

# Communicating to patients about evidence-based decisions



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# Using “media” to communicate evidence to patients

- Medicines assessment (HTA)
- Patient needs from evidence
- Role of patient groups in communicating evidence

# Deadly cost of delays over drug approval

'Lives being put at risk by deeply flawed system'

**HELEN PUTTICK**

HEALTH CORRESPONDENT

THE system for approving new drugs for use on the NHS in Scotland is bureaucratic, deeply flawed and could cost lives, according to a Labour MSP.

Dr Richard Simpson, a former doctor, said his constituents are confused by the process and it had created a postcode lottery.

He was speaking as an investigation into access to expensive, potentially life-saving

"The consistency we have across Scotland is if you have your heart attack in the west, you'll get your drug; if you're in the east, you won't. For my constituents it is confusing.

"We have a system that is deeply flawed at that level."

Dr Simpson gave the example of the drug Brilique. It was given general approval by the SMC in April last year but is still not available to patients in Scotland.

"The evidence given to the

The approval process for newly licensed medicines is under scrutiny at Holyrood's Health Committee. During an evidence session, MSPs questioned experts from the SMC and several health boards.

Dr Simpson's concerns were echoed by Andy Powrie-Smith, director of the Association of the British Pharmaceutical Industry Scotland.

He said the UK is 11th in Europe in terms of

# The 'expert' patient

There are at least two bodies of knowledge that are relevant to the exchange between a doctor and a patient – the doctor's and the patient's.

Both are experts in their own fields

- the doctor in clinical matters,
- the patient in his or her experiences, feelings, fears, hopes, and desires.

Sir Ian Kennedy, Chairman Bristol heart inquiry, 1999

# Patients (Courtesy of Ann Single)

expectations

interests

experience

genetics

ethnicity

values

age

beliefs

location

roles



community

education

hopes & dreams

medical history

**(health) literacy**

# European Council Recommendation (2009)

WHO has defined empowerment of patients as

- a pre-requisite for health
- encouraging proactive partnership and patient self-care to improve health outcomes and quality of life among the chronically ill.

**Patient groups** are crucial to directly support individuals living with the disease and in terms of collective work they carry out to improve conditions.

# Patients use of guidelines?

- Gain knowledge about high quality care and treatment choices
- Advocacy to ensure guidelines are enacted
- As a resource to train/inform other patients
- Engaged in development (from selection of topics through to dissemination)

# What evidence is interesting to patients?

(Bastian, 2011)

- Conclusions drawn in 124 Cochrane reviews
- 194 survey responses
- 50% from healthcare professionals and researchers, 50% from members of patient groups members
- 50% from Germany, 50% international



# What's Interesting? (Bastian, 2011)

- 8% of statements significantly interesting
- 50% of statements significantly uninteresting
- Best evidence to communicate to patients is considered to be right, relevant and interesting (sufficient evidence to reach a concrete decision)

# Patient communications

- Website
- Emails/newsletters
- Blogs
- Facebook/twitter
- Discussion fora
- Parliamentary lobbying
- Research report – “Plain English” summaries

# Patients resourcing themselves

- Spanish patient forum
- Italian patient academy
- International patient organisations in one condition
- Umbrella patient organisations in one country across conditions

**Resources**

- ▶ Evidence library
- ▶ Research project database
- ▶ Putting it into practice database
- ▶ Publications by INVOLVE
- ▶ Briefing notes for researchers
- ▶ Involvement Cost Calculator
- ▶ Exploring the impact: examples
- ▶ Developing training and support
- ▶ Plain English summaries
- ▶ Useful information

# Resources

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The INVOLVE Resource centre contains links to all our publications, databases and other online resources on public involvement in research.

## Search our databases

Evidence library



### Evidence library

References on the impact and nature and extent of public involvement in research

### Research project database

A database of published and unpublished research projects with active public involvement

### Putting it into practice

Resources for people who are planning or developing public involvement in research



<http://www.patientsacademy.eu> – [info@patientsacademy.eu](mailto:info@patientsacademy.eu)



# EUPATI: 2012-2017



## EUPATI Certificate Training Programme

- Academic Modular Certificate Programme
- Patient Ambassadors in committees, R&D teams, ...
- Patient Journalists raising awareness
- Patient Trainers for patient communities/networks

100  
patient  
advocates

## EUPATI Educational Toolbox

- Educational tools for patient advocates
- Variety of formats: Paper-based booklets, presentations, eLearning, webinars, videos etc.

12,000  
patient  
advocates

## EUPATI Internet Library

- Patients & public, e.g. on specific aspects of the development process of medicines for patients with low (health) literacy
- Wiki, YouTube, films and/or cartoons

100,000  
individuals



# Sarcoma and Pancreatic Patients

**If only I'd found the SIGN  
guideline earlier**

# Tablet to treat early stage MS approved for

## use

Carolyn Churchill, The Herald, 12 March 2014

A NEW drug which is the first available tablet for early stage multiple sclerosis has been approved for use on the NHS in Scotland.

More than 10,000 people in Scotland have the condition and the country has the among the highest rates of MS in the world.

People with an active relapsing remitting form of MS have normally had to give themselves regular injections but the new treatment aims to block the action of the immune cells which cause damage to the brain and spinal cord through an oral tablet.

Aubagio, is the first pill to be made available for use in this way after being given approval by the Scottish Medicines Consortium.

It became available in England and Wales last month.