A pilot survey by IFKF-WKA
Access to healthcare information by the kidney patients
Jan-Feb 2022
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?
### What kind of healthcare/medical information on the treatment of kidney disease/failure you want to know?

| 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) |

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

| 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) |

### List up to three places where you have obtained the best healthcare/medical information on kidney disease and kidney treatment in order of preference (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, booklet) |
| 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) |

### List up to three places where you would prefer to obtain the best healthcare/medical information on kidney disease and kidney treatment in order of preference (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, booklet) |
| 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) |

### Please list any other suggestion

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

1. You are (or Care 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. Age:

3. Your Education level:
- High school level / Grade 10 or above - higher education in institution
- Junior school level / Secondary school / Grade 1-9
- No formal school education

4. Do you have enough medical information about your kidney and kidney disease to care for yourself? Please grade 1-10, 10 points = not enough, 10 points = very positive

5. What kind of healthcare or medical information on kidney and kidney disease do you want to know? (up to 5 items)
- About the kidney and kidney function
- The common causes of kidney disease and failure
- Symptom of kidney disease
- How to set of kidney disease/kidney failure?
- How can I protect my kidneys?
- Are my kidneys working (the status of my kidney function)
- Other (please list)

6. You are from:
- Bangladesh
- Barbados
- Egypt
- Ethiopia
- Hong Kong
- Hungary
- India (Tanker Foundation)
- India (Pondicherry Kidney Foundation)
- Malaysia
- Turkey
- Mexico
- US (Hawaii)

Access to the information for patients with kidney disease renal

1. Eres paciente o cuidador de (Marque una)
- Algun con problemas
- Alguna en diálisis (peritoneal, automática)
- Alguna en hemodiálisis
- Alguna con trasplante renal

2. Edad (ingrese la edad en número)

3. Nivel de educación (Marque una)
## Pilot survey conducted Jan – Feb 2022

<table>
<thead>
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<th>Place</th>
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<td>3  Ethiopia</td>
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<td>9  Malaysia</td>
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<td>10 Mexico</td>
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<td><strong>TOTAL</strong></td>
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You are (or the carer of):

- **a** With kidney disease: 13%
- **b** With kidney failure (not yet on dialysis): 2%
- **c** On peritoneal dialysis: 21%
- **d** On haemodialysis: 57%
- **e** With a kidney transplant: 7%
Do you have enough healthcare/medical information about your kidneys and kidney disease to care for yourself?

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

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

- About the kidney and kidney function: 1018 (34%)
- The common causes of kidney disease and failure: 1490 (50%)
- Symptoms of kidney disease: 986 (33%)
- Am I at risk of kidney disease/kidney failure?: 639 (21%)
- How can I protect my kidneys?: 1230 (41%)
- Are my kidneys working OK? (the status of my kidney function): 625 (21%)

- Bangladesh
- Barbados
- Ethiopia
- Guatemala
- Hungary
- Hong Kong
- India (P)
- India (T)
- Turkey
- Malaysia
- Mexico
What kind of healthcare/medical information on the treatment of kidney disease/failure you want to know?

- Treatment of kidney disease: 961 (32%)
- When will I need dialysis*: 531 (18%)
- What are my options for dialysis treatment*: 641 (21%)
- Information on peritoneal dialysis: 578 (19%)
- Information on haemodialysis: 903 (30%)
- Information on kidney transplant: 1085 (36%)
- Information on palliative care: 720 (24%)
- Information on complications of kidney disease: 1121 (37%)
- Can alternative medicine help me?: 1126 (38%)
What kind of healthcare/medical information on living well with kidney disease do you want to know?

- How to live well with kidney disease? 1611 (54%)
- How to eat well with kidney disease? 1622 (54%)
- How to keep fit with kidney disease? 1348 (45%)
- How to manage psychological stress? 965 (32%)
- How can I enhance the care for myself? 1012 (34%)
- The social support for patient? 982 (33%)
- How to reduce the impact on family and friends? 893 (28%)
- How can I continue or return to work or study? 611 (20%)
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

• Hong Kong Kidney Foundation
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• Hong Kong Society of Nephrology
  YL Cheng, Jack Ng, KM Chow

• Hong Kong Association of Renal Nurses
  Maggie Lee, Windy Lee

• IFKF-WKA members
  Bangladesh
  Barbados
  Egypt
  Ethiopia
  Guatemala
  Hong Kong
  Hungary
  India
  Malaysia
  Turkey
  Mexico