Rehabilitation 2</b>	Living well with kidney disease	Ms. Sabrina Mok (Dietitian) Ms. Maki Mak (MSW)	Dr. Samuel Fung Ms. Maggie Lee
9	24 January 2022	<b>Rehabilitation 3</b>	Walk with you (support)	Dr. John Chan Ms. Dora Leung (nurse)	Dr. KF Chau Dr. CY Yung



International Federation of Kidney Foundations – World Kidney Alliance

## World Kidney Online Webinar



- To set up a series of online webinar for
- Healthcare professionals
  - Healthcare providers/organizations/foundations



## Kidney health for all: bridging the gap in kidney health education and literacy

Robyn G. Langham<sup>1</sup>, Kamyar Kalantar-Zadeh<sup>2</sup>, Ann Bonner<sup>3</sup>,  
Alessandro Balducci<sup>4</sup>, Li-Li Hsiao<sup>5</sup>, Latha A. Kumaraswami<sup>6</sup>, Paul Laffin<sup>7</sup>,  
Vassilios Liakopoulos<sup>8</sup>, Gamal Saadi<sup>9</sup>, Ekamol Tantisattamo<sup>2</sup>, Ifeoma Ulasi<sup>10</sup> and  
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**... Kidney organizations  
should work towards  
shifting the patient-deficit health literacy narrative  
to that of being the responsibility  
of healthcare providers  
and health policy makers.**

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