EBC Seminar

“Criteria for success: The future of collaborative brain research”

Brussels, 3th March 2015

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GAMIAN-Europe

Global

Alliance

Mental

Illness

Advocacy

Networks

59 members in 28 countries

GAMIAN–Europe

A patient-driven pan-European organisation, which represents the interests of persons affected by mental illness and provides:

- Advocacy
- Information and education
- Fighting stigma, discrimination and exclusion
- Patients' rights
- Cooperation, partnerships and capacity building
- Promoting self help and community care
- Surveys and Research projects

Research Projects (FP7)

MOODFOOD

Impact of food and nutritional behaviour, lifestyle and the socio-economic environment on depression.

MA

Mar ough

adv d r the

MIN

E-C t eness

rese iz gs on

the (cost) effectiveness of internet-based treatment for depression in comparison with standard care.

Dissemination

- Newsletter (4/year)
- Website
- Facebook
- Events

Patient Advisory Board

Surveys

Stigma 2006, 2010

Physical and Mental health, 2011

Adherence to treatment, 2012

Mental health and Workplace, 2013

Exploring the links between mental health and work: The patients experience

GAMIAN-Europe 2013

Paul Arteel, Inge Neyens, Rebecca Muller.

Exploring the links between physical and mental health: The patients experience

GAMIAN Europe 2012

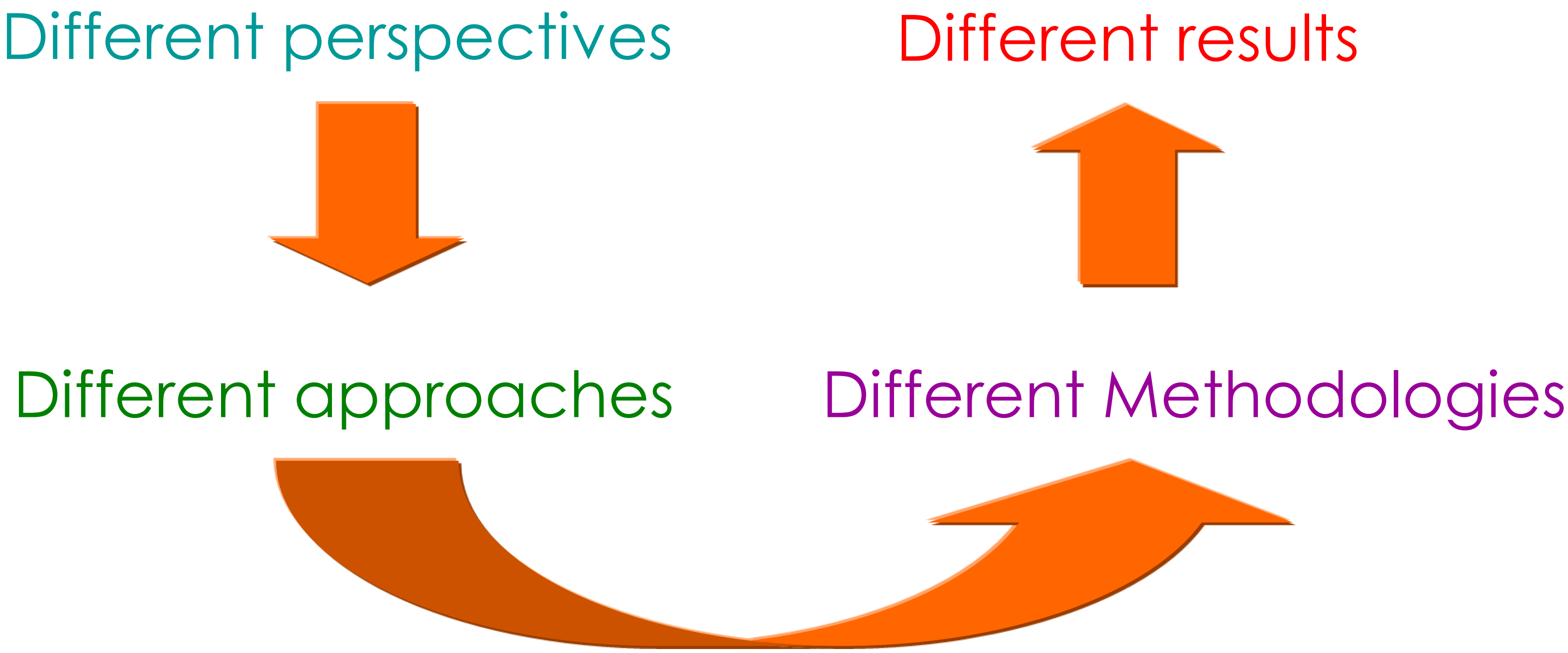
Adherence to treatment: The patients view

GAMIAN Europe 2012

Gamian-Europe Adherence to treatment survey 2012

This project was financially supported by/sponsored by an educational grant from Janssen page: 1

User-lead .vs. main stream



Different perspectives

Different approaches

Different Methodologies

Different results

Those differences are...

a tremendous opportunity!!!

What could be the role of patients in Brain research?

Setting priorities and cross-cutting issues (EUPATI)

- ✓ Contributing to early horizon scanning, **target product profile definition, intended research outcomes**
- ✓ Ensuring that **patients' needs** are considered within the research process
- ✓ **Facilitating relationships between key stakeholders**, e.g. bridge gap between authorities, researchers, payers at the research design stage
- ✓ Acting as advocates and lobbyists to **influence research priorities**
- ✓ Defining **patient-relevant added value** (as measures for HTA on conclusion of research), engaging with HTA.
- ✓ Informing industry about a condition (**giving a personal perspective of living with a disease or an illness**.)

Design and Planning

- **Defining the level of involvement** (research subject, information provider, advisor, reviewer, co-researcher or driving force in clinical research
- Being **involved in research protocol design** (e.g. in the patient-centric definition of relevant endpoints, inclusion/exclusion criteira, target population, diagnostic procedures and monitoring, patient-reported outcomes/ quality of life measures, risk/benefit assessment, cross-over, patient safety, ethical issues, mobility issues, data collection methodology, data protection)
- Obtaining **research funding**
- Defining, evaluating or revising **informed consent procedures and patient information documents** (content, visual design, readability and language)

Research conduct and operations

- Acting as a **co-researcher** or driving force of research (patient-led research)
- **Informing and recruiting potential research participants** through providing information to members, etc. via website, social media, conferences etc.
- **Improving information to research participants** (e.g. in case of protocol amendments, if new safety information becomes available, if research is discontinued)
- **Improving patient access to trials**
- **Managing and retaining research participants**, and re-contacting them for follow up purposes
- Being actively engaged in data monitoring committees e.g. for risk/benefit monitoring, adherence/drop-out issues, amendments to protocol.

Dissemination & communication

- **Contributing to publications**, actively involved and or supporting the **creation of lay summaries**
- Being engaged in the **dissemination strategy of research results to the patient community and professional communities**
- Supporting patients in making **informed decisions** about taking part in clinical research
- Communicating about **first-hand patient experiences** in research to encourage others to take part.
- The active participation in research (or patient engagement in research) can potentially **lead to improvement in the credibility of results.**

SYSTEMATIC REVIEW

Domecq et al. BMC Health Services Research 2014, 14:89
http://www.biomedcentral.com/1472-6963/14/89

Results: We included 142 studies that described a spectrum of engagement.

In general, **engagement was feasible** in most settings and most commonly done in the beginning of research (agenda setting and protocol development) and less commonly during the execution and translation of research.

We found no comparative analytic studies to recommend a particular method. **Patient engagement increased study enrolment rates and aided researchers in securing funding, designing study protocols and choosing relevant outcomes.**

The most commonly cited **challenges were related to logistics** (extra time and funding needed for engagement) and to an overarching worry of a tokenistic engagement.

Conclusions: Patient engagement in healthcare research is **likely feasible in many settings**. However, this engagement comes at a cost and can become tokenistic. Research dedicated to identifying the best methods to achieve engagement is lacking and clearly needed.

THANK YOU

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