

Transparency in Europe: patients and doctors

Dominic Way^a and Frederic Boudier^b

^aKing's Centre for Risk Management, King's College London

^bMaastricht University

dominic.way@kcl.ac.uk

Our research (2012-2015)

- **What can be learnt from the perspectives of patients and doctors? What are the policy implications?**

Empirical research:

- ✓ Experiment(s) (Lofstedt and Way, 2014a, 2014b)
- ✓ General public survey (Bouder et al. 2015; Way et al. 2016)
- ✓ Patients survey (Way et al., 2015)
- ✓ Doctors survey (Lofstedt et al., 2015)

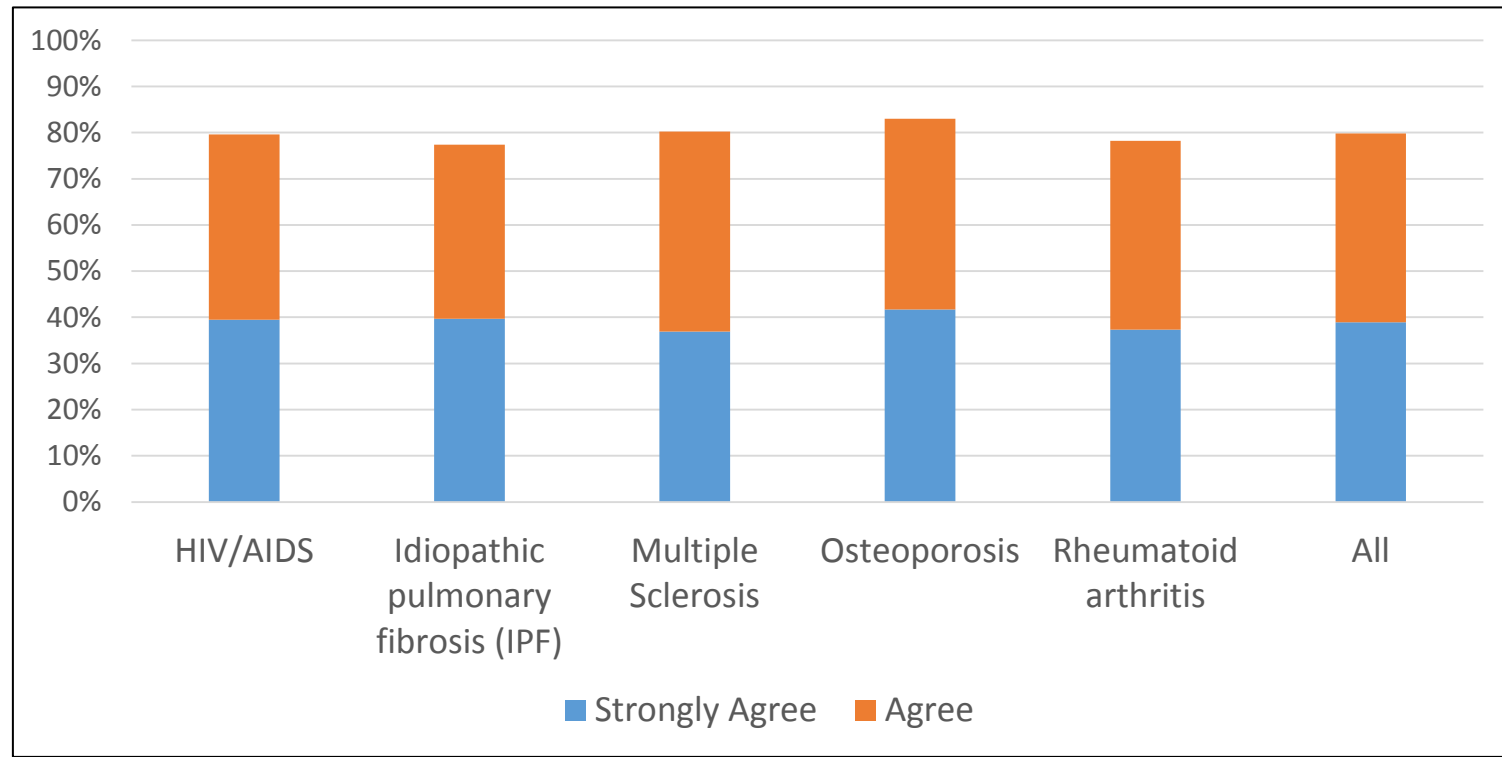
Online surveys



	General public	Patients	Doctors
Dates (year)	2013	2014/2015	2014/2015
Size	5,648	1,010	1,005
Type	European adults	HIV/AIDS, IPF, MS, Osteoporosis, RA	GPs (50%) + Specialists (HIV/AIDS, IPF, MS, Osteoporosis, RA)
Countries	Fr, De, Sp, UK, Swe, NL	Fr, De, Sp, UK	Fr, De, Sp, UK
Questions	32	30	36
Authors	Bouder <i>et al.</i>	Way <i>et al.</i>	Lofstedt <i>et al.</i>
Response rate	12-24%	4.5%	5%

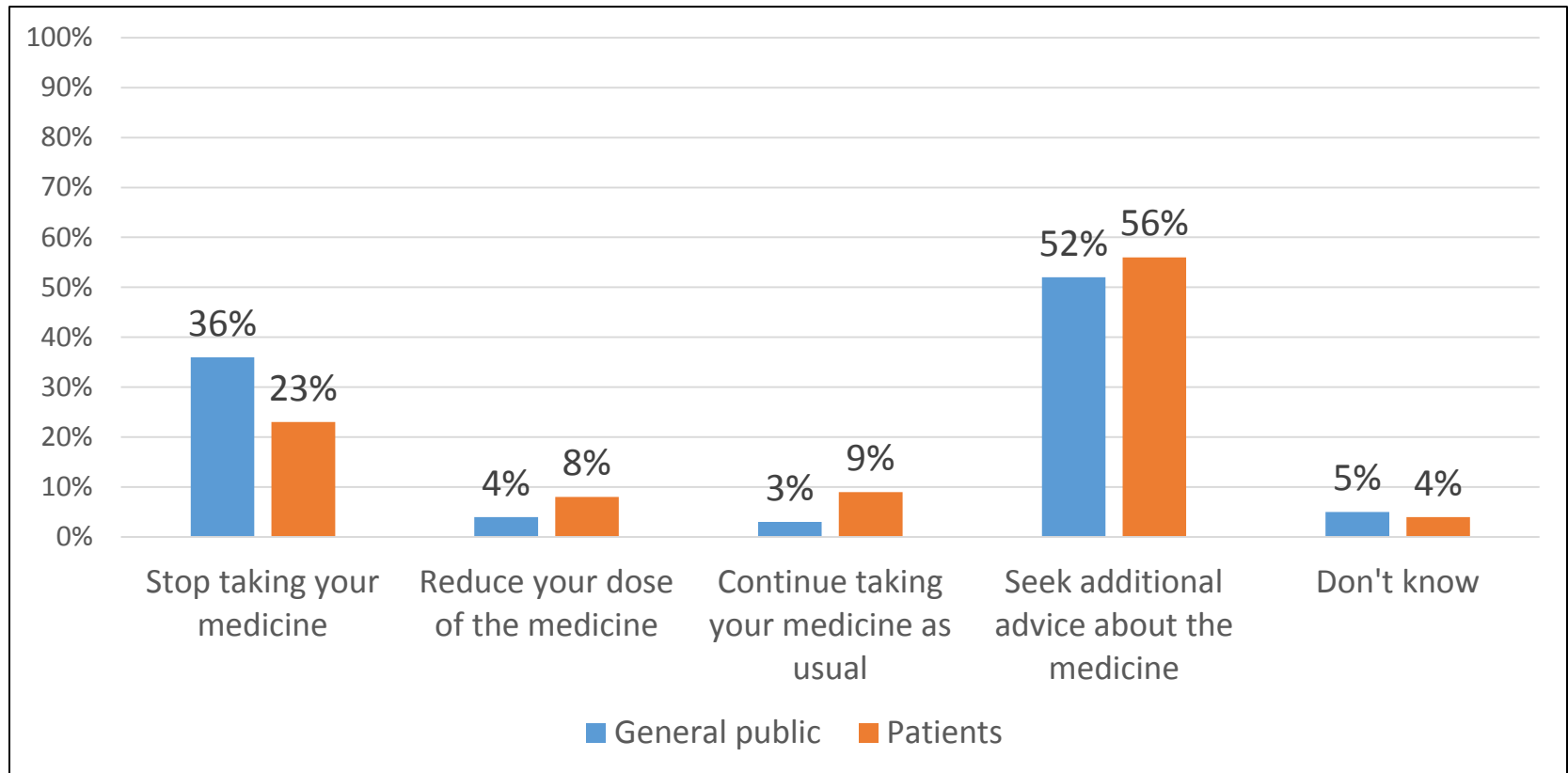
Patients desire more info

➤ Supports Lofstedt and Way (2014a, b)



Q10A: Please indicate the extent to which you 'agree' or 'disagree' with each of the following statements: "Patients receiving more information on the safety of medicines would increase their confidence in taking medicines" (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree).

And...how will patients react?



Q9B If the information you personally receive (via letter, telephone, email etc...) points to safety problems with a **[Insert specialty group]** medicine you are currently taking, do you think you are more likely to...

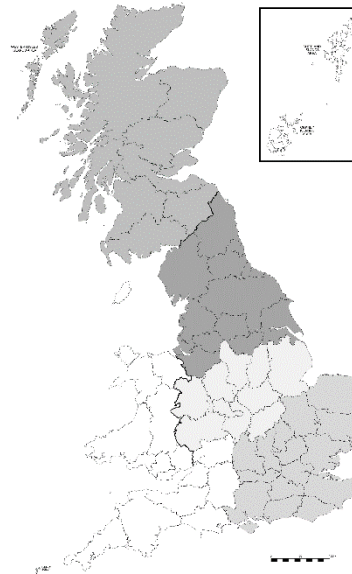
Clear regional
variations for
stop and reduce
combined

KEY

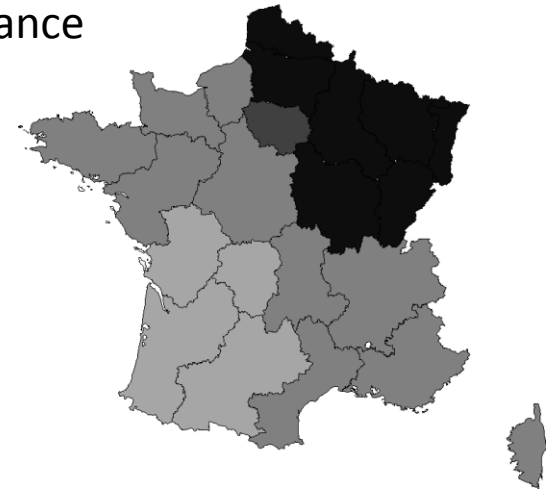
5-10%
10-15%
15-20%
20-25%
25-30%
30-35%
35-40%
40-45%
45-50%
50-55%



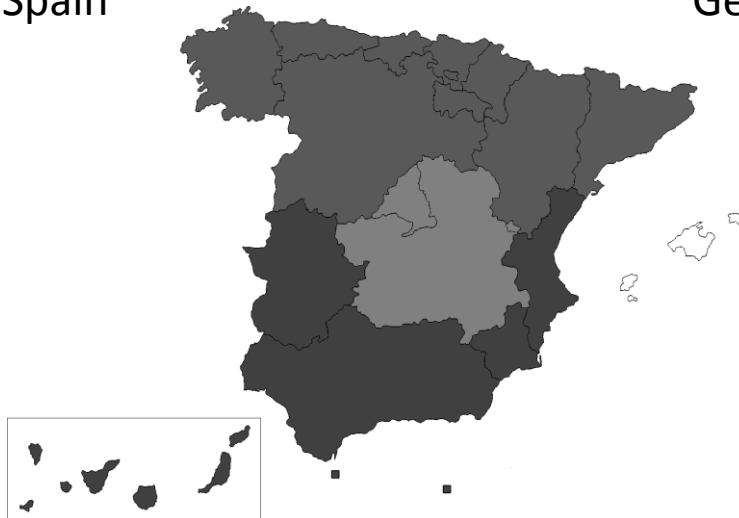
UK



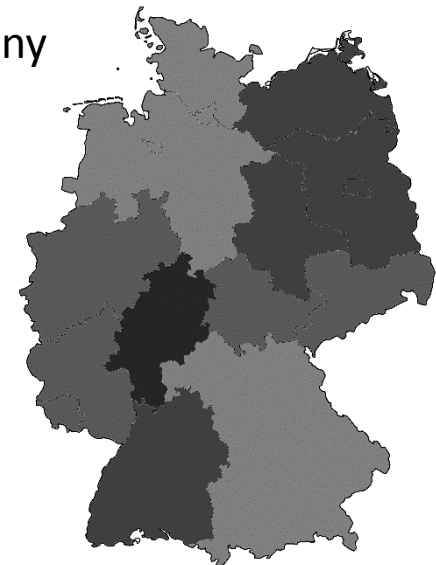
France



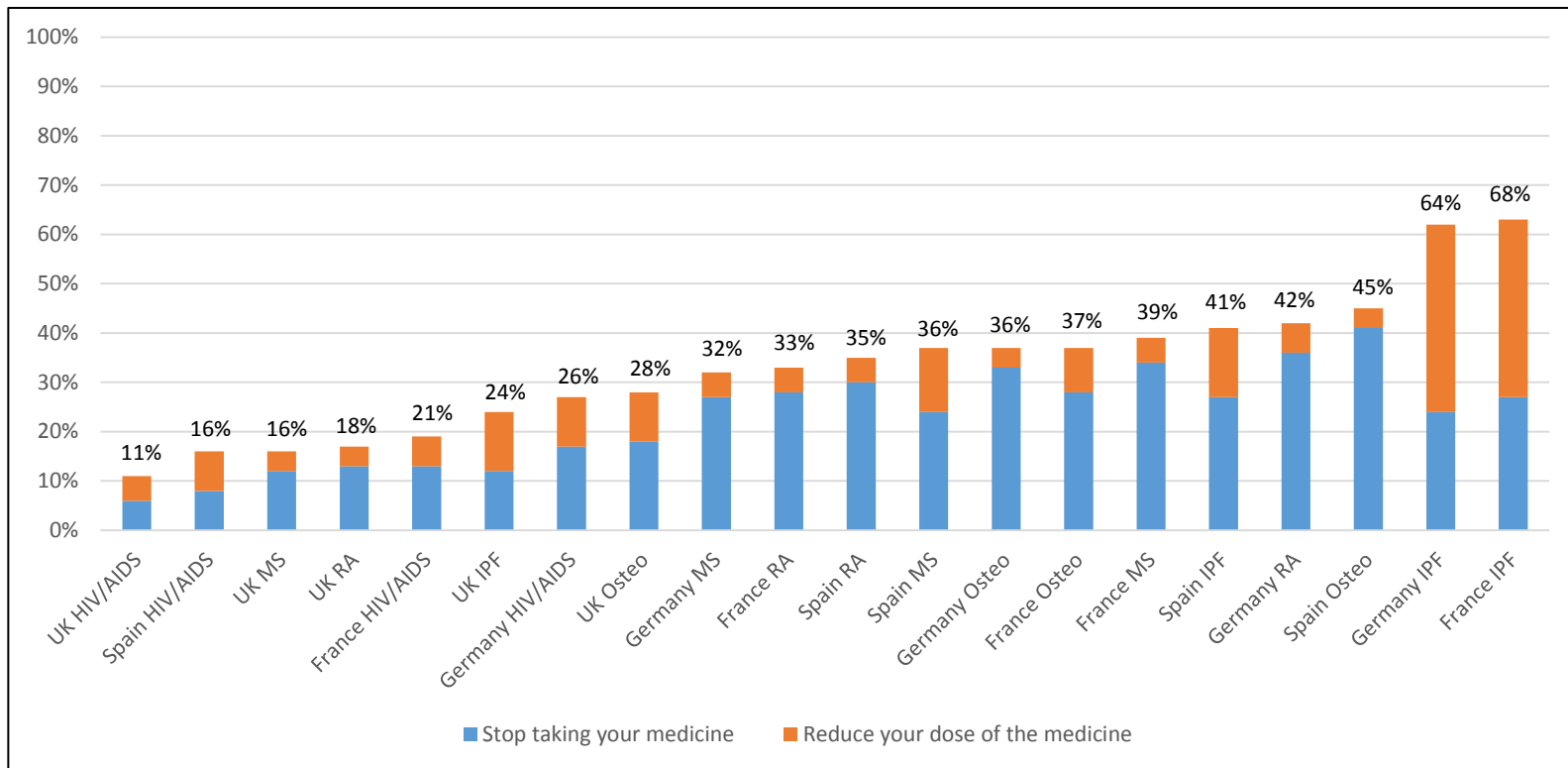
Spain



Germany



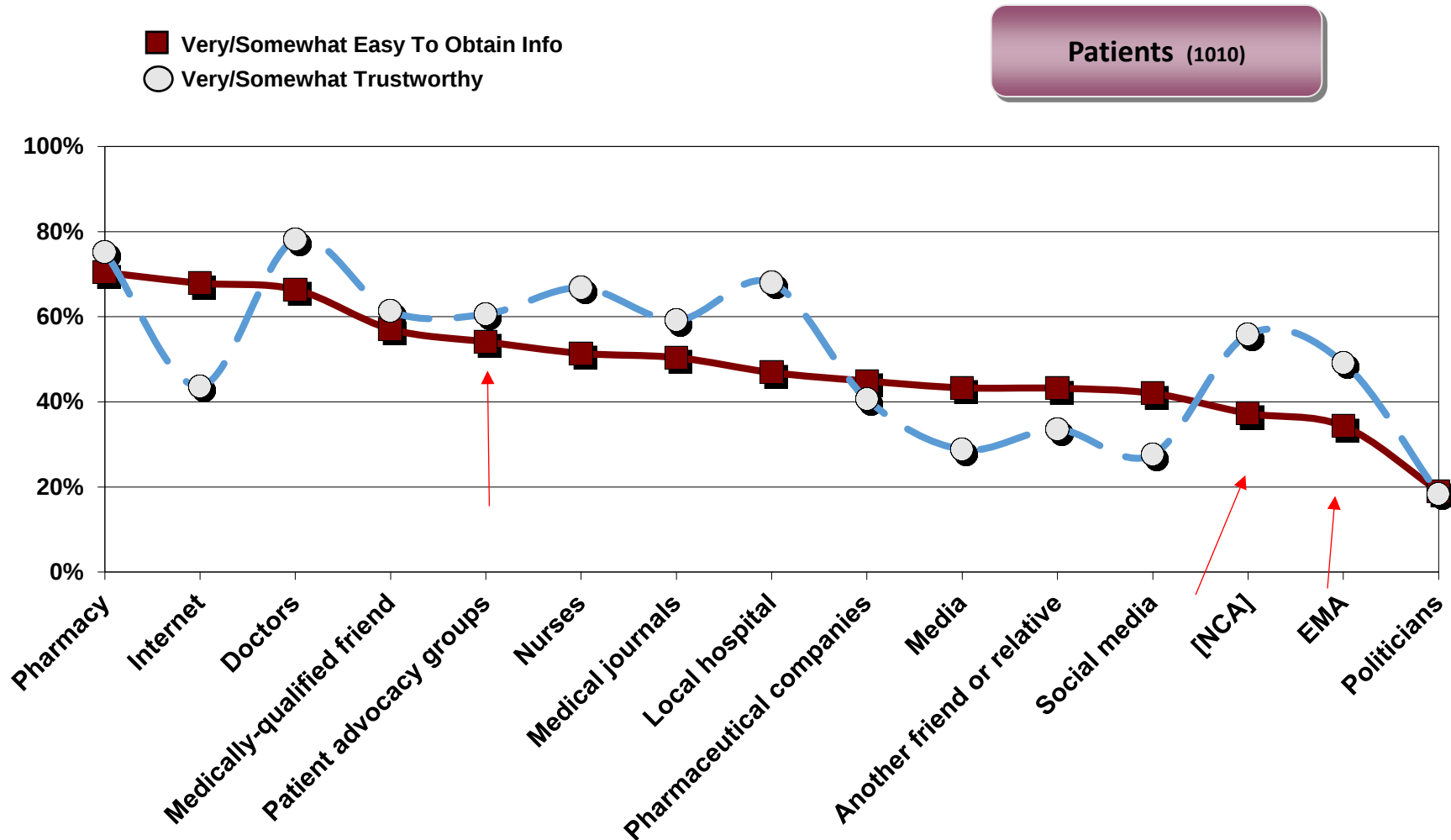
Context matters (patients)



Q9B If the information you personally receive (via letter, telephone, email etc...) points to safety problems with a **[Insert specialty group]** medicine you are currently taking, do you think you are more likely to... (Stop taking your medicine/Reduce your dose of the medicine/ Continue taking your medicine as usual/ Seek additional advice about the medicine/ Don't Know).

Patients and Doctors

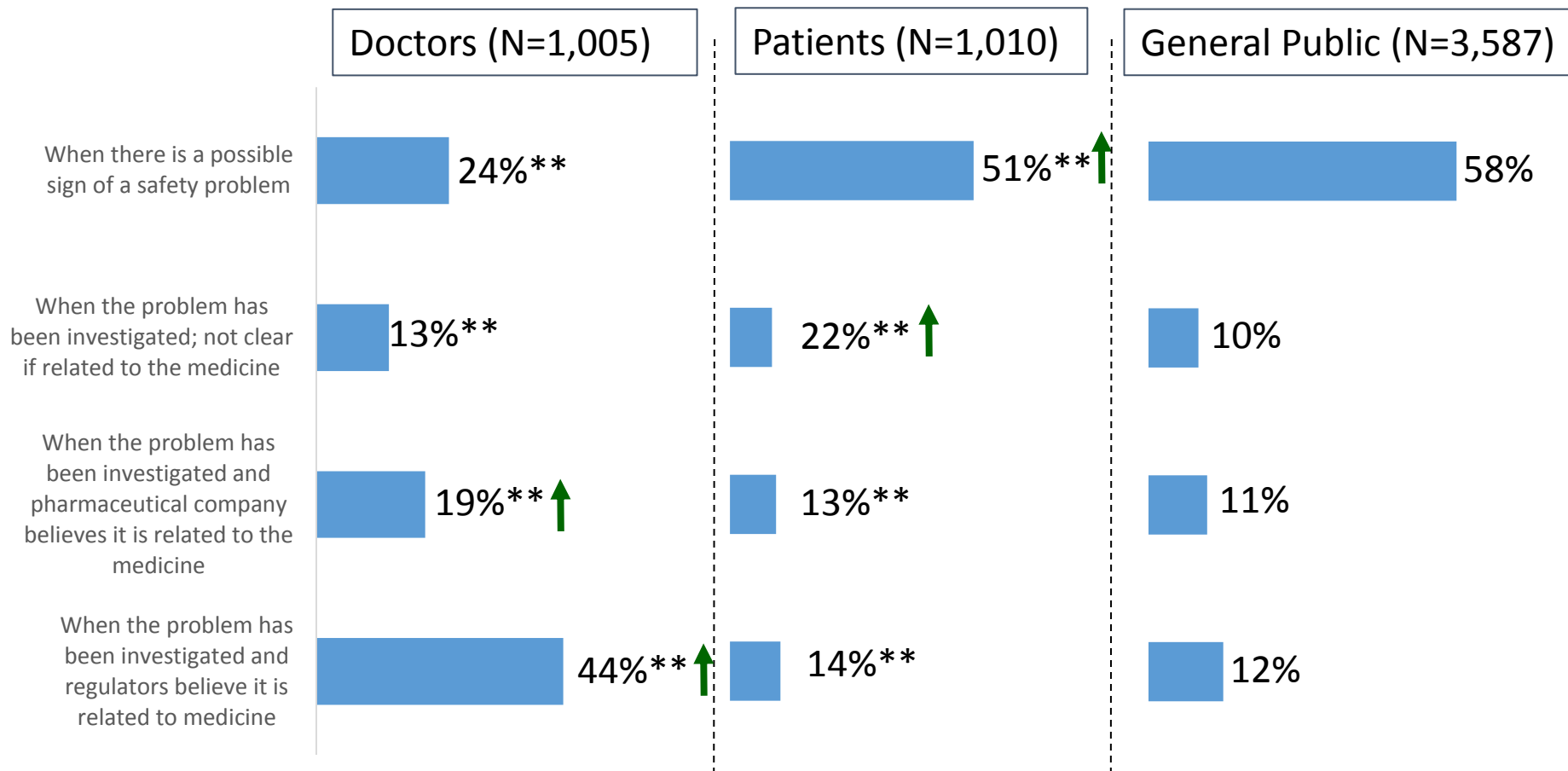
Where do patients obtain trusted info?



Q5(a): How easy is it for you to find information about medicines from each of the following sources?

Q5(b): How trustworthy do you believe the following sources are in providing you with advice on the side effects associated with specific medicines

Ps vs. HCPs: when should medicines info be communicated?

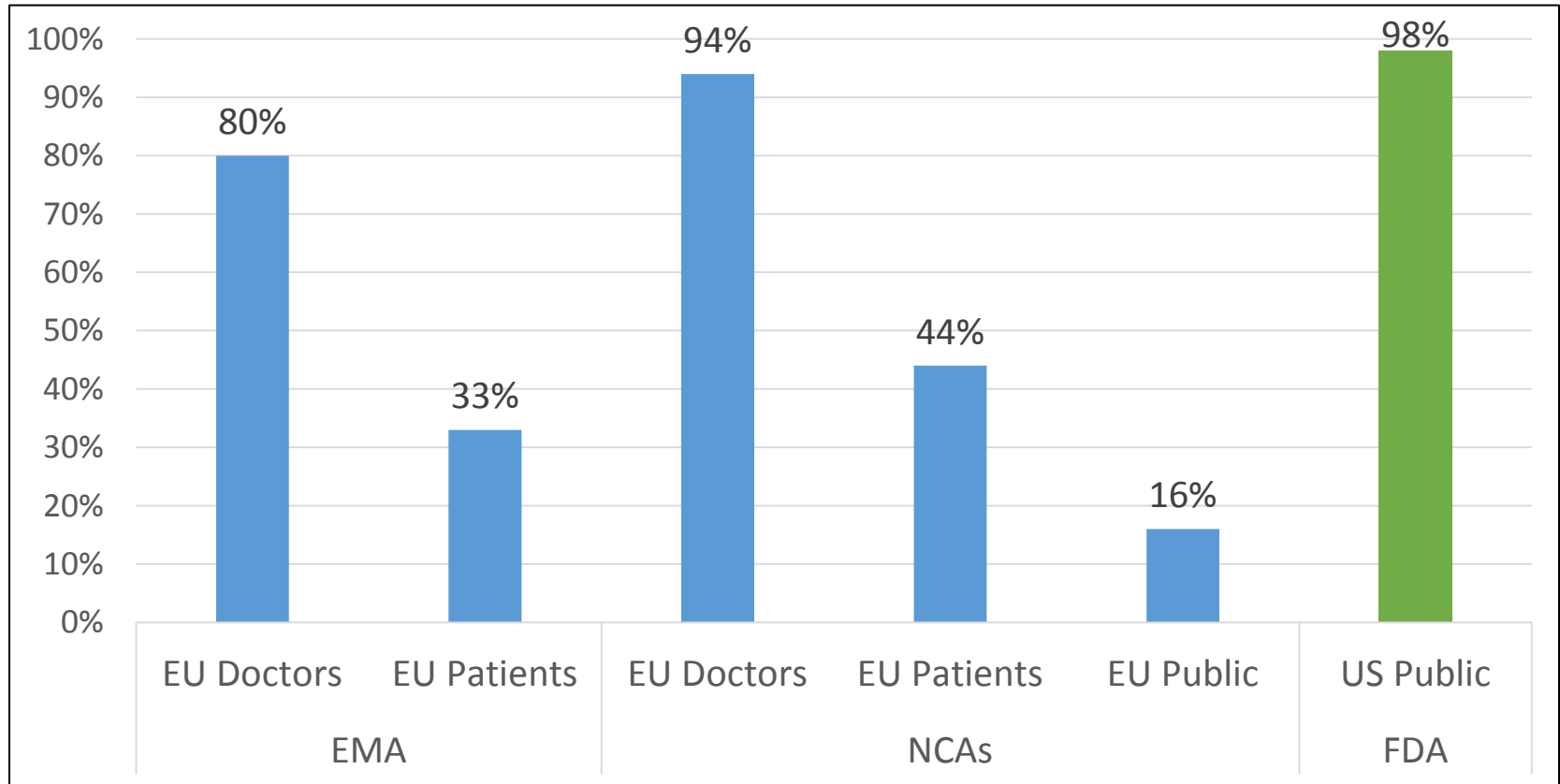


Q9. At what stage do you think information should be conveyed to the public about a possible safety issue of a medicine that they use or may use? (*Please choose one answer only*)

****All differences between doctors and patients are significant** at $p < 0.001$ (pairwise comparisons in a generalised linear model with a binomial distribution, logit link function, and doctor/patient as a factor variable).

The regulators' role

Awareness of regulators



Q11/Q16: Have you heard of the [insert NCA]/EMA/FDA?

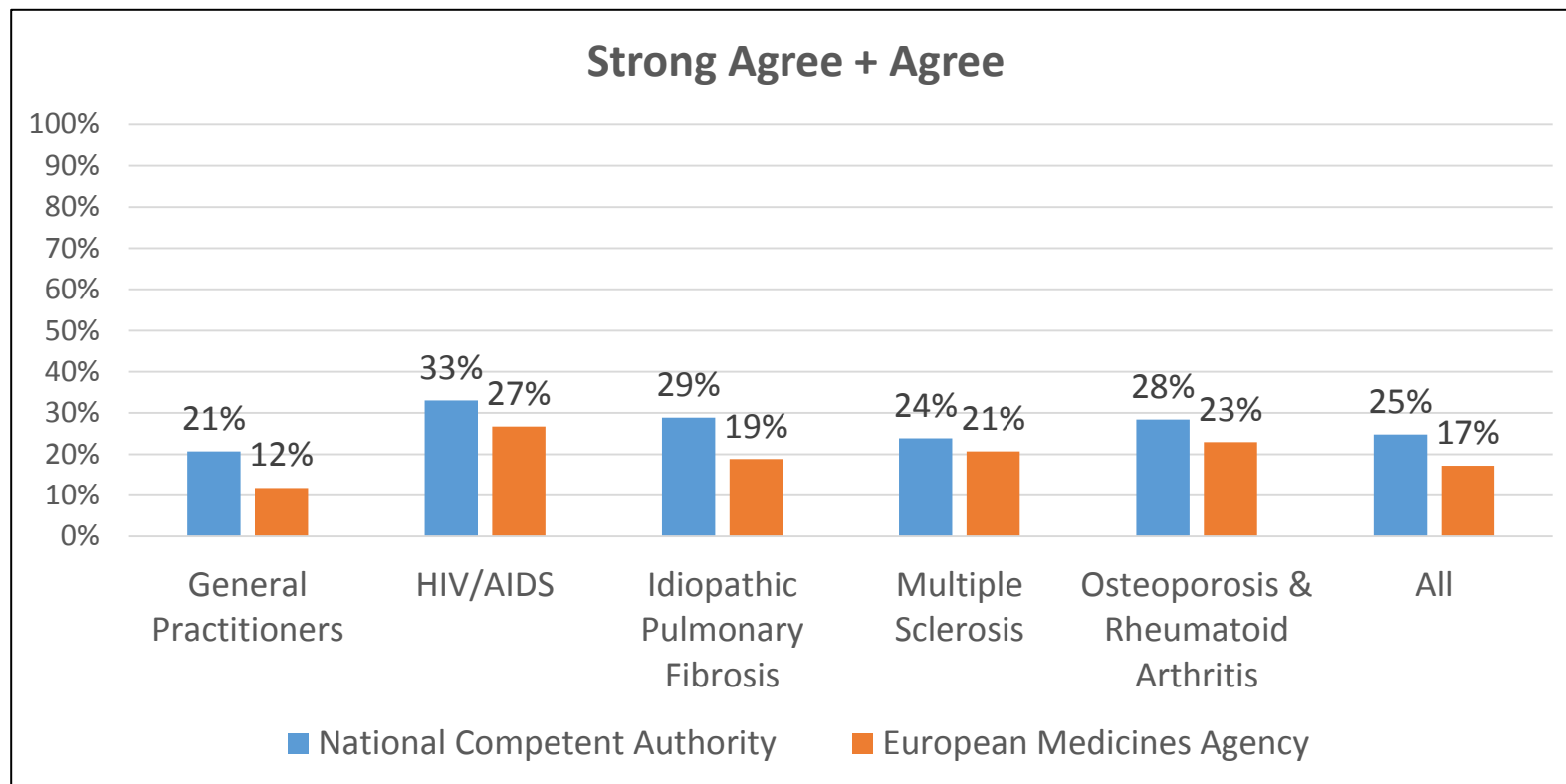
Variation across Europe (general public)

	UK (MHRA)	Sweden (MPS)	Netherlands (CBG-MEB)	Spain (AEMPS)	Germany (BfArM)	France (ANSM)
Yes	25 ^a	67 ^b	2 ^c	7 ^d	8 ^e	15 ^f

Have you heard of [INSERT relevant national authority]?

^a all superscript letters that differ between nations denote a statistically significant difference ($p < 0.05$) in the percentage of respondents answering “yes” between those nations (determined by pairwise comparisons in a generalized linear model with logit link, binomial distribution, and Bonferroni corrections for multiple comparisons)

Do doctors know how regulators assess medicines safety?



N.B.



Q15(a)/20(a): I have good knowledge of how [Insert NCA/EMA] assesses the safety of [insert medical speciality] medicines.

***Only statistically significant differences between GPs and specialists in treating HIV/AIDS.**

Main findings

➤ Opportunities

- Ps have a large appetite for more medicines info
- Patients trust HCPs

➤ Challenges

- Ps nation and condition underpins their reactions to safety info
- Ps don't know the regulators and trust them moderately
- Ps trust MDs but disagree over when info should be conveyed
- Ps + MDs unfamiliar with the contribution of the regulators
- Ps+ HCPs unlikely to be aware of or understand the regulators' transparency comms
- Could regulators work through HCPs? MDs are time poor in enabling empowerment (e.g. BMA 2015 survey of 15,562 GPs)

Our on-going research...

- Transparency deserves effective B-R comm
- Role of patient and doctor groups is essential for effective medicines transparency

How can we improve B-R communication to enhance transparency?

Stage One: Interviews with P + MD representatives

Stage Two: In-depth patient focus groups