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Acute Leukemia Advocates Network

ALAN GLOBAL SUMMIT

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UNDERSTANDING THE POSSIBLE FUTURE DIRECTIONS OF PATIENT INVOLVEMENT IN DRUG DEVELOPMENT

Moderator: Tamás Bereczky

Panelists: Giovanni Marconi, Alexey Salamakha, Anne-Pierre Pickaert, Jens Hasskarl

Meet our panelists



Giovanni Marconi



Alexey Salamakha



Anne-Pierre Pickaert



Jens Hasskarl

Introduction

- Tremendous development in patient involvement over the last 10 years
- Role of patient education, activism, and advocacy
- Strong theory and practice
- Still, there are shortcomings and gaps, and even blind spots
 - New technologies and methods
 - Evidence generation and deployment
 - Policy advocacy (access, affordability, barriers beyond prices)
 - Practice does not follow the theory
 - Industry performing much better than other stakeholders

Access and affordability

- Complex and difficult environment to navigate
 - Global systems, regimes, and global challenges
 - Particular problems around low- and middle-income countries, and also in some regions
 - Funding challenges of policy related work
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- **Table 1**
 - Alexey Salamakha
 - Zack Pemberton Whiteley
 - Gabriel Tirelly
 - Wonyoung Jang
 - Lusine Harutyun
 - Bahija GOUIMI
 - Marine Tullet
 - Stefan Tondl

Patient involvement and evidence generation (and deployment)

- Evidence generation in low- and middle-income countries
- Distribution of information and resources
- Challenges around publication
- Still little cooperation, and too much competition for attention and resources
- Systems are vague and often determined by nepotistic structures and traditions

- Table 2
 - Giovanni Marconi
 - Jana Pelouchova
 - Felipe Tapia
 - Lauren Pretorius
 - Dražen Vinček
 - Elo Mapelu
 - Julie Powell

Practical aspects of patient involvement

- The recent round of IHI/Horizon calls was a very offputting experience for many
 - Structures and practice of patient involvement still very weak at some stakeholders (academia, researchers, HCPs)
 - Epistemic injustice in everyday practice
 - Even if we preach and demand patient involvement, the infrastructure and skills are often lacking
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- **Table 3**
 - Anne-Pierre Pickaert
 - Giora Sharf
 - Rita O. Christensen
 - Jose Castro
 - Ivana Angelovska
 - Apendavyo Mshana
 - Andre Sebastian Sorolla Ruiz de Castilla
 - Yasmine Hassan

New paradigms in research

- Platform and basket trials
- Big data and artificial intelligence
- Wearables and other tools used for PROs and trials in general
- Ethical considerations – data ownership and safety
- Rare diseases and personalised medicine
- Table 4
 - Jens Hasskarl
 - Jan Geissler
 - Silvia Diaz
 - Catherine Moura
 - Pasusant Wattanaboonya
 - Patricio Fabián Vaca Castro
 - Rosa Maria Cristiana Genovese
 - Amy Dembeck
 - Stéphanie Chatin

Panel discussion



Giovanni Marconi



Alexey Salamakha



Anne-Pierre Pickaert



Jens Hasskarl