EU|EYE

A Patient’s quest to the Magical Land of Clinical Trials: Is there a Yellow Brick Road?

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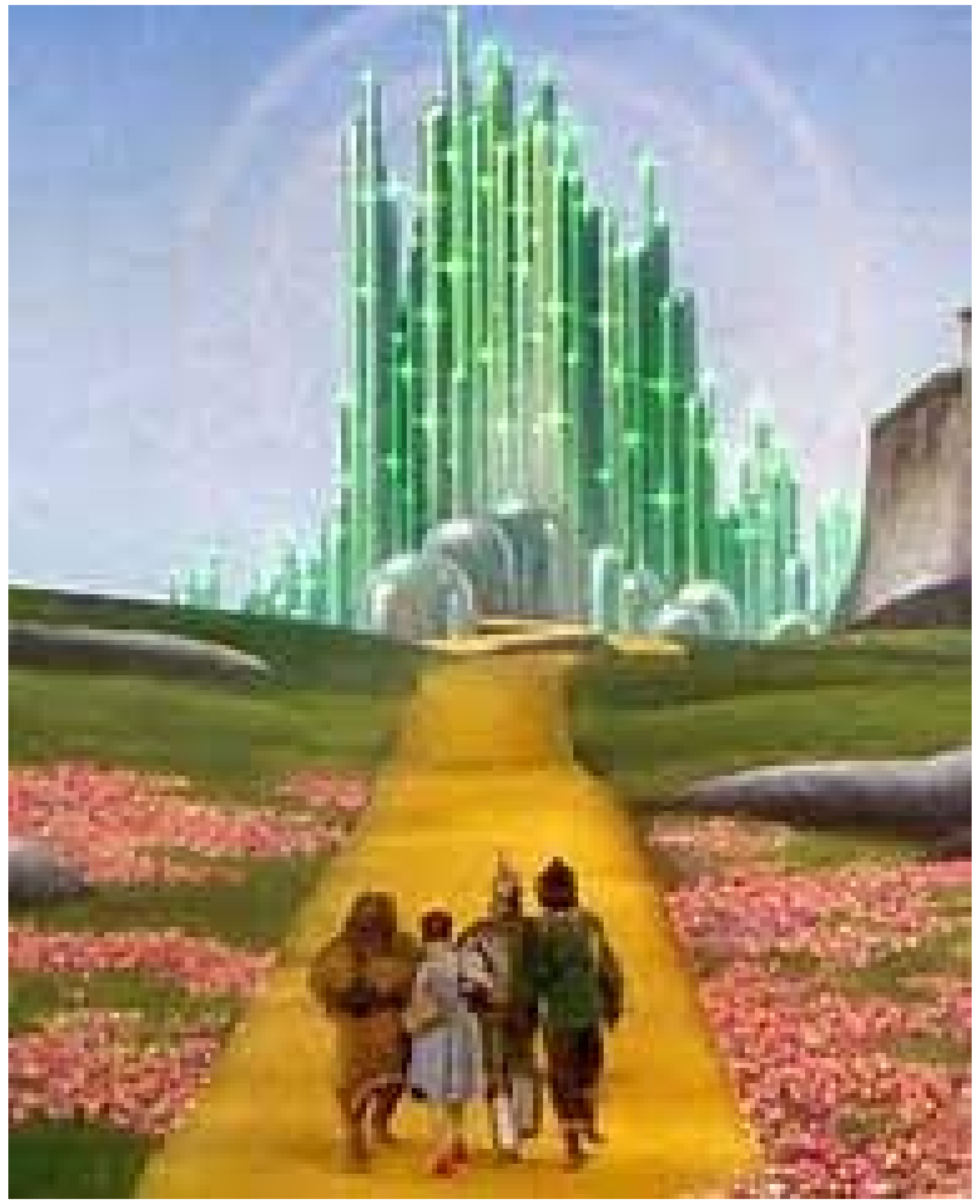
Ioanna S M Psalti
European Alliance for Vision Research and Ophthalmology

a ‘*Yellow Brick Road*’ - a path to a desired goal



Historic note. The Yellow Brick Road is a famous pathway featuring in the 1939 film adaptation of L. Frank Baum's novel, The Wonderful Wizard of Oz, written in 1900. In the story, a young girl, Dorothy, must follow it to reach the Emerald City and seek help from the Wizard.
The term entered the English language in popular usage following the release of the film although the novel referred to the concept as the "road of yellow bricks”.

The term and other concepts from the novel have found use in various contexts from health projects to business frameworks e.g.

- YellowBrickRoadProject each character representing different aspects of the quest for cure for the neurodevelopmental disorder caused by HNRNPH2 mutations;
- eClinical: A Yellow Brick Road how productivity and efficiency in clinical trial processes is achieved through a hybrid data capture system;
- The Oz Principle centred on personal and organisational accountability in parallel to the storyline of The Wizard of Oz where characters learn that the solutions to their problems already existed within themselves.

Sources
2021 Study: The Patient Journey of People Actively Looking for CTs;
2019 Survey: The Patient Perspective on Clinical Trials;
Paying participants: The impact of compensation on data quality;
Paying Research Participants: Regulatory Uncertainty, Conceptual Confusion, and a Path Forward
Reddit Clinical Studies & Subreddit CS.

Walking in people's shoes

Motives for wanting to participate in research

Treatment option

Dissatisfaction with my current treatment; either no improvement or many side effects

No available treatment for my condition

I cannot afford to pay for treatment (for effective but not reimbursed treatments)

Self-interest (conditional altruism)

Awareness of value of participating in research

Curiosity about new treatments

I want/need to generate income (other than travel expenses)

Motivation differences relate to condition and its severity,
availability of alternative treatments, potential for direct personal benefit,
household income, education, ethnicity, and gender.
There may not be a one-size-fits-all path that gets a person to the right clinical trial.

Choosing the pathway to a Clinical Trial for income

Outside the EU

- Marketplaces e.g. Craiglist - under Jobs in “Misc”: $75 per visit/blood sampling/flu project to thousand dollars for intensive trials; income is taxable, affecting eligibility for benefits in USA.
- Social media platforms e.g. Facebook adverts - $10 Amazon gift card
- Contract Research Organisations (CROs) e.g. Trials4us, UK up to £250 for recommendations friend/family member for a CT (payment after successful participation)

In EU

Sponsors may pay participants as research shows that financial incentives improve enrolment and increase diversity in the research participant pool.

Significant differences in paying practice among countries.

Compensation is explicitly forbidden in EU law for individuals who are incapacitated, cannot give informed consent, are pregnant, or are minors.

There are ethical and legal dimensions of offering payment to research participants.

Pathway to a Clinical Trial
either as treatment option or wanting to contribute to research

One’s one physician

Non-profit patient or HCP organisations and foundations (often through personal recommendation)

Official Databases: CTIS, EU; ClinicalTrials.gov, USA; ICTRP, WHO; etc.

Other official information resources helping patients understand trials e.g. NCI, NIH, etc.

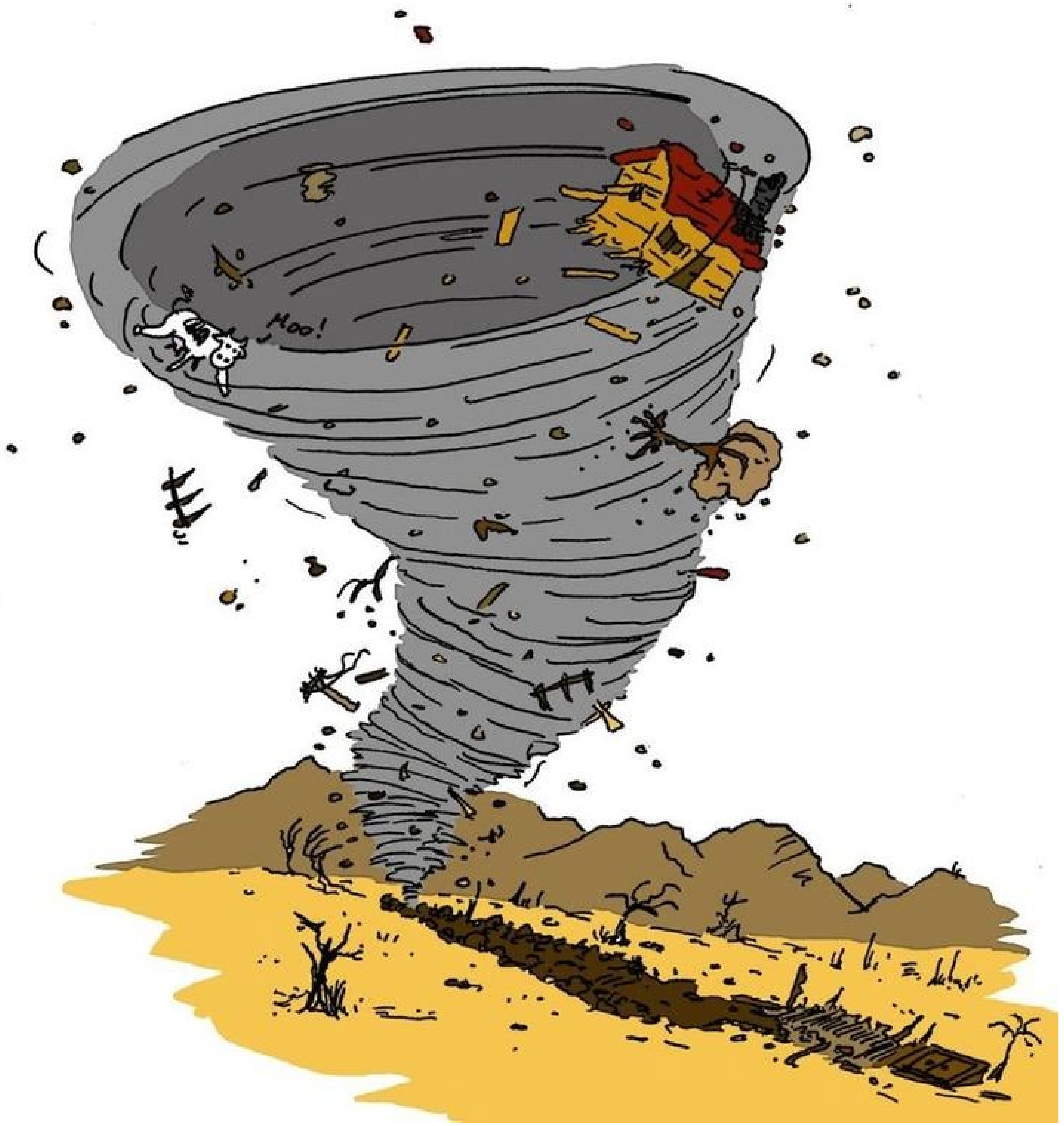
Contract Research Organisations for CTs e.g. European CRO, part of SOFPROMED

CT search tools and digital platforms e.g. Antidote Match Clinicaltrials.eu CISCRP TrialX

Social media platforms and their thematic communities e.g. Reddit Clinical Studies & Subreddit CS

The increasing reliance on search engines to find CTs introduces
new challenges and risks at individual and system levels.

You just found that you have a condition



When you decide to find out about participating in a clinical trial…

EUClinicalTrials

CTN, Canada

CTIS, EU

ICTRP, WHO

ERN EYE Trials

What is the difference among them?

Which one is official?

Clinicaltrials.eu

ClinicalTrials.gov

WCGClinical

Researchmatch, USA

CISCRP

Be Part of Research, UK

MAC CTs, UK

… overwhelming … too many online resources … information overload…decision fatigue

Choosing a path to CT is challenging

In person

Physicians may have all medical details of people but only ~16% of people are made aware by own doctor or medical team at hospital about CTs

‘Difficult to find online information that I understand or relate easily’

- Complex technical language and eligibility criteria
- Context gap
- Multiple national/regional databases/registries and jurisdictions

Discussing with one’s physician does not translate in having all information one needs.
Patient empowerment is not enough.
Health literacy may not prevent misunderstandings or build-up of unrealistic expectations

Feedback from those who tried to participate through online means

- No response from research centres when participant expressed interest in a trial
- Contacts not up to date
- Refusal to provide information with no doctor’s referral
- Automation to manage patient requests for CTs does not allow people to ask questions
- Search engine results depend on search terms used e.g. typing “*Clinical Trials to participate* needs + *Europe* or *choice of EU country* …. otherwise top results are for UK only and mostly for paid trials.

Digital equity is a new challenge.
Digitalisation is not a guarantee for user friendliness or content quality and reliability.

Each path to find a CT presents different risks

CT as business opportunity for non-profit organisations

- Who has the oversight of organisations offering CT search tools (incl. tools)?
- Potential privacy violations as CT search tools request personal data.
- What is excessive or unnecessary when sharing personal information?
- How can people be mindful of data privacy and security?
- Is informed decision compromised given the business interests involved
- How matching services identify a suitable CT that truly delivers what the patient needs given the increasing AI involvement in such searches?

CT for income

- participating in improperly registered trials (registered in an unapproved registry, unregistered) & associated risks
- overlooking significant risks
- misrepresenting one’s own health status in order to enrol

Informed consent process may not fully address risk of coercion/undue influence/unjust inducement.

Non-profit status does not guarantee a lack of bias or the absence of specific interests.

What about that Yellow Brick Road
that delivers people to the right destination that meets their expectations?

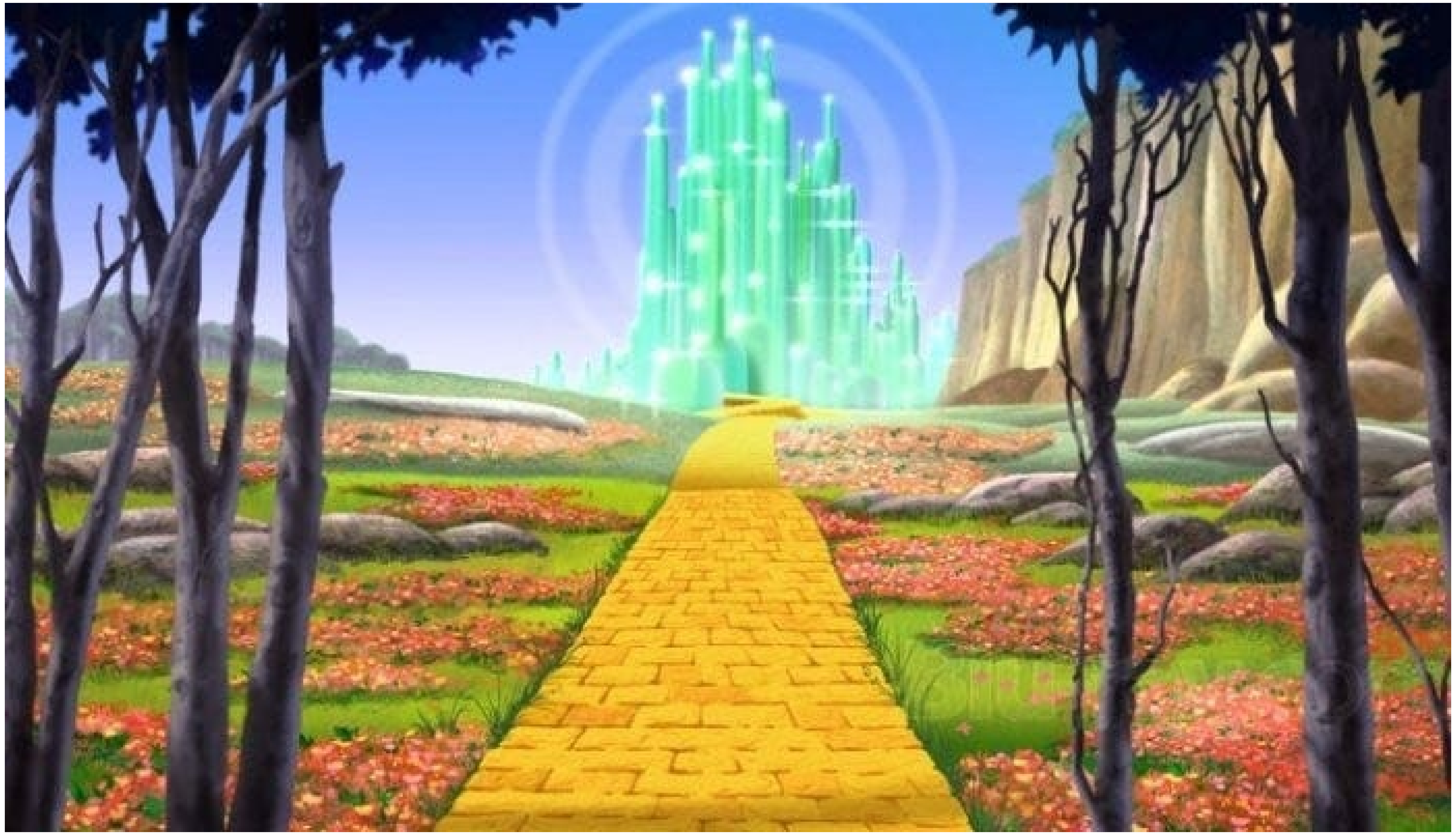
Creating a good enough path can be a shared task evolving around:

- how challenges and risks are perceived including compensation frameworks and related concepts
- how each stakeholder can realistically contribute
- what awareness/educational activities are needed for a wider audience
- how search tools can become comprehensive and holistic?

Considerable paradigm shifts may be required in:

- how research participants are viewed
- how the role and scope of regulators, patient and HCP societies are perceived
- how the responsibilities of clinical/medical teams are perceived

A more holistic engagement at system level
is needed across the entire life cycle of the path to research participation.



Shaping a safe path for the right individual to the right clinical trial is a co-creation opportunity
for patient, healthcare professional organisations, regulators and sponsors,
that may contribute further to the integrity in informed consent process
and the overall success of the clinical trial ecosystem.

Thank you for listening!

ioanna.psalti@eueye.org

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Ioanna S M Psalti
European Alliance for Vision Research and Ophthalmology (EU EYE; https://www.eueye.org/members/)