

WECAN Training Module on Patient Involvement in Publications

Developing and providing an open-access publications training module for patient advocates in partnership with Envision. Compiled by Jan Geissler, Tamás Bereczky, Zack Pemberton-Whiteley



“As patient advocates we know we should publish research, but HOW do we do that?”

Publish your own data

Being co-author

Proposal outline

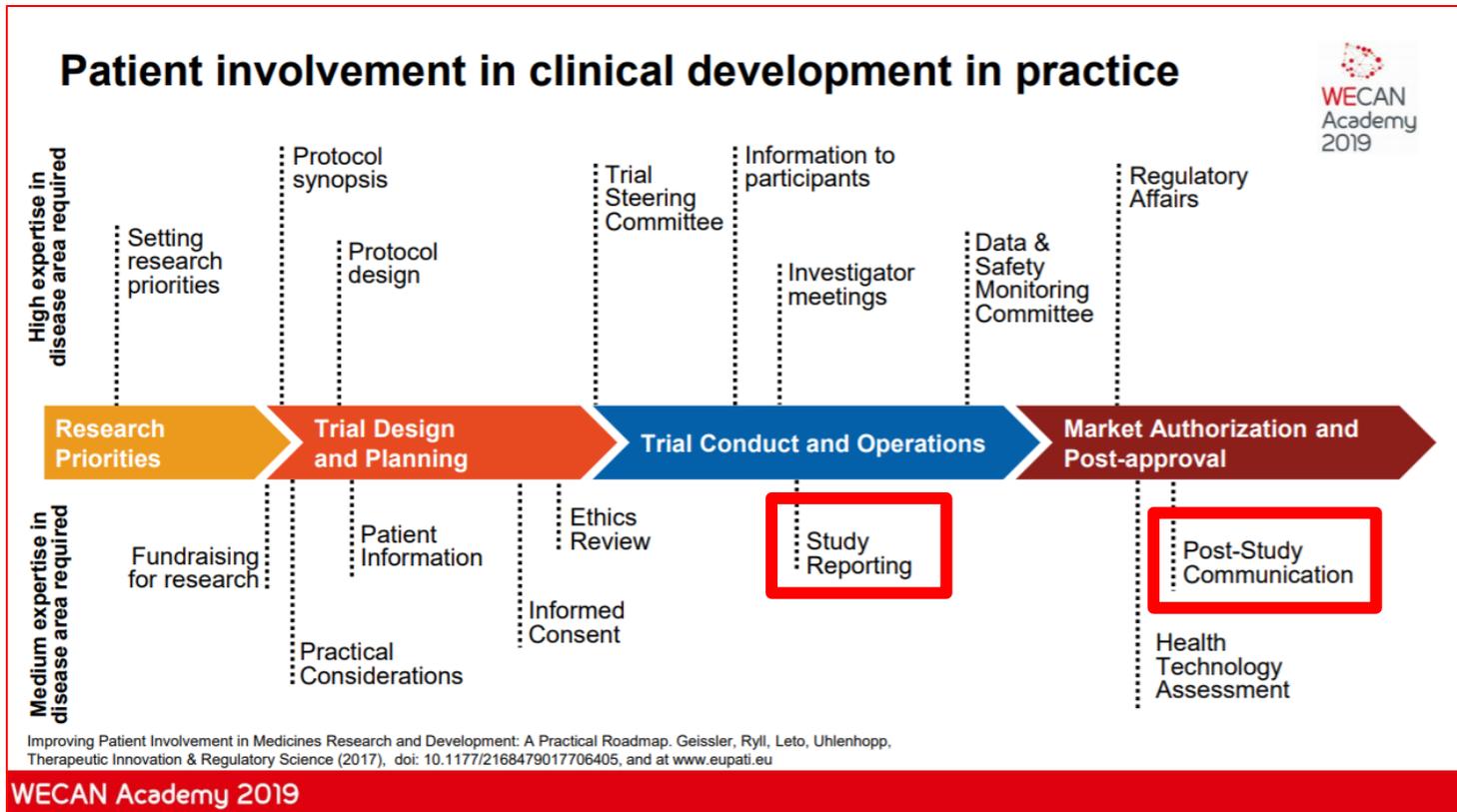
- Why? Rationale for publications training module
- What? Publications training module - topics
- Who? Proposal team and request for leadership from WECAN
- How? Project delivery team, process, funding
- When? Timelines
- Summary and next steps

Why? Rationale for publications training module



- WECAN (& others) encourage patient involvement in study reporting and post-study communication (publications!), BUT there is no dedicated training course available i.e., unmet need.

Leading patient advocates encourage patient involvement in publications



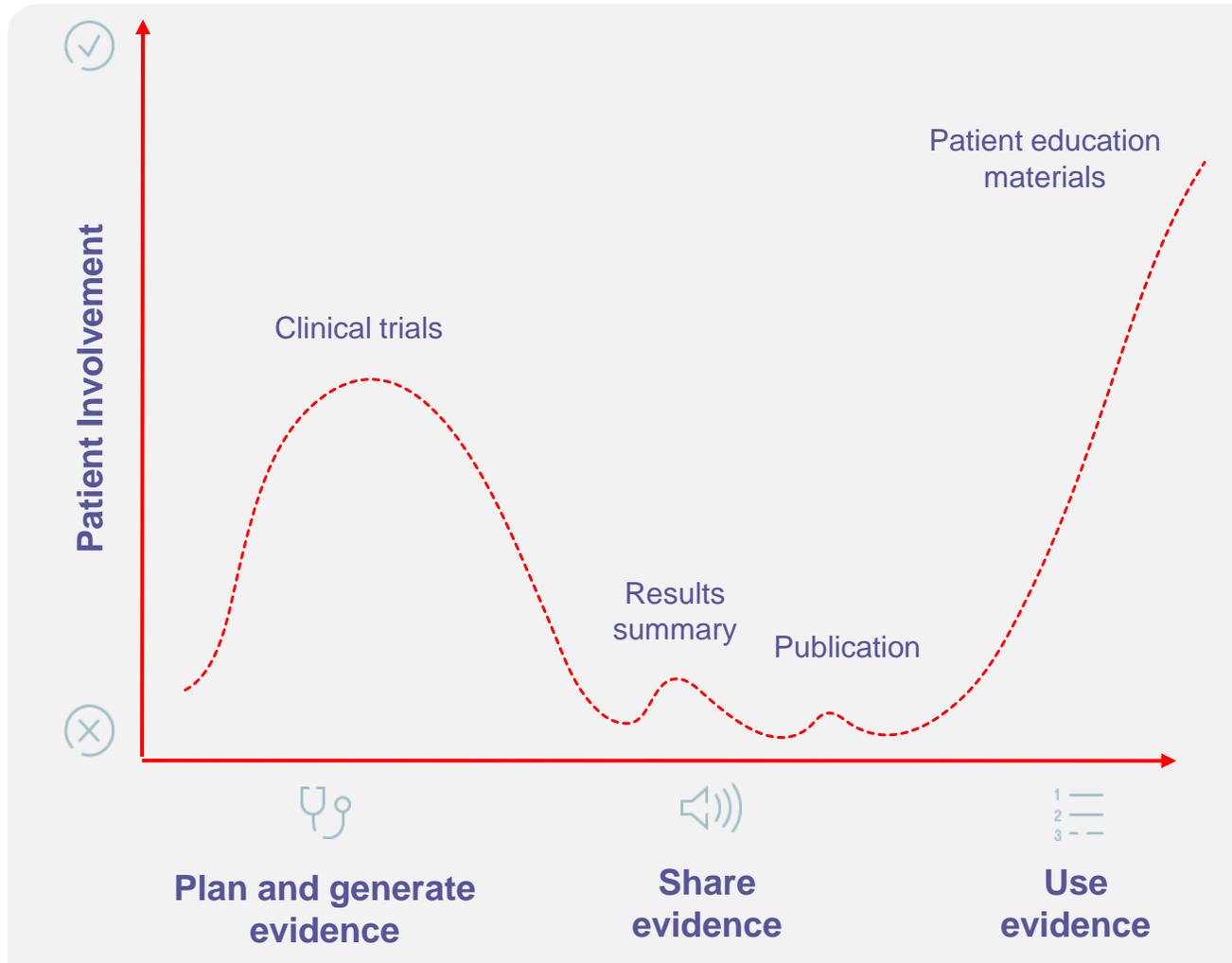
“Of course patients should be involved as co-authors of medical research papers. It’s our story you’re telling.”

“Patient authors can help make publications relevant and readable. Change the input, enhance the output.”

“Patients should be involved as authors – it’s a no brainer!”

Insights from patient co-authors in a systematic review of patient involvement in publications; Woolley KL et al., Oral presentation ISMP Annual Meeting USA 2019; *Curr Med Res Opin* 2019; 35 (Suppl 2)

Patient involvement in publications is lagging



- Patients have been involved in patient education materials (as reviewers) and, more recently, in clinical trials (as advisors)
- Relatively few patients have been involved in publications (as authors)
- When patient advocates conduct research, it is often not published – and for some stakeholders, only published stuff counts!
- Patient involvement is increasingly a requirement when publishing about trials or research.

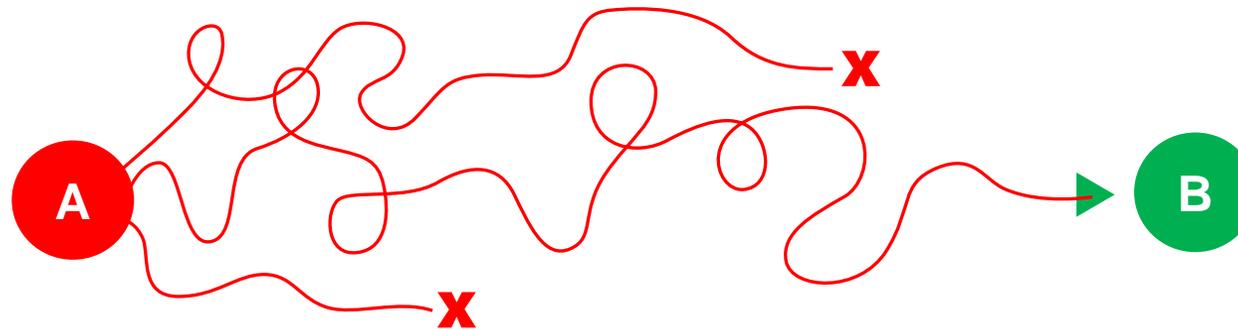
“Nothing about us without us”

The (efficient) pathway to successful patient authorship

*Nil or rare
patient authorship*

*Successful
patient authorship*

Trial and error



Publications training module



Why is WECAN engaging in this?

■ Why WECAN?

- Track record of success in addressing patient advocacy needs
- Proven partner for collaboration with different stakeholders
- Publications module (knowing how to WRITE publications) would build on the successful training module on how to READ publications (WECAN Academy, 2019; Dr Bettina Ryll)
- Aligns with WECAN's first educational pillar: Advocacy Tools and Skills
- Oncology is the leading community for evidence-based advocacy

*"WECAN aims to increase collaboration, alignment and mutual support between pan-European cancer patient umbrella organisations. A key area where we join forces is in the systematic and continued **education of our patient advocates**, to ensure they are fully equipped to lead in **evidence-based advocacy**."*

Ananda Plate, Chair, WECAN



Recommendations and tools that will be part of the publications training module for patient advocates

Evidence-based recommendations*
(maximize potential benefits and minimize potential harms for patient authors, non-patient authors, and the publication)



* N = 21 evidence-based recommendations from a systematic review of patient involvement in publications; Woolley KL et al., Oral presentation ISMPP Annual Meeting USA 2019; *Curr Med Res Opin* 2019; 35 (Suppl 2)

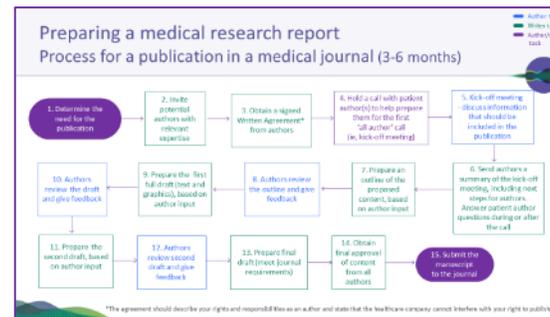
Practical tools for patient authors
(to support ethical and effective practices)



Plain language ethical guidelines (GPP3)



Plain language authorship agreement



Publication process overview

Patient Authorship Experience Tool: Patient Author Version

Patients can be authors of peer-reviewed publications in scientific journals. However, patient authorship is still uncommon. We are keen to know how to make the authorship experience a positive one for all authors. This tool has been designed to gain feedback directly from patient authors about their authorship experience. Your feedback may help improve the authorship experience for other patients.

Name (desired, but optional): _____

Please circle the answer that best describes the number of peer-reviewed publications you authored before this publication

0 1-5 6-10 11 or more

Please read each statement, then circle the answer that describes how much you disagree or agree with the statement

Statement	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. Shared purpose					
a. Aiding with my co-authors, I understood the aim of the publication	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
b. My co-authors understood the importance of having a patient author	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

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Patient authorship evaluation tool (online)

Content of the publications training module



Course content (Part A)

- Purpose and scope
- Learning objectives
- Self assessment quiz – likelihood of publishing your research
- The big picture – the publication process
- Guidelines to guide you – *ethical* publication practices
- Planning your publication(s)
 - Publication Steering Committee
 - Time, cost, resources
 - Selecting authors and contributors
 - Selecting conferences and journals
 - *Top 3 tips for patient advocates*

Course content (Part B)

- Writing your publication
 - Roles and responsibilities (author, writer, funder)
 - Identifying the right *reporting* guideline
 - 3 key questions for publication success
 - The structural outline – critical document
 - Drafting cycle(s)
 - Supplementary materials (plain language summary, vlogs, etc...)
 - Submission
 - *Top 3 tips for patient advocates*
- Peer review and beyond
 - Responding to reviewers
 - Raising awareness of your published research
- Summary – review of learning objectives

Target audience for training module: patient experts

Increasing attention on science

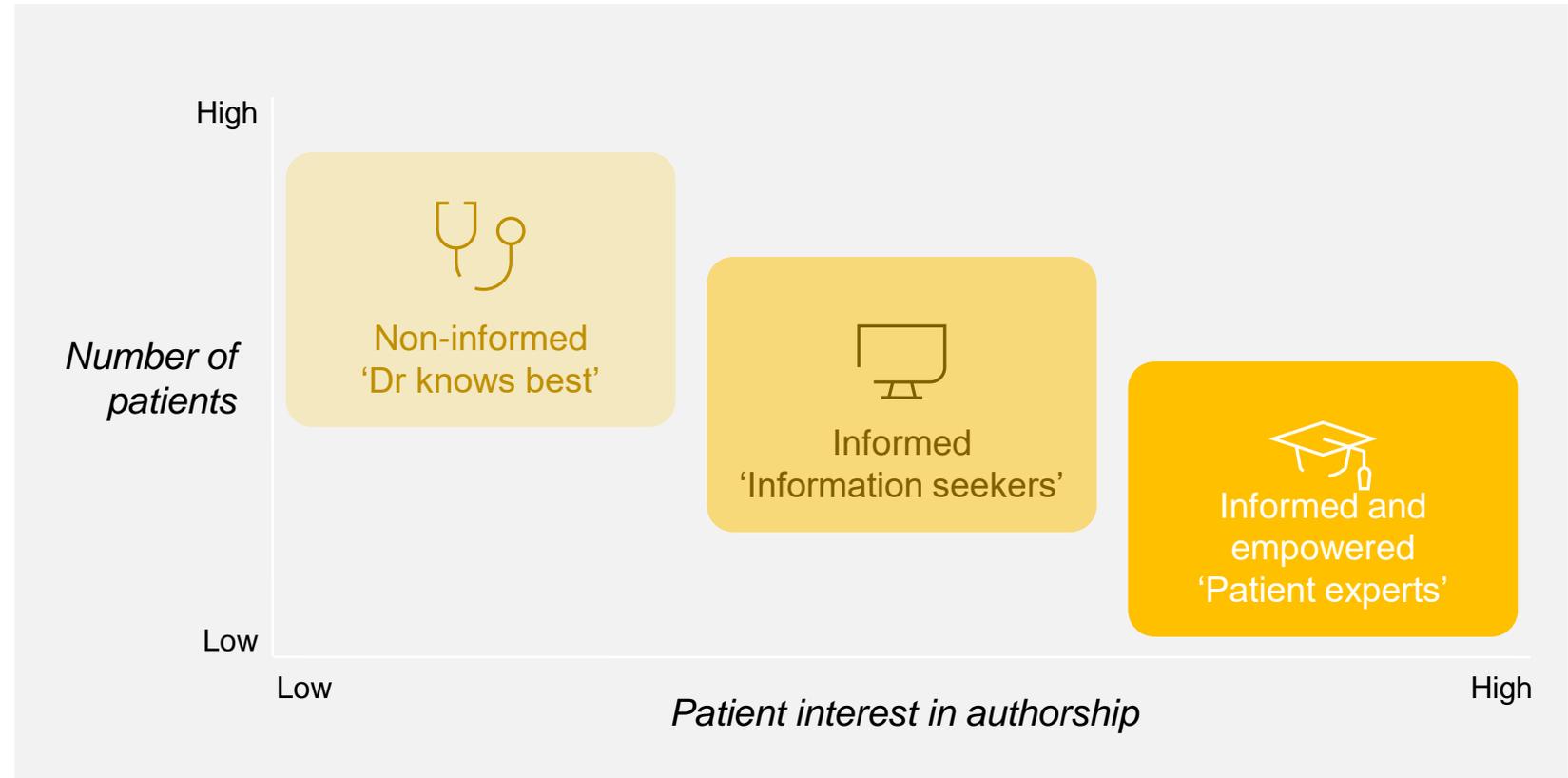
EUPATI, WECAN and others have been consistently training patient communities about critically **READING** and understanding science.

Diversity:

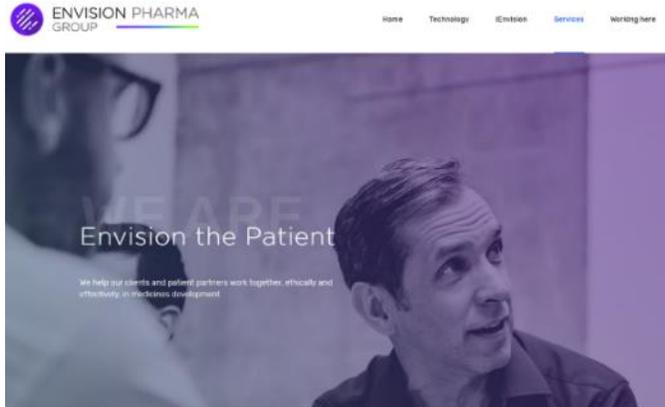
Not all patients will be interested in a publications training module

Representativeness:

We need to focus on the patients most likely to succeed as patient authors



WECAN's partner for implementation of this project: Team of "Envision the Patient"



Envision Pharma Group

- Industry-leading publication services and technology organization (est. 2001)
- Works with authors to prepare 2000+ publications each year, ethically and effectively
- **Specialist division (Envision the Patient) focused on enhancing patient involvement in medical communications**
- World first systematic review – with patients - on the evidence to guide best practice for patient authorship
- Working for 28 of the top 30 pharmaceutical companies, academic & patient advocacy groups

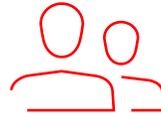
Envision the Patient	Relevant expertise
<p>Prof. Karen Woolley</p> 	<ul style="list-style-type: none"> • Author – Good Publication Practice Guidelines • Editorial Board – Research Integrity and Peer Review • Invited speaker (US, Europe, Asia) and researcher on patient involvement in publications • Certified Medical Publication Professional • Chair, Plain Language Summaries of Publications initiative (partnership with PFMD)
<p>Dr Dawn Lobban</p> 	<ul style="list-style-type: none"> • Certified Medical Publication Professional • Member of ISMPP EU committee, advising on the importance of patient collaboration in the development of publications • Involved in the co-creation of Plain Language Summaries of Publications toolkit • Current member of PFMD working group to optimize PLS
<p>Dr Lauri Arnstein</p> 	<ul style="list-style-type: none"> • Medical doctor, trained at the University of Cambridge and University College London • Medical writer with experience across a broad range of therapy areas • Researcher on patient involvement in publications – lead author of systematic review on evidence to guide best practice for patient authors

How? Project delivery team, process, funding



Process

- Ensure patient advisor input on proposed content
- Prepare content
- Review cycle
- Finalise content
- Launch module (online on WECAN Academy and/or EUPATI)
- Train on module at WECAN Academy or WECAN EBA Program training



Delivery team

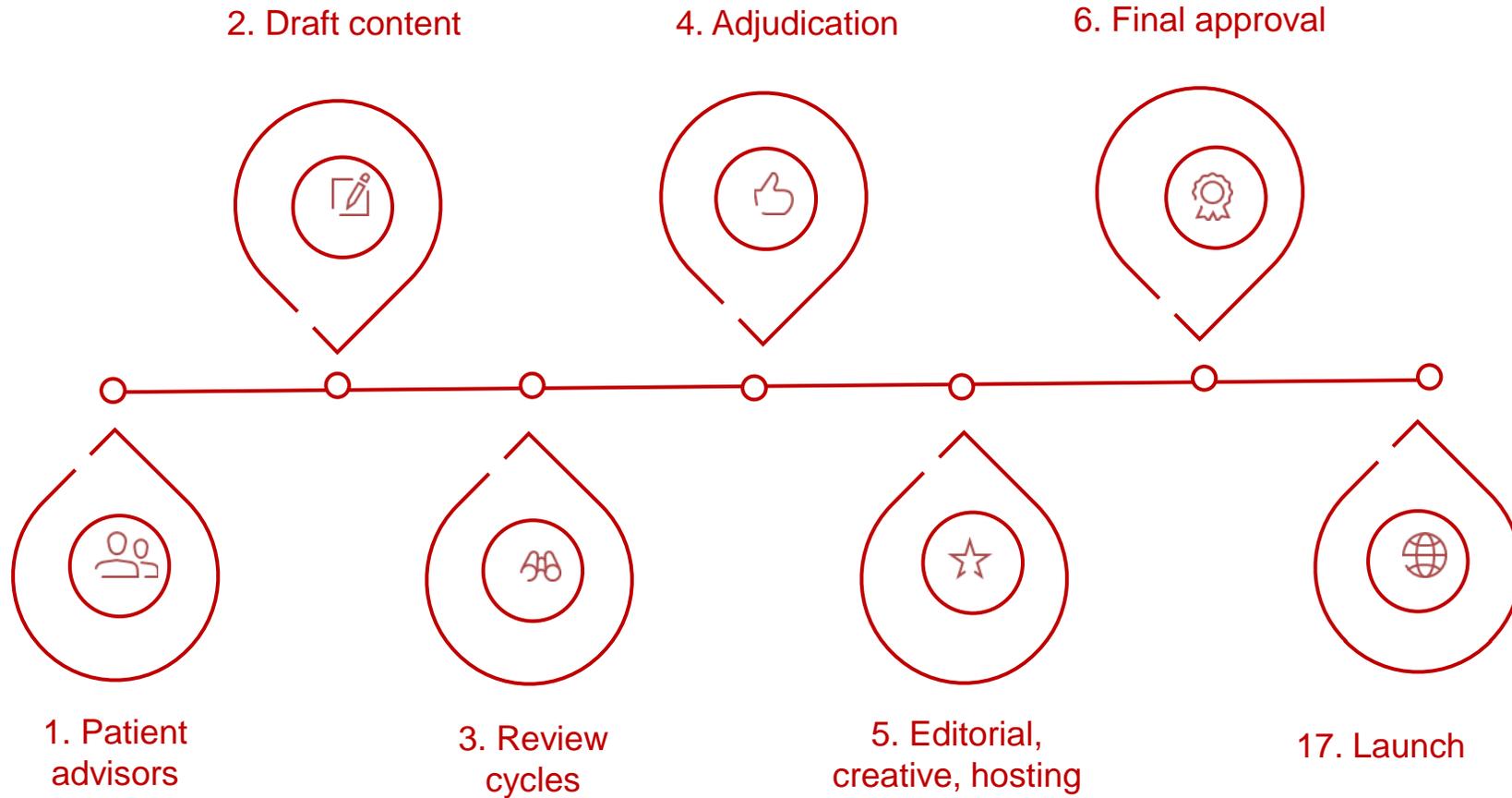
- WECAN members
 - Provide guidance, advice and oversight
- Jan, Tamas, Zack
 - Project manage
 - Enlist patient advisors
- Envision the Patient
 - Prepare course materials with patient advisor input and review
 - Provide materials with CC BY license i.e., free to use



Funding

- Industry and non-industry funding sources
- Delivery team agreement to work at reduced rates for this not-for-profit project
- EUPATI gUG Germany – host legal entity

When? Timeline (approx. 5-6 months) – October 2020



Summary and next steps

WECAN do this!

- W** WECAN alignment
- E** Expert team available (patient advocacy + publication expertise)
- C** Co-created course will be evidence-based and practical
- A** Audience for course exists
- N** Need for course exists

It's time put the public into publications

PUBLIC

“of the people”

PUBLIC-ation

*“of the people,
BY the people,
FOR the people!”*