

PATIENT ADVOCATES
FOR CANCER RESEARCH
AND TREATMENT



“Que veut dire la santé personnalisée pour moi comme patiente?”

Karin Holm
President & Founder
Patient Advocates for Cancer Research & Treatment
(PACRT)
Geneva, Switzerland

Swiss Personalized Health Network
Patient Organisation Event

Lundi 28 août 2017, 13h30-19h
Auditorium E.Rossi, Hôpitale de l'île
Bern

Karin Holm

- Naturalized Swiss citizen from U.S. living in Geneva for 19 years.
- Master of Business Administration from Tuck @Dartmouth College, New Hampshire, USA.
- Technical Collaboration Coordinator and in-house content Editor for the Council for International Organizations of Medical Sciences (CIOMS).
- Diverse positions & consultancies with WHO and non-governmental organizations in the field of global health public-private partnerships to meet LMIC needs.



Le cancer du sein en Suisse

*estimation 2015**

uniquement cancers du sein invasifs



76'500 femmes atteintes

1/8 ♀

6200 femmes par an

1'400 décès par an

1ère cause de mortalité féminine

entre 40 et 50 ans



asap | association savoir patient

réseau cancer du sein

comité qualité de vie
et cancer du sein

observatoire des
effets adverses

* <https://www.savoirpatient.ch>

Genève

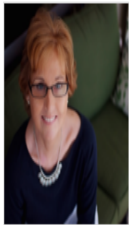
A mes amies bien-aimées



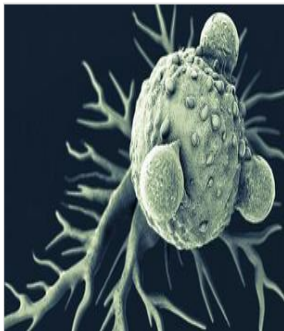


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See How



Jami Cameron Contributor



How CAR-T Therapy Has Helped One Woman Survive and Thrive, Despite Cancer

June 2, 2017

'My experience with this therapy has me convinced that we could be on the verge of changing cancer treatment for the better.'

About Jami

Jami Cameron was fir non-Hodgkin lymphoma in 1994. At the time of diagnosis, Jami was 30 years old, working as a nurse practitioner in a neonatal intensive care unit. Jami describes her cancer journey as a marathon. Over a span of 22 years, she would have cancer six times, involving two types of cancer. In 2016, after exhausting all standard of care treatment options, she entered a clinical trial of chimeric antigen



DNA-based test can spot cancer recurrence a year before conventional scans



'Liquid biopsy' diagnosed cancer recurrence up to a year before CT scans are able to in major lung cancer trial, and could buy crucial time for doctors



Eileen Rapley, who joined the trial after being diagnosed with lung cancer a year ago. She hopes the new test might lead to the kinds of improvements that screening techniques like mammograms have brought about for breast cancer. Photograph: Graeme Robertson for the Guardian

LE TEMPS

INIONS BLOGS MULTIMÉDIA - **T MAGAZINE**

Avec le soutien de la  FONDATION
LEENAARDS 



Santé personnalisée: espoirs et enjeux

Les techniques de séquençage du patrimoine génétique de chacun, de moins en moins coûteuses,

Nouveaux traitements chers vs la prévention ?



Note: le Centre de Recherche sur le Cancer de l’OMS à Lyon: “IARC works amid a maelstrom of lobbying, advocacy, and vested interests, often indirect and difficult to uncover.” *IARC the first 50 years*, p.245

“...primary prevention of cancer has stumbled from the very beginning because of the interference of powerful economic interests...” *IARC, op. cit*, p.143.

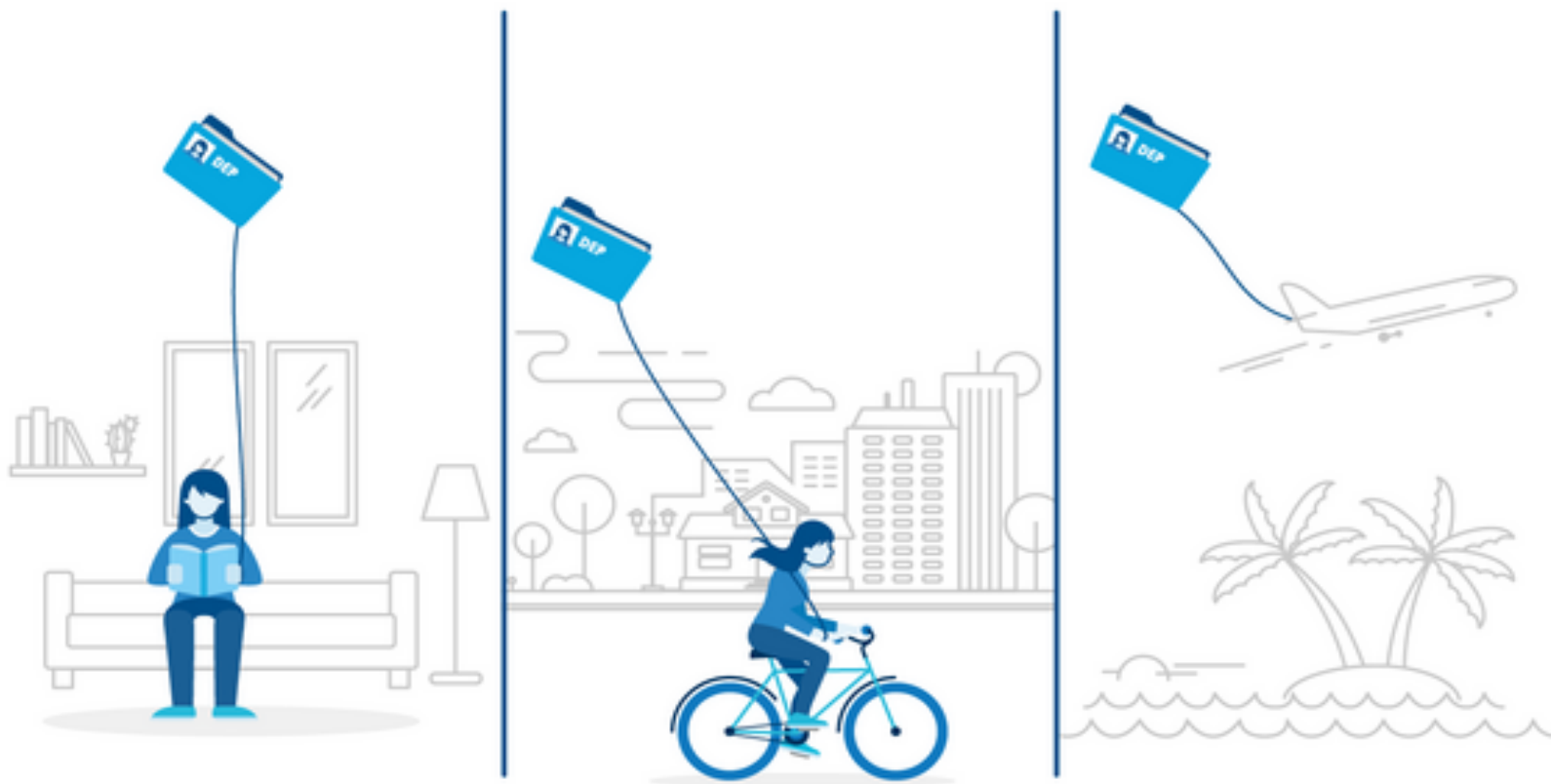
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glasbergen.com



“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”

Vos documents toujours à portée de main

www.e-health-suisse.ch/



Karin Holm

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Pays avec e-Health en 2017

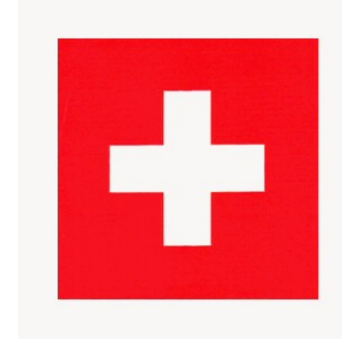
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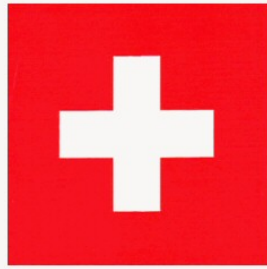
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Pays sans





www.eupati.eu



- La plateforme de patients EUPATI Suisse
- EUPATI est une académie européenne de patients pour l'innovation thérapeutique, qui gère des plateformes régionales dans différents pays.
- Informer les patients sur les nouveaux traitements et options thérapeutiques et de les impliquer activement dans la recherche et le développement de nouveaux médicaments.





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The A to Z of how medicines are developed

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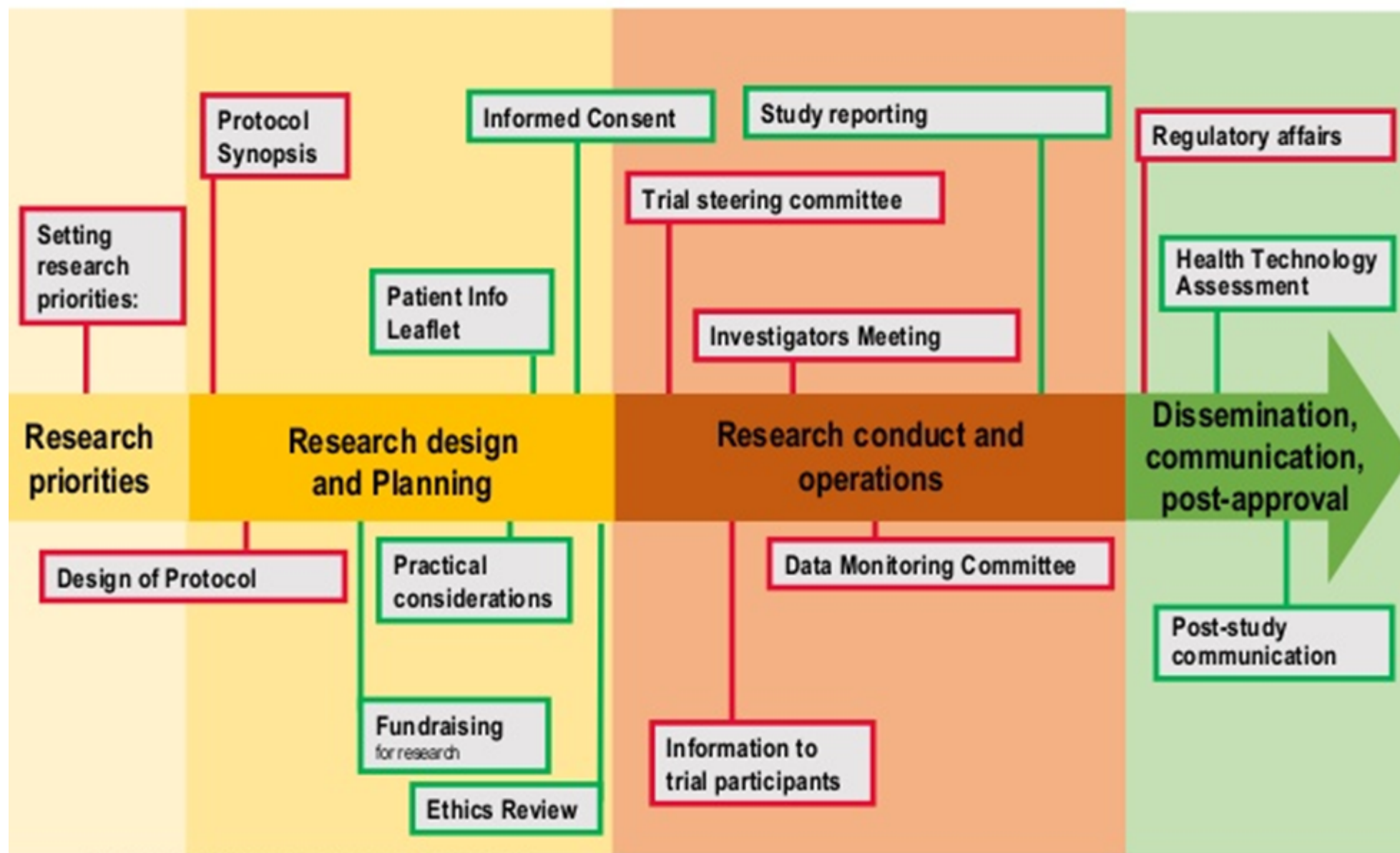
For example: How are drugs made?



www.eupati.eu



Practical “Roadmap” on patient involvement in R&D



Level of expertise in the disease area required:

High Medium

Source: Geissler, Ryll, Leto, Uhlenhopp
EPALCO/EUPATI (2015, unpublished)



www.careum.ch/coss-study

Self-management program for breast cancer survivors



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Funding: Swiss Cancer Research

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Co-creating and testing the effectiveness of an integrated peer-to-peer Self-management program for breast cancer Survivors: A pilot study (COSS)

Current European and Swiss health policy emphasizes the relevance of supporting self-management as a means to improve health literacy, delivery of care and quality of life for people living with chronic illness. The Swiss national strategy against cancer 2014-2017 also defined the necessity to foster patient expertise and defined the development of self-management programs of cancer patients as one of their strategic priorities.



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Christine Bienvenu
epatientesuisse.wordpress.com



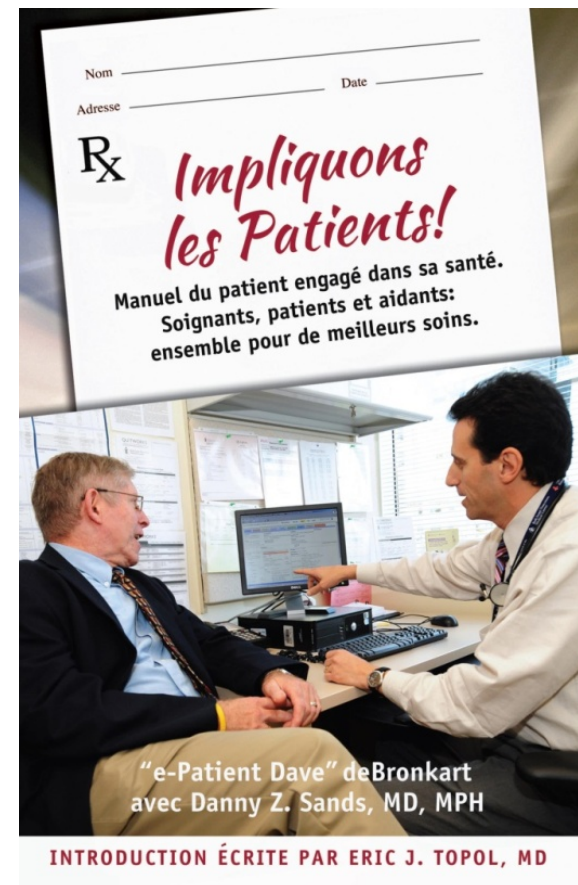
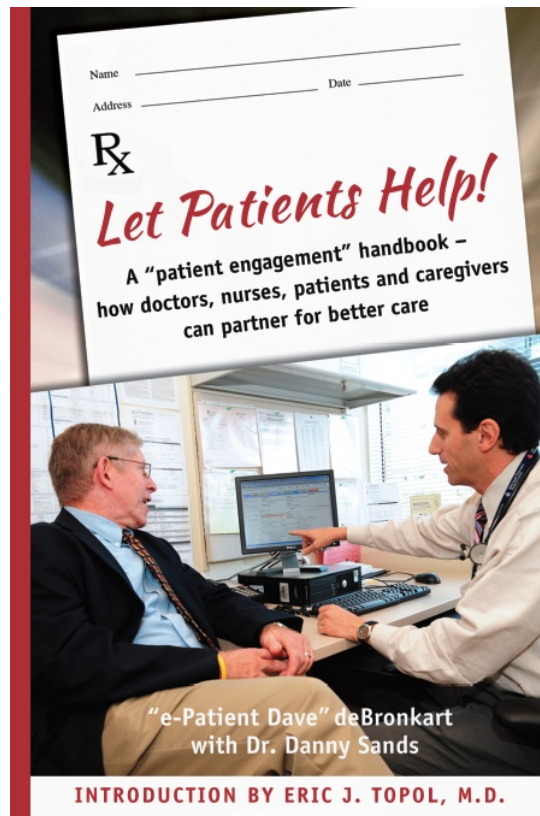
ePatiente spécialiste en médias sociaux, communautés de patients et santé digitale



- Création de la plateforme **Seinplement Romand(e)s**
- Speaker à **Doctors 2.0 & You**, Paris et divers autres conférences santé digitale
- Formation au personnel de la **Policlinique Médicale Universitaire PMU** de Lausanne
- Enseignement de la **culture ePatient** et santé digitale aux étudiants Bachelor en pharmacie, le personnel médical et les patients aux **HUG**, Genève.

Impliquons les Patients! (Christine l'a traduit en français) un manuel clair et concis proposant des actions concrètes pour un partenariat éclairé, proactif et empowered entre le patient et les professionnels de la santé écrit par le plus connu ePatient Dave de Bronkart.

Version originale anglaise imprimé et version francophone ebook from Amazon.com or amazon.fr



REVIEW ARTICLE

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Biobanking from the patient perspective

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available at the end of the article

Plain English summary

Biobanks are collections of donations of biological material (DNA, cells, tissue etc.) and related data which are very valuable for research into human diseases. A variety of biobanks exist for example within hospitals, research institutes, pharmaceutical companies and patient organisations. The role of patients in biobanking is changing from being seen simply as donors, to actual collaborators in the design, development and the running of biobanks. In this article, we provide a number of examples of patients acting as partners at the heart of biobanking, where their voice and perspective is being seen and used as a valuable resource for the biobank. Our aim is that these examples can be used by those who work with patients in biobank-based research, to design future strategies for patient and public involvement in all biobanks.

Abstract

Biobanks and biobanking research plays an increasingly important role in healthcare research and delivery as health systems become more patient-

Les Points à Retenir



1. Savoir c'est pouvoir.
2. La santé personnalisée peuvent nous aider.
3. Il faut que nous nous informons et demandons.
4. On a besoin d'un dossier électronique du patient comme on a besoin d'un compte bancaire.
5. Il serait logique en Suisse! Impliquons-nous!

Merci pour votre attention!

Karin Holm

www.pacrt.org