



Patient Engagement in Clinical Trials -- Innovative Approaches in Communication

Perspective of Global Kidney Cancer Patient Advocates

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Deborah Maskens, M.A., M.S.M.

Vice Chair, International Kidney Cancer Coalition

Core Assumptions



3 Radical Statements:

1. Patients will not enroll in clinical trials that they do not know about

2. We cannot assume that the physician can/will play the role of gatekeeper for clinical trials

3. We need to educate patients and the public at large about:

- Clinical trials in general
- Specific clinical trial opportunities
- Results of clinical trials

Social Media Campaign



Campaign aims to make #clinicaltrials a standard option of care

Think Treatment? Think Trials!

**To find out about clinical trials,
ASK and keep ASKING.**

#kidneycancer

@ikccorg

@IOkidney

Social Media Campaign



Common myth is that trials are the very last consideration...

Think Treatment? Think Trials!

**It's never too early to start asking
about clinical trial opportunities.**

#kidneycancer

@ikccorg

@IOkidney

Trials specific to #kidneycancer



Understanding immuno-oncology for kidney cancer

- ✓ trusted
- ✓ evidence-based
- ✓ patient-focused
- ✓ understandable



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- Understanding Therapy Options in Kidney Cancer
- Understanding Immuno-Oncology
- How Does The Immune System Work
- Understanding Clinical Trials
- How Can I Find a Clinical Trial for My Cancer?
- Trial Results
- 10 Questions About Clinical Trials to Ask
- 10 Things to Know About Side Effects

How Can I Find a Clinical Trial for My Cancer?

Last Updated: 22 September 2016 |

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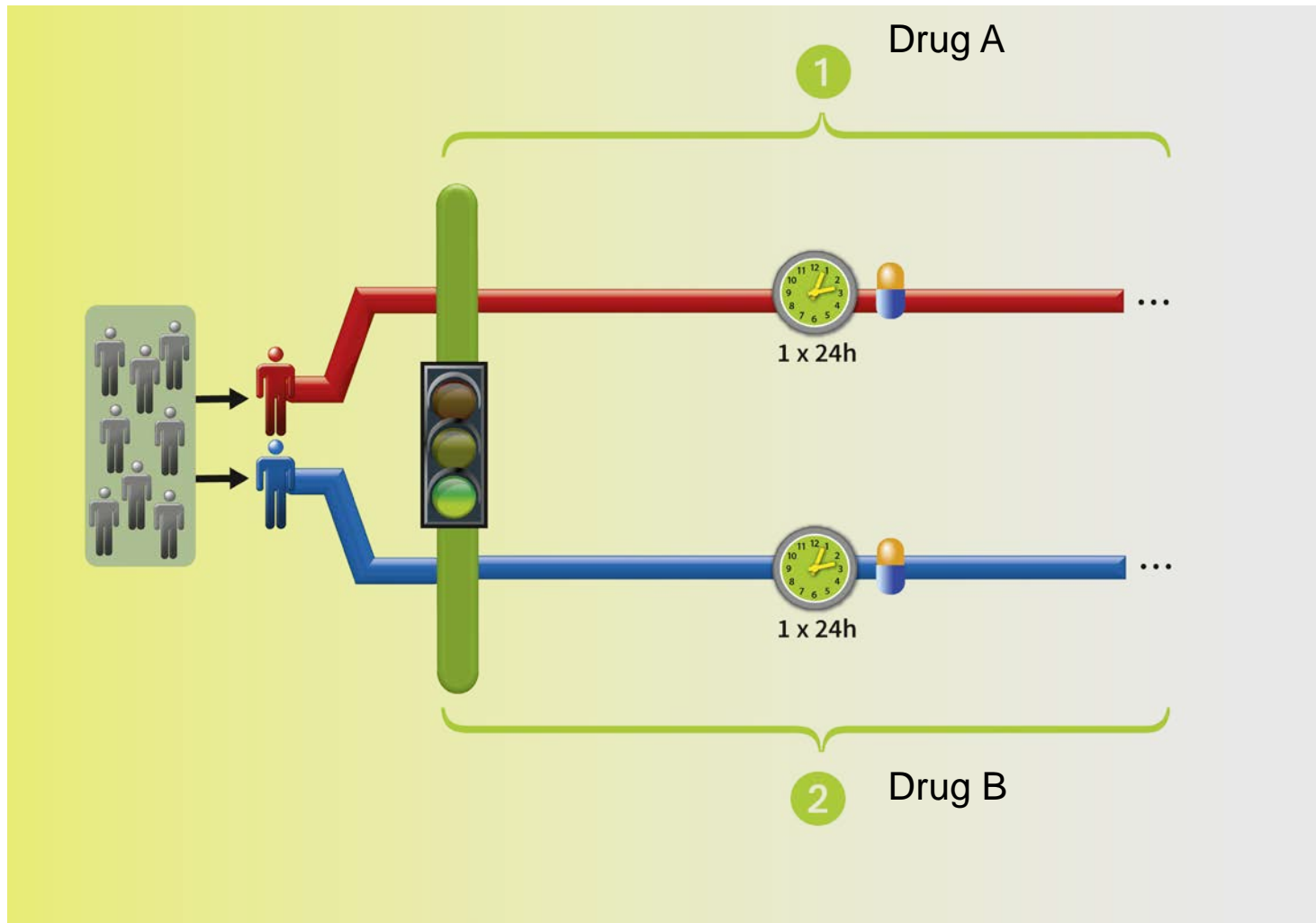
Taking part in a clinical trial can be a good choice but it is often hard to find a clinical trial that is right for you. Many patient organisations and websites maintain lists of clinical trials. The following tables list some of the many clinical trials available worldwide and focus primarily on immuno-oncology trials for kidney cancer patients. Please note: this is not an exhaustive list, so please check with your local patient organisation. Other trials may be available in your country. If you are aware of an open trial that should be listed here, please send us the trial information to: info@10forIO.info

For more information about understanding and finding trials, [click here](#).

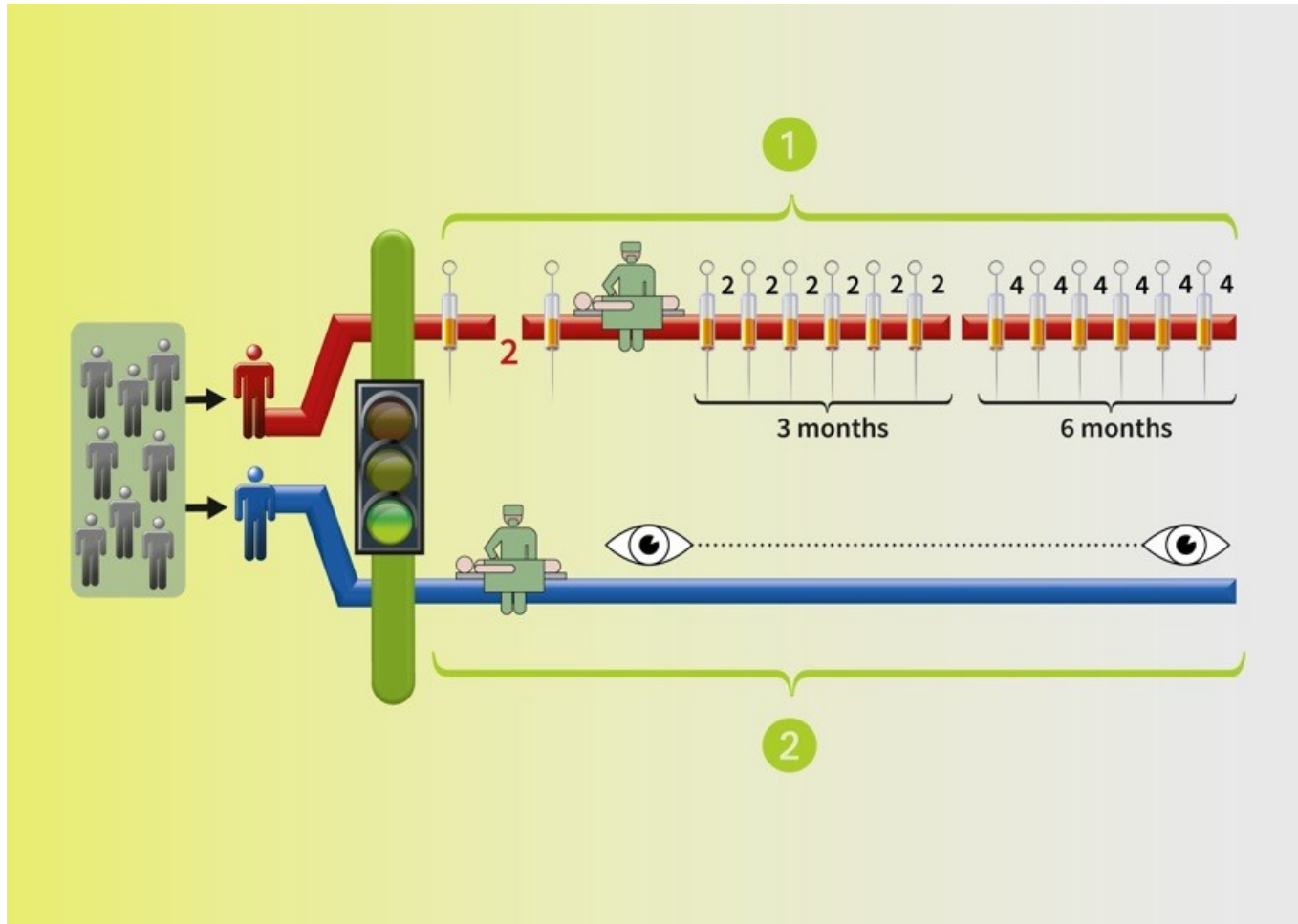
- + Pre-surgery (neo adjuvant) trials (for patients before surgery to remove the kidney tumour)
- + First line treatment (for patients who have not yet had any systemic therapy for advanced kidney cancer)
- + Second line treatment (for patients who have had only one prior systemic therapy)
- + Third line treatment (for patients who have had up to two prior systemic therapies)



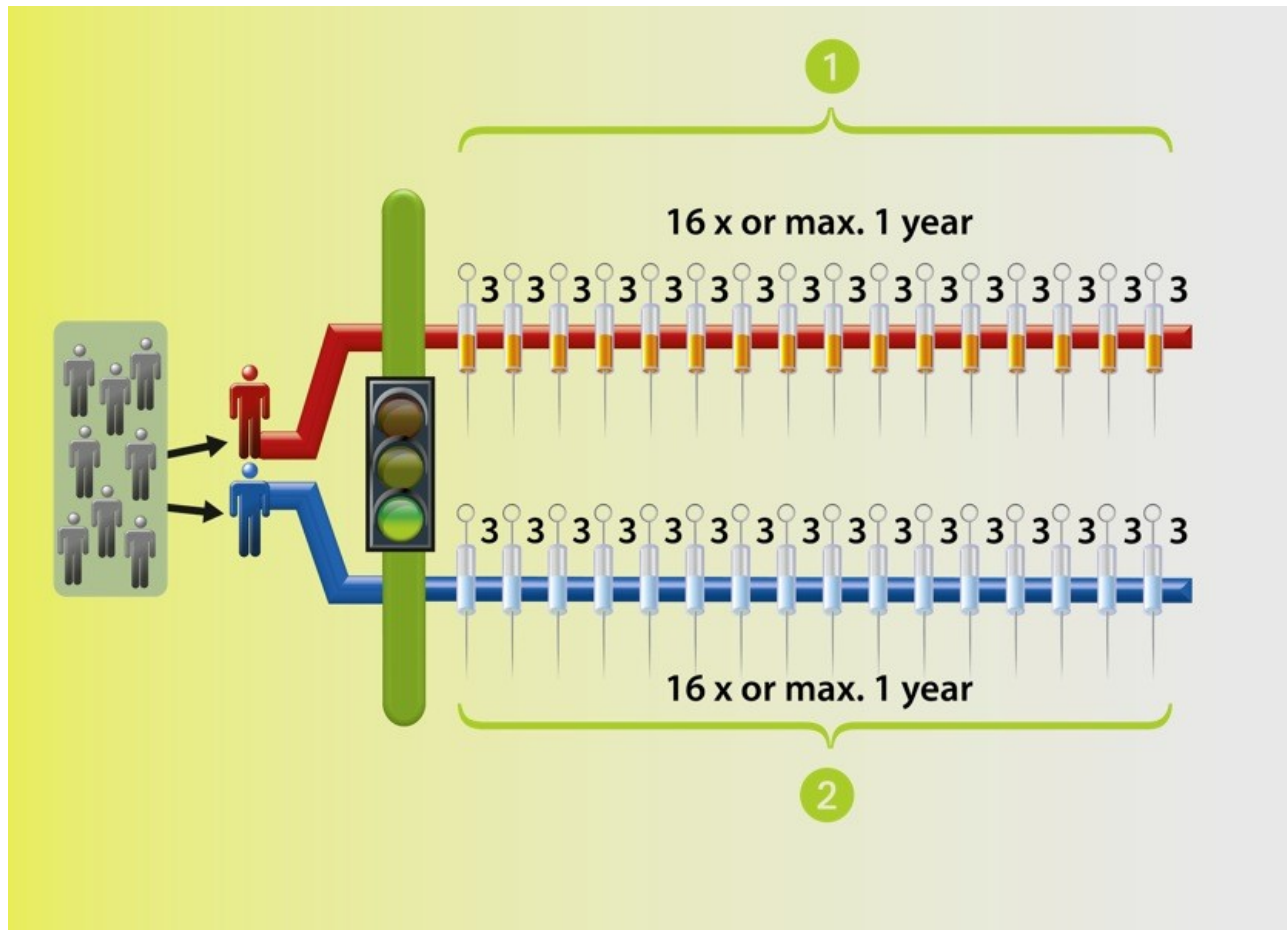
Easy To Understand Trial Graphics



Complex trial designs simplified



Patient-centric design?



When the Trial Reports...



Study Results METEOR

cabozantinib versus everolimus in advanced kidney cancer

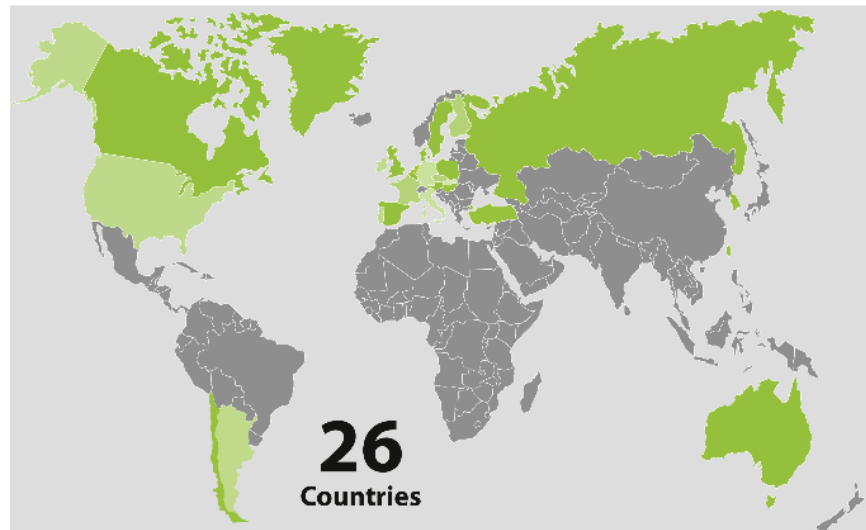
source: The New England Journal of Medicine, November 2015¹⁾, Lancet Oncology, July 2016²⁾, Ipsen Pharma Germany, August 2016³⁾



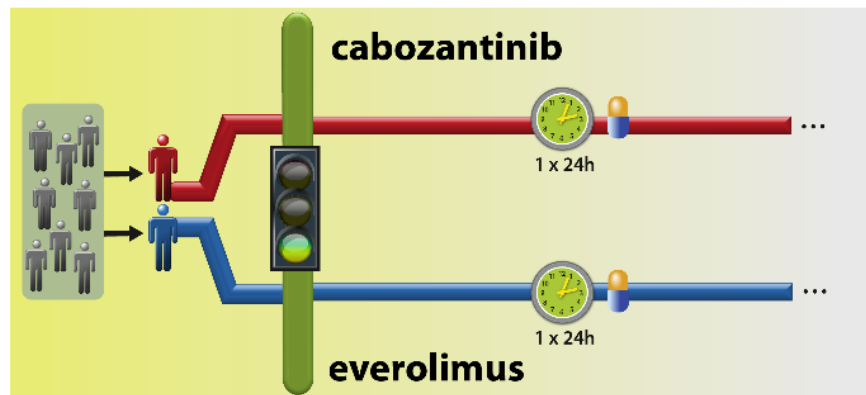
658
Patients



173
Trial Sites



Trial Design



From our Infographics



Objective Response Rate (ORR)



17% vs 3%²⁾

% of Patients with Partial or Complete Response

Progression Free Survival (Average PFS)



7.4 Months¹⁾

3.8 Months¹⁾

Stable Disease



65% vs 62%³⁾

Overall Survival Benefit (Average OS)



+4.9 Months²⁾

Results of Clinical Trials



Complete Response



0%²⁾



0%²⁾

Side Effects

Grade 3 or Grade 4



68%¹⁾



58%¹⁾



© IKCC = International Kidney Cancer Coalition,
www.ikcc.org, www.10forio.info

Sources: 1 www.nejm.org/doi/full/10.1056/NEJMoa1510016#t=article
2 [www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(16\)30107-3/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(16)30107-3/abstract)
3 Information provided by IPSEN GmbH Germany



Embedding Advocacy in Research



Research Advocates:

1. Ensure research priorities map with patient goals, unmet needs
 - E.g., James Lind Alliance process to map research priorities

2. Design clinical trials with real patients in mind
 - Accessible, convenient, positive experience
 - Ensure PROs, endpoints are meaningful

3. Support research & researchers
 - Help to get the word out about all available trials, registries, opportunities

4. Work to move research to reimbursement to RWE.



Thank You

Deborah Maskens – dmaskens@rogers.com

@DebMaskensKCC

@IKCCorg