



A pilot survey by IFKF-WKA  
**Access to healthcare information**  
**by the kidney patients**  
Jan-Feb 2022

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

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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.

# 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 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 60 100

\* 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)

世界腎臟日 2022 - 全民腎康 增強腎臟照顧 · 填補認知不足

國際腎臟基金聯合會-世界腎臟聯盟的世界腎臟資訊調查

香港腎臟基金會、香港腎科學會、香港腎科護士學會主辦

腎病及腎衰竭患者如何獲取醫療信息及期望

請於 2022 年 2 月 14 日星期一之前完成調查 · 感謝您積極參與 ·

\* 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 60 100

\* 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 60 100

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

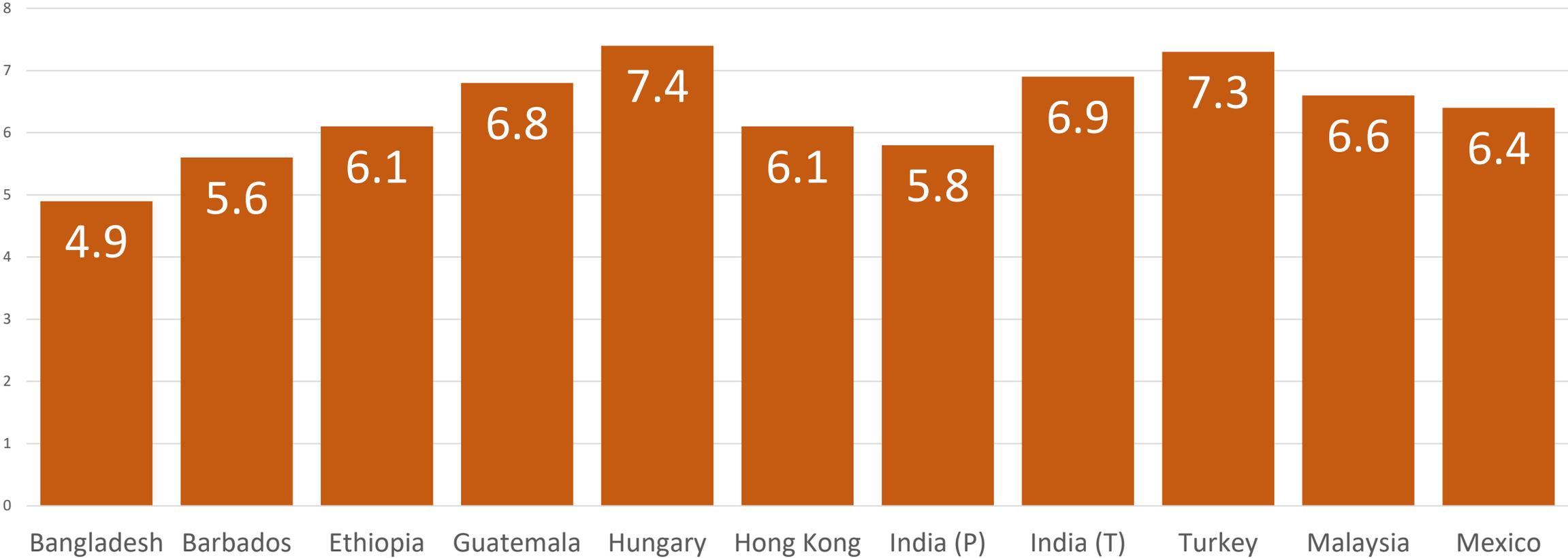
# Pilot survey conducted Jan – Feb 2022

	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>

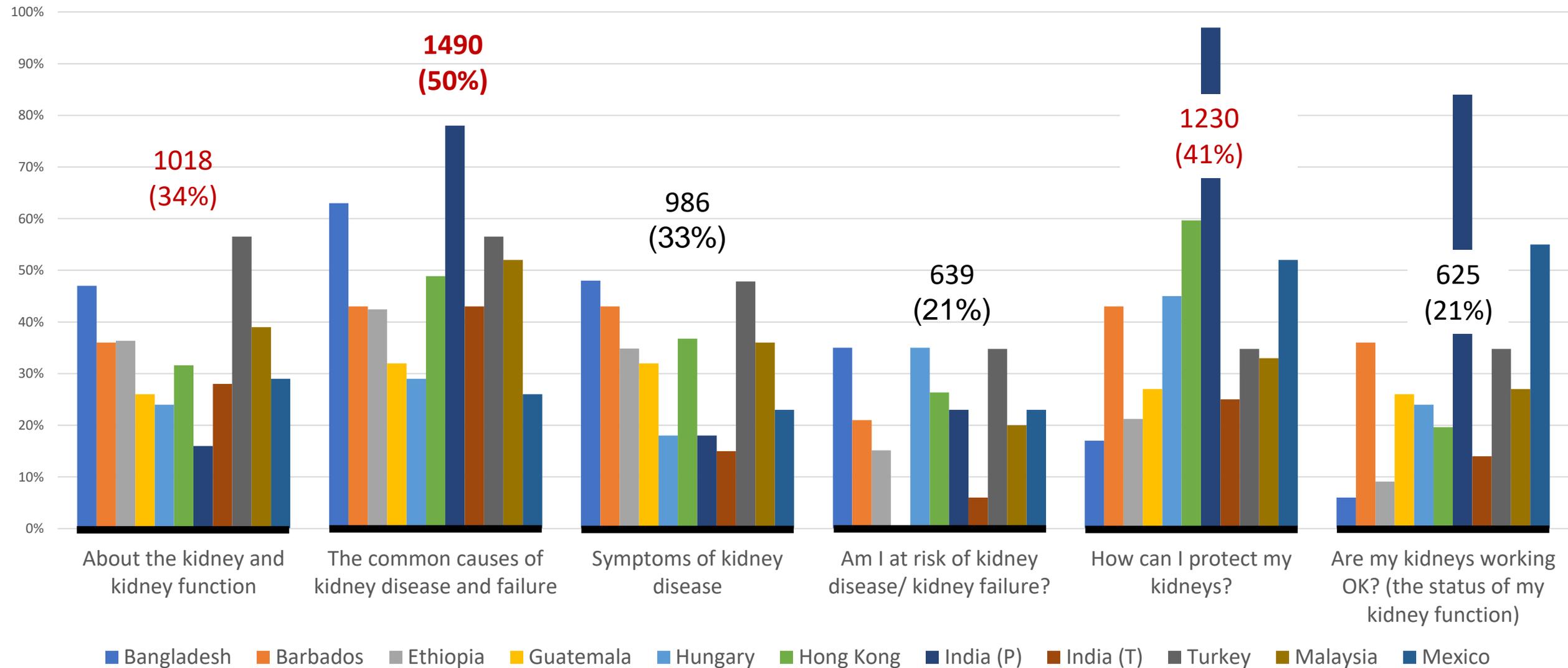
Do you have enough healthcare/medical information about your kidneys and kidney disease to care for yourself?

**Mean Score (out of 10) = 6.4**

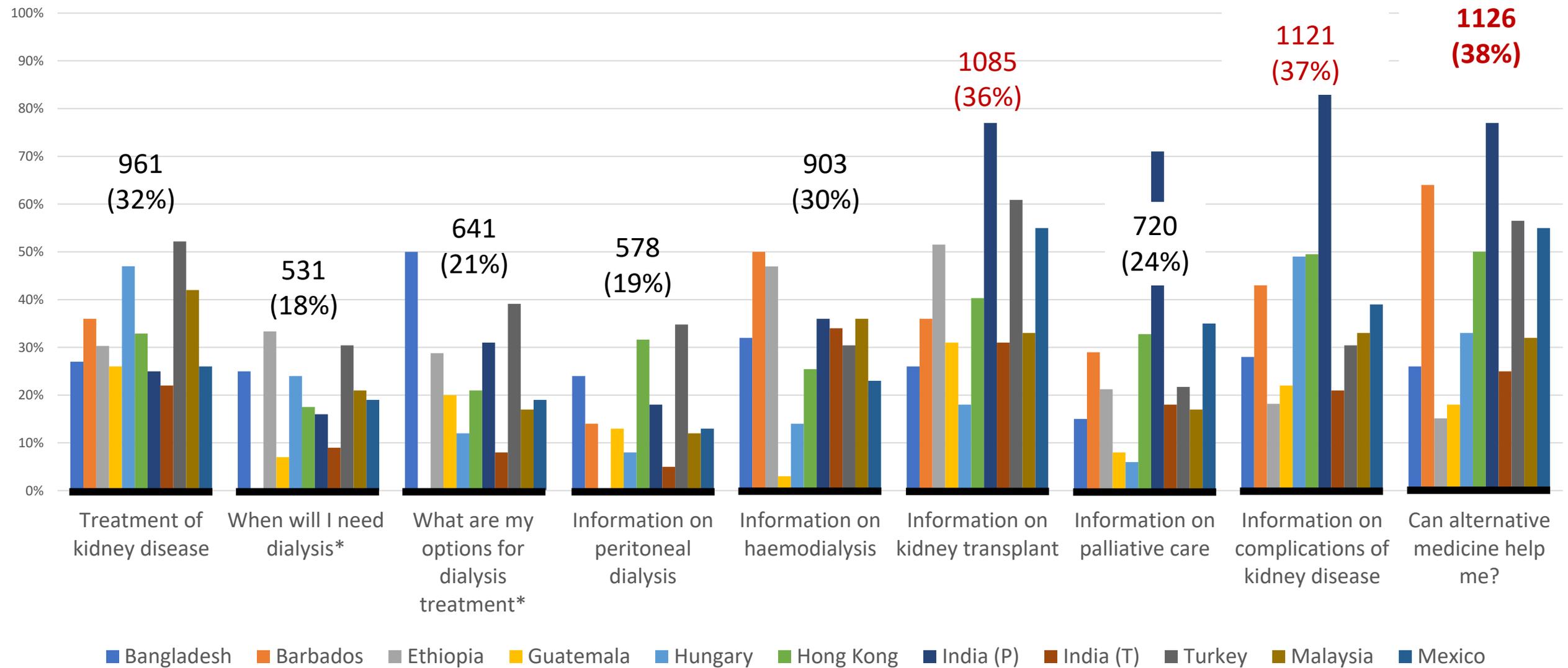


	Bangladesh	Barbados	Ethiopia	Guatemala	Hungary	Hong Kong	India (P)	India (T)	Turkey	Malaysia	Mexico
No.	350	14	66	91	51	1090	77	556	23	652	31

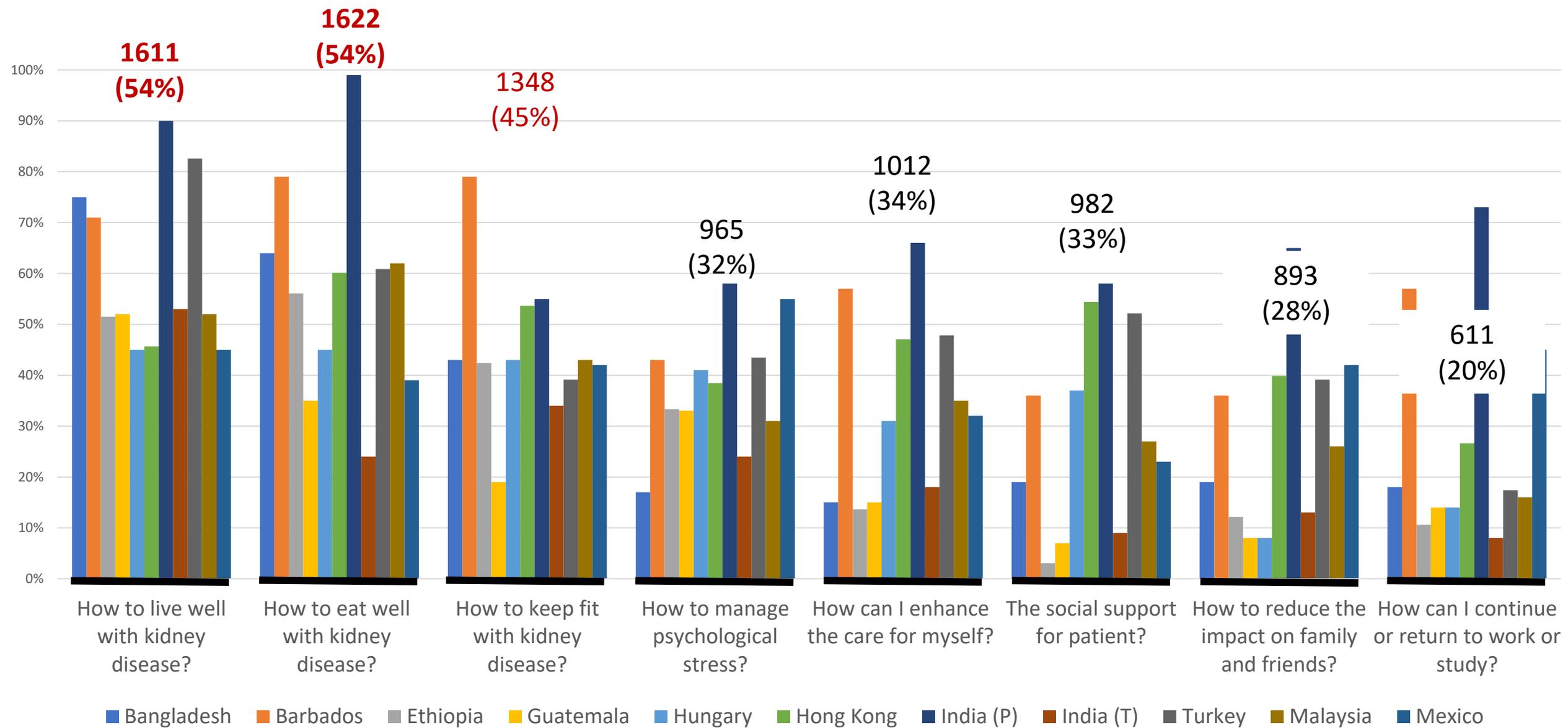
# What kind of healthcare/medical information on kidney and kidney diseases you want to know?



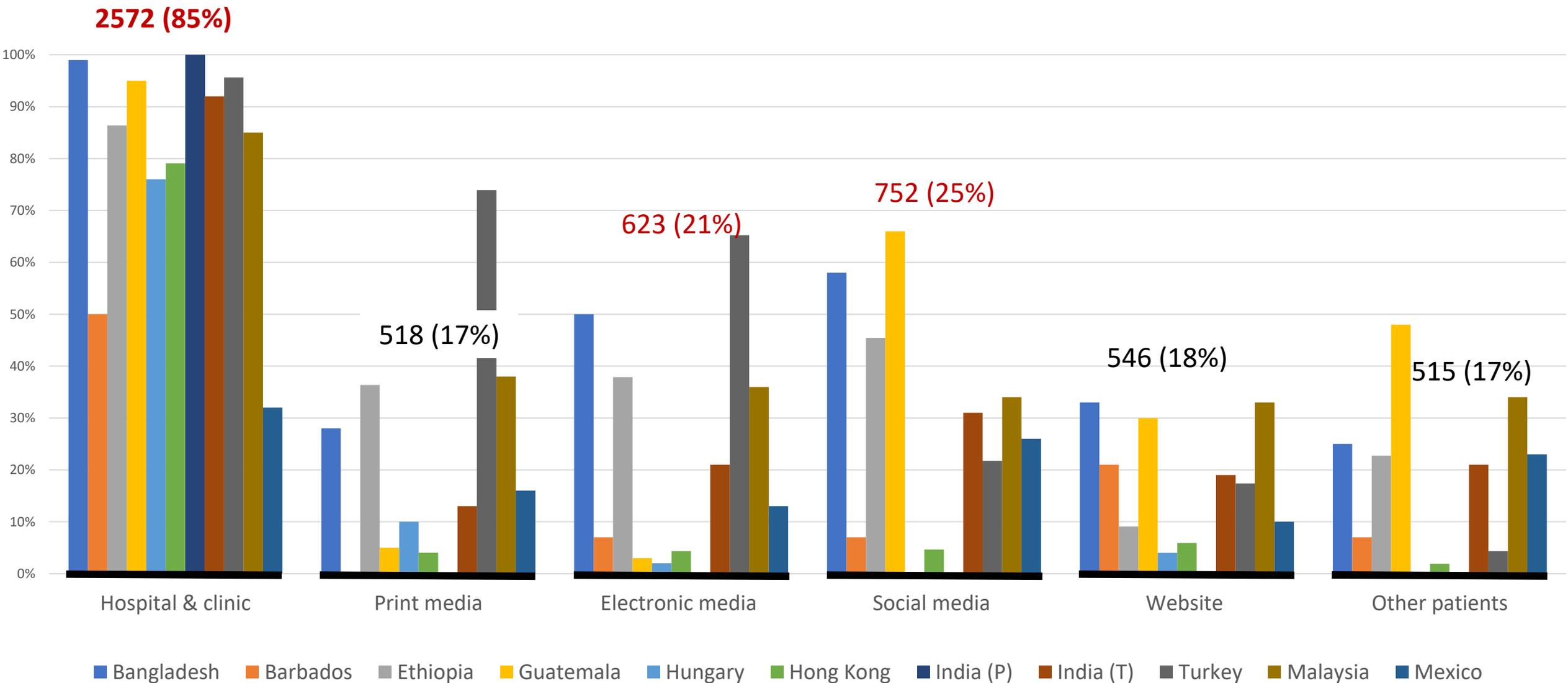
# What kind of healthcare/medical information on the treatment of kidney disease/failure you want to know?



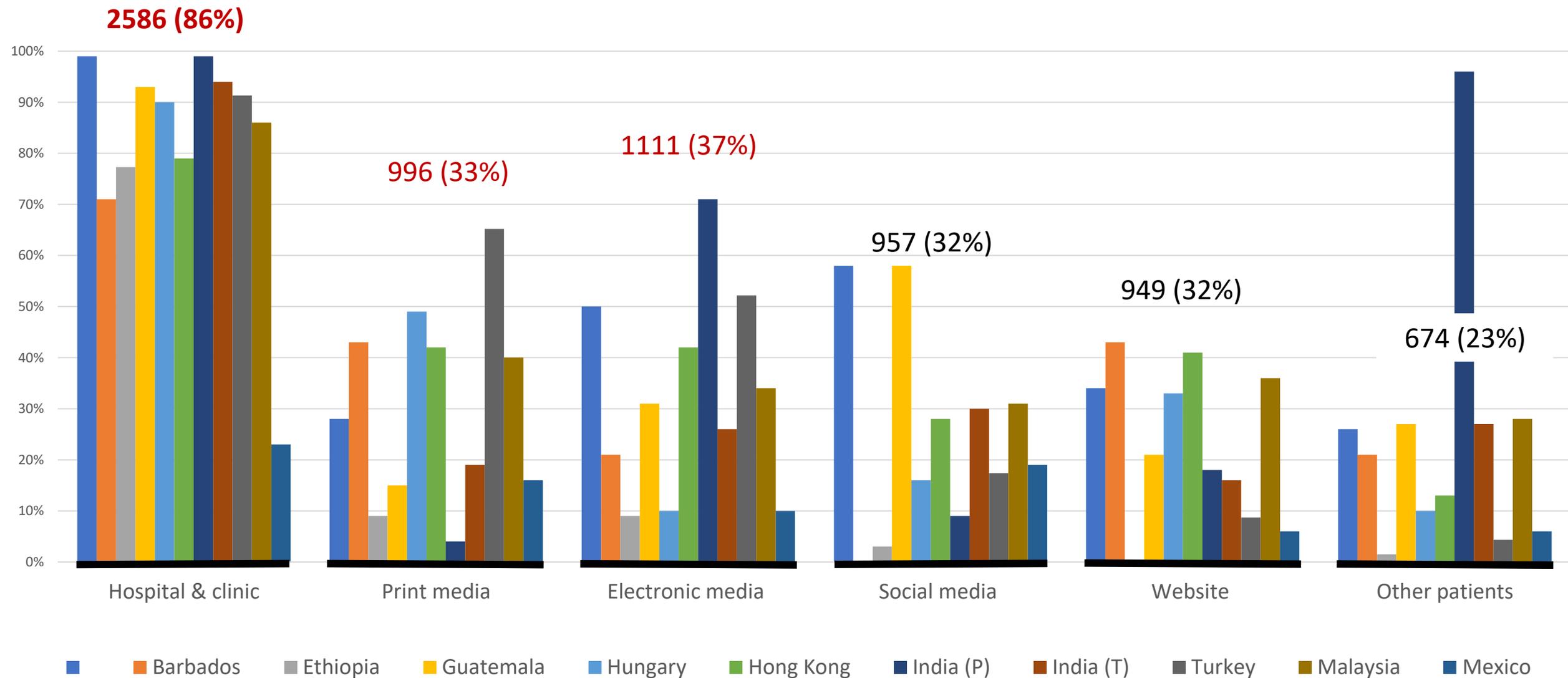
# What kind of healthcare/medical information on living well with kidney disease you want to know?



# 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)*

# Acknowledgement

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Maggie Lee, Windy Lee

- **IFKF-WKA members**

Bangladesh

Barbados

Egypt

Ethiopia

Guatemala

Hong Kong

Hungary

India

Malaysia

Turkey

Mexico