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Patient perspective on biosimilars safety data and other concerns

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26 January 2017
Changing Services, Changing Minds, Changing Lives
for people with RA and JIA

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Director of External Affairs
Biosimilars …………… The Patient Perspective

• What really matters to patients about biosimilars?

• What are NRAS’s top concerns about the present and future of biosimilars for patients?
What really matters to patients about switching?

Well, unsurprisingly safety and efficacy

Patients, consulted in the right way seem to be actually very altruistic

But switched inappropriately or the threat of being switched inappropriately, without consultation ……..

Big Poll Question on HealthUnlocked

If your biologic was switched to a cheaper but equally good/safe drug to save money for NHS, what would be most important for you to know?

230 Voters

- 40.4%: I don't mind so long as the treatment works as well as my existing treatment
- 27.3%: That someone who couldn't otherwise get onto biologic treatment would benefit
- 13.4%: That savings would be used to improve access to effective treatments for others with RA
- 6.5%: That savings would be used to improve access to effective treatments for any other conditions
- 4%: That savings would fund improvements to the service other patients with RA receive at my hospital
- 4%: That savings would be used to improve access to effective treatments for other rheumatological conditions
- 3.4%: That savings would be used to improve the finances of the NHS
- 3%: That savings would fund improvements to the service I receive at my hospital
The aim of the Right Care Shared Decision Making Programme is to embed Shared Decision Making in NHS care. This is part of the wider ambition to promote patient centred care, to increase patient choice, autonomy and involvement in clinical decision making and make “no decision about me, without me” a reality.

Quality Improvement Productivity and Prevention (QIPP) Right Care programme, 2012

To achieve this, (SDM) we are encouraging the development of new relationships between patients, carers and clinicians, where they work together, in equal partnership, to make decisions ..........Without these changes, we cannot achieve the required transformational culture change to support Shared Decision Making.
Comments & concerns from patients

If only all savings would be put back into research for treatment of RA but I don't trust the management of the NHS to do it. I would be suspicious about the efficacy of the cheaper drug. Why is it cheaper? Would the delivery service be compromised? But as long as I experienced at least the same effect, I would be happy if the money was ploughed back into research, helping others to get onto Biologics or have whatever treatment is best for them. This sounds rather selfish, but if my RA is kept under control, this saves hospital time and, as we know, time means money.

Would this biosimilar be monitored by the BSR Biologics Register or a register set up for biosimilars? This change is obviously cost saving exercise for my Trust, however, if problems arise with the use of this biosimilar would the funds be there for patients to return to the original biologic?
We had to be assessed for the need for the biologic in the first place. (a long process when you're desperate!) If something cheaper had the same effect of course I'd be happy to have that and for savings to be used on others. The whole point is to control the disease and limit damage which then costs the NHS a fortune in treatments, operations, disability aids, appointments etc.

Can we be absolutely sure they are as safe? My understanding is that they only have to do short, small studies to show this, unlike the original medications.

I know when I see my Rhuemy next Wednesday and I tell him I don't want to try this medication he will get very cross with me so I'm dreading the appointment.

What is the safety and effectiveness record of this drug [biosimilar]? Where can I read about this data?
What particularly concerns us?

Bearing in mind that each product from the different manufacturers will drive cost down, will we, the patients, be at risk of being flipped from one brand to another depending on which is cheapest that month?

- NHS staff taking huge decisions without proper stakeholder input
- Switching from drug to drug – flip flopping
- Time taken to negotiate gain-share
- Fact we are once again in a less flexible situation than much of the rest of Europe
Would be very pleased if the biosimilar drug had the same efficacy and lack of unpleasant side effects as current biologic/anti-Tnf. I would be particularly supportive if the drug company's price for biologic drugs was reduced to make it affordable for NICE to change their guidelines and open the door for many more to be given a another chance and/or choice in the fight to control this RD and reduce disability.
What is NRAS doing to support patients and rheumatology teams?

We’re developing a new booklet on all medicines in RA.

The NRAS position paper on biosimilars is available online at www.nras.org.uk.

We’re collaborating with the BSRBR on production of patient information to encourage patients to sign up to the Register.
NRAS position on Biosimilars

We have updated our position paper twice since 2014 to reflect current data on safety and efficacy and pragmatism about what’s really happening on the ground

There are 4 key areas we want to see being properly addressed at a national level:

☑️ Patients must be properly informed through robust shared decision making mechanisms about being switched – a round robin letter from Trust with inadequate information is not satisfactory
☑️ The manufacturers must agree to long term safety data collection through the BSR Biologics Registers
☑️ Gain share from the savings must benefit rheumatology and patients in an equitable way (i.e. it doesn’t all go to the CCG or Trust for use in other therapeutic areas or for plugging deficits)
☑️ Both we and the BSR would like to see NICE review the health economic model as we believe that calculated today, given the drop in pricing the ICERS would be well within the £30,000 limit so more could benefit from treatment with biosimilars.
Other resources
Thank you
Questions?
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