



Patient Advocacy and Safety Conference

15 November 2016

Brussels, Belgium

**PATIENT PERSPECTIVE:
Lessons drawn from the
Biologics and Biosimilars survey**

Sanna Lönnfors

EFCCA

Background



- Aim: to find out patients' perspectives about biosimilars
- An online survey of 14 questions run between November 2014 and October 2015.
- 1181 respondents, 56% Crohn's disease, 34% ulcerative colitis, mostly from Europe, mostly 21-50 years old.
- 48% currently treated with biologicals; 42% never exposed to biologicals.
- 38% had heard of biosimilars. Only they continued to the final twelve biosimilar-specific questions.

Outcomes



Familiarity with and concerns about biosimilars:

- 62% had never heard of biosimilars
- Respondents worried about biosimilars' safety profile (47%), efficacy (40%), molecular basis being different than in originator (35%), and tolerability (31%)
- Only 25% had no specific concerns about biosimilars

→ Many IBD patients have not heard of biosimilars, and those who have, have worries. More information is needed.

Outcomes



Biosimilars in the market:

- 43%: patients should systematically be given information about biosimilars
- 25%: patient associations should be informed and able to give their opinion in biosimilar-related matters

→ Patients want to be informed and involved in the decision-making process.

Outcomes



Interchangeability:

- 28%: accepts switching if treating physician approves
- 27%: accepts if evidence-based data available
- 22%: accepts if patient systematically informed
- 21%: opposed if patient not aware

→ *NOR-SWITCH study 2016: Remicade[®] can be safely switched to Remsima[®]*

→ Patients want transparency and want to be aware of what they are taking.

Outcomes



Distinguishing the biosimilar from originator:

- 44%: want to know what they are receiving
- 22%: not being able to distinguish is acceptable, if efficacy/safety are the same
- 21%: all necessary information prior to treatment
- 11%: trust the pharmacist / treating physician

→ Patients want to know what they are receiving.

→ Traceability is important also for patients.

Conclusions



Patients' needs in regards to biosimilars:

- Many IBD patients have not heard of biosimilars, and those who have, have worries. More information is needed.
- Patients want to be informed and involved in the decision-making process.
- Patients want transparency.
- Patients want to be aware of what they are taking. Traceability is important also for patients.

Next steps



Project “Mapping of innovative treatments and devices in EFCCA member countries” in pilot phase

- General overview of health care systems
- Better understanding of e.g. the level of involvement of different payers and the role of national health authorities
- Supporting exchange of knowledge and experience among EFCCA members
- Improving the mobility of people with IBD, facilitating access to treatment in other countries

Next steps



Patient advocacy – fulfilling patients' needs

- More information through patient education
- Facilitating involvement in decision-making through better understanding of health care systems
- Improving transparency and patients' rights through facilitating equal access to medication
- Exchanging knowledge with other countries



EFCCA
European Federation of Crohn's &
Ulcerative Colitis Associations

U
N
E
T
W
O
R
K
I
N
G

S
O
L
I
D
A
R
I
T
Y

A
D
V
O
C
A
C
Y

E
M
P
O
W
E
R
M
E
N
T
A
W
A
R
E
N
E
S
S

U
N
I
T
E
Y
W
E
S
T
A
N
D

THANKS FOR YOUR ATTENTION!