



WHAT YOU ALWAYS WANTED TO KNOW ABOUT PATIENTS

BUT NEVER DARED TO ASK...

Results ReumaNet Survey Spring 2015



eular

London
8-11 June 2016



DISCLOSURES

- Nothing to declare

eular

European League Against Rheumatism

Survey ReumaNet 2015

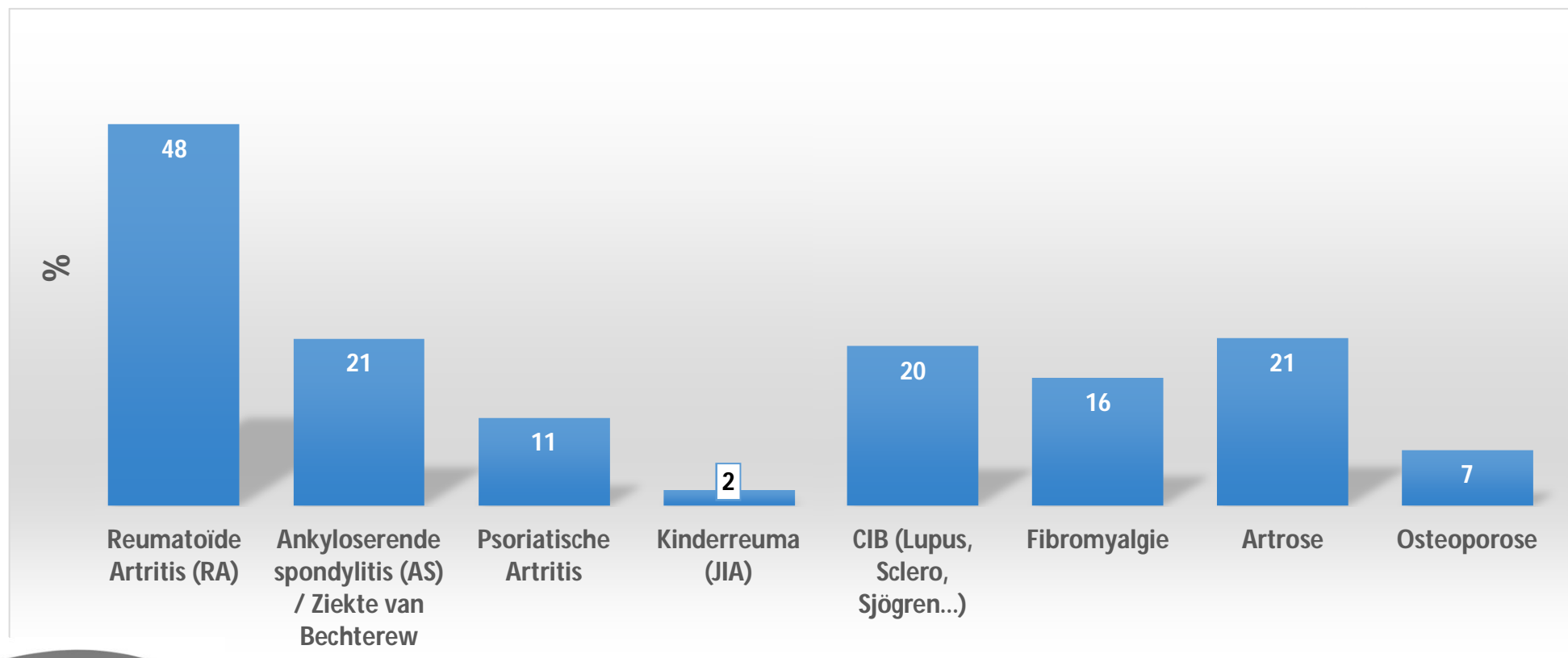
- Developed by ReumaNet and her partners
- February – June 2015
- Online survey with the help of Mediplanet
- Spreading through websites, social media, flyers, personal mailings...
- Around fifty paper surveys
 - Upon personal request
 - Via Patient organisations
 - Via rheumatologists
- **TOTAL: 711 participants with rheumatic & musculoskeletal diseases (RMD's)**



Conditions of participants:

* *patient reported*

* *some patients have more than one condition*

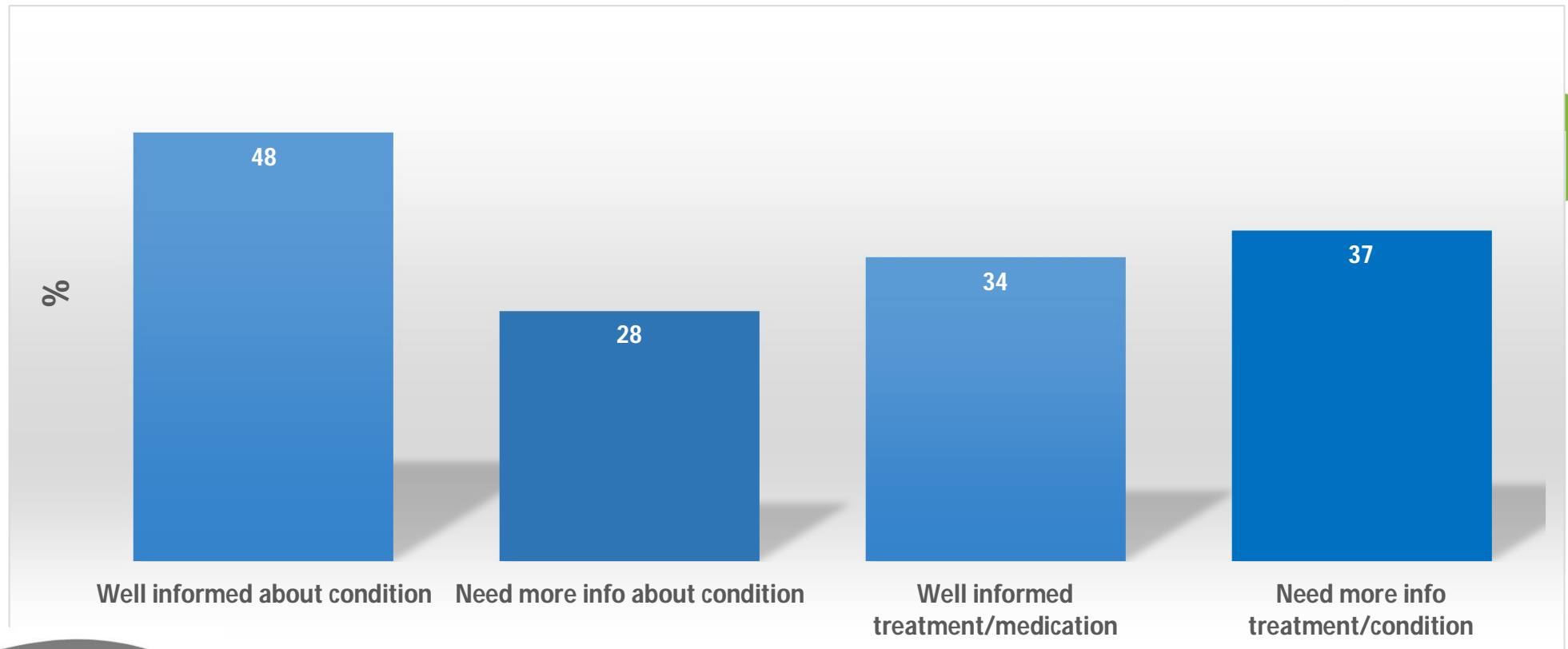


Part 1: What do you want to know (more) about RMD's?

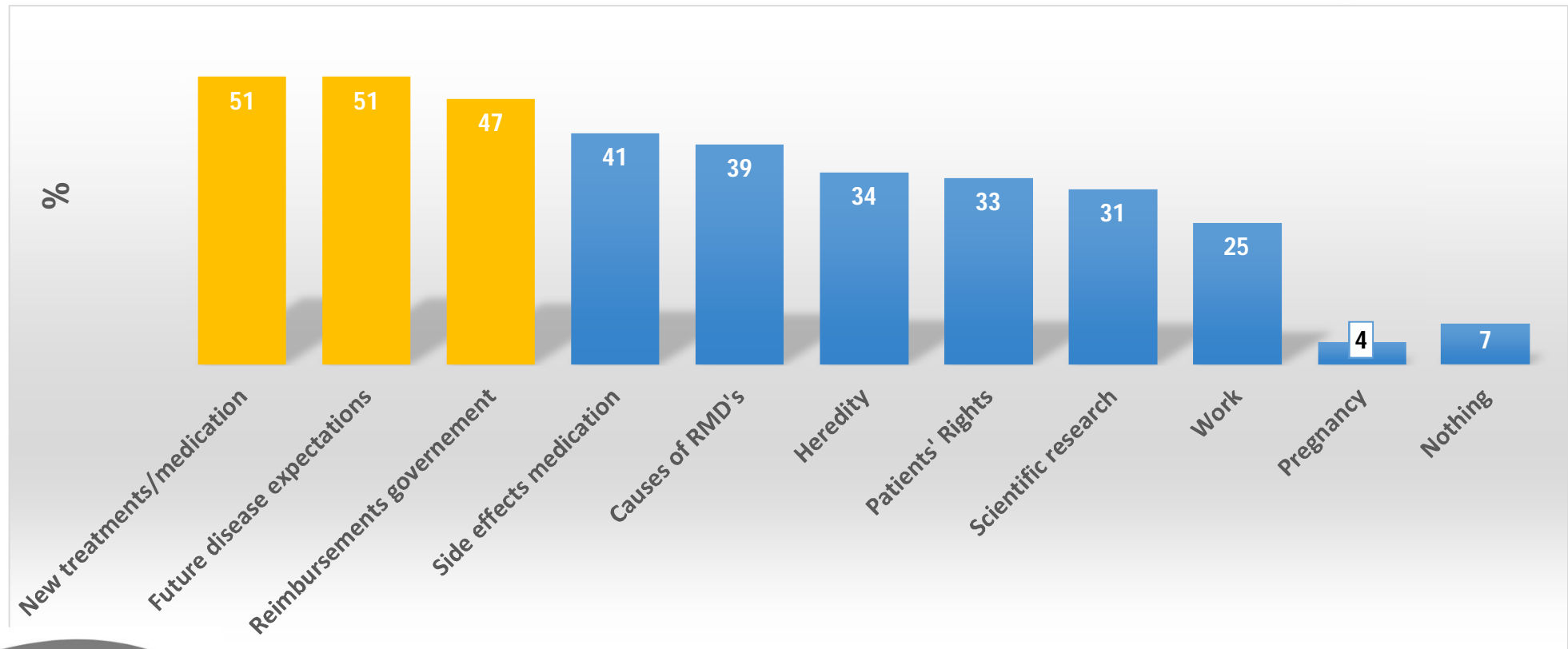
Questions related to your need for information



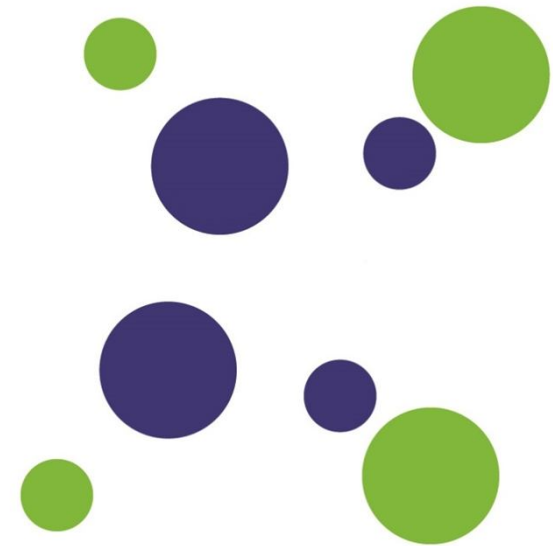
Do you consider yourself well informed?



I am looking for information on...

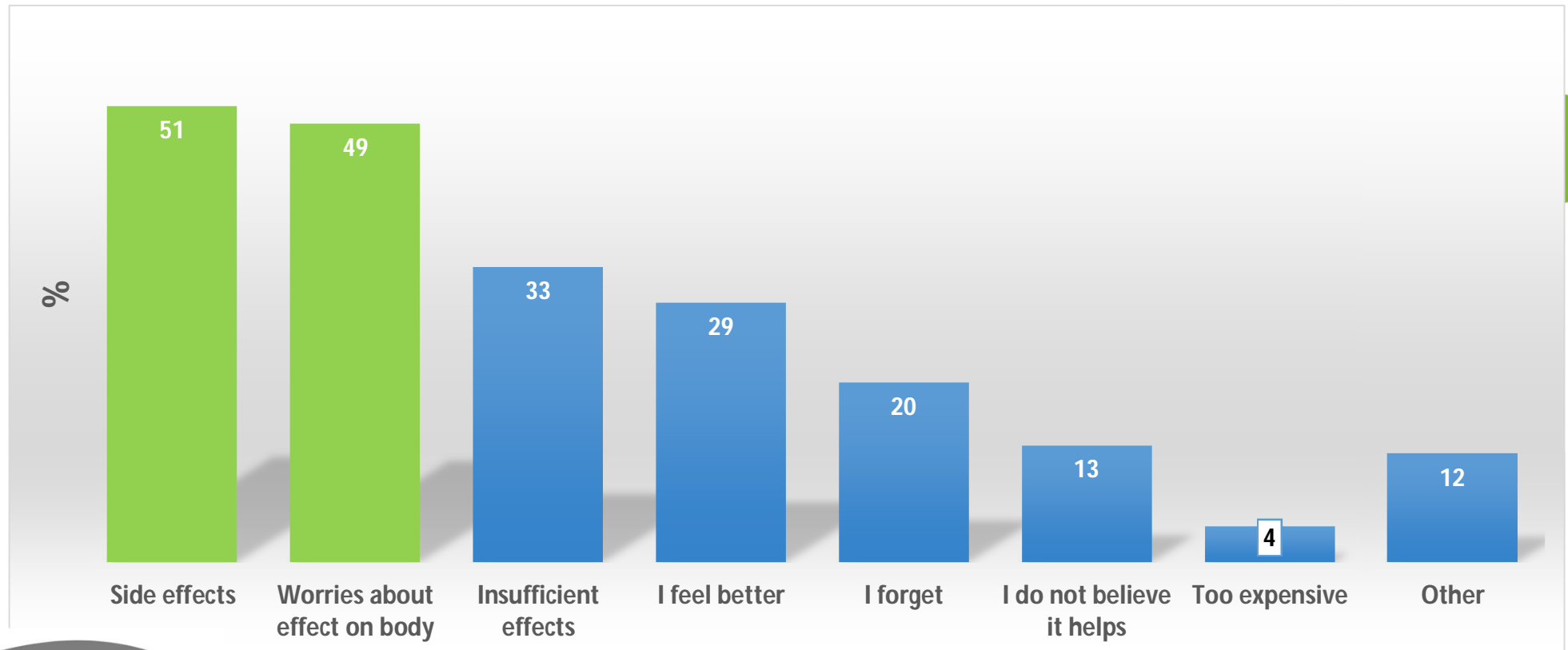


Part 2: Questions about your medication



**“Each capsule contains your medication,
plus a treatment for each of its side effects.”**

I do not take medication as prescribed because...



Part 3: Scientific Research

What do you believe is important?



Subjects for scientific research:

- Fatigue 360 people
- Heredity 210 people
- Causes of RMD's 121 people
- Side effects medication 114 people
- Pain 104 people
- New medication
- Course of disease
- Psychological factors
- Comorbidities
- Diet
- Work
- Exercise



Part 4: You and the rheumatologist

Questions about your relationship with your treating physician



“If I don’t go to the doctor, he can’t find anything wrong with me. That’s how I stay healthy!”

How satisfied are you with your rheumatologist?

>65yrs:

8,1/10

Overall:

7,4/10

Fibromyalgia:

6,9/10

10%
scores 10/10

12%
gives 5 or less

Plus – and workpoints:

Eases pts, confidence,
human approach

69 persons

Willing to listen

69 persons

Gives sufficient
information

63 persons

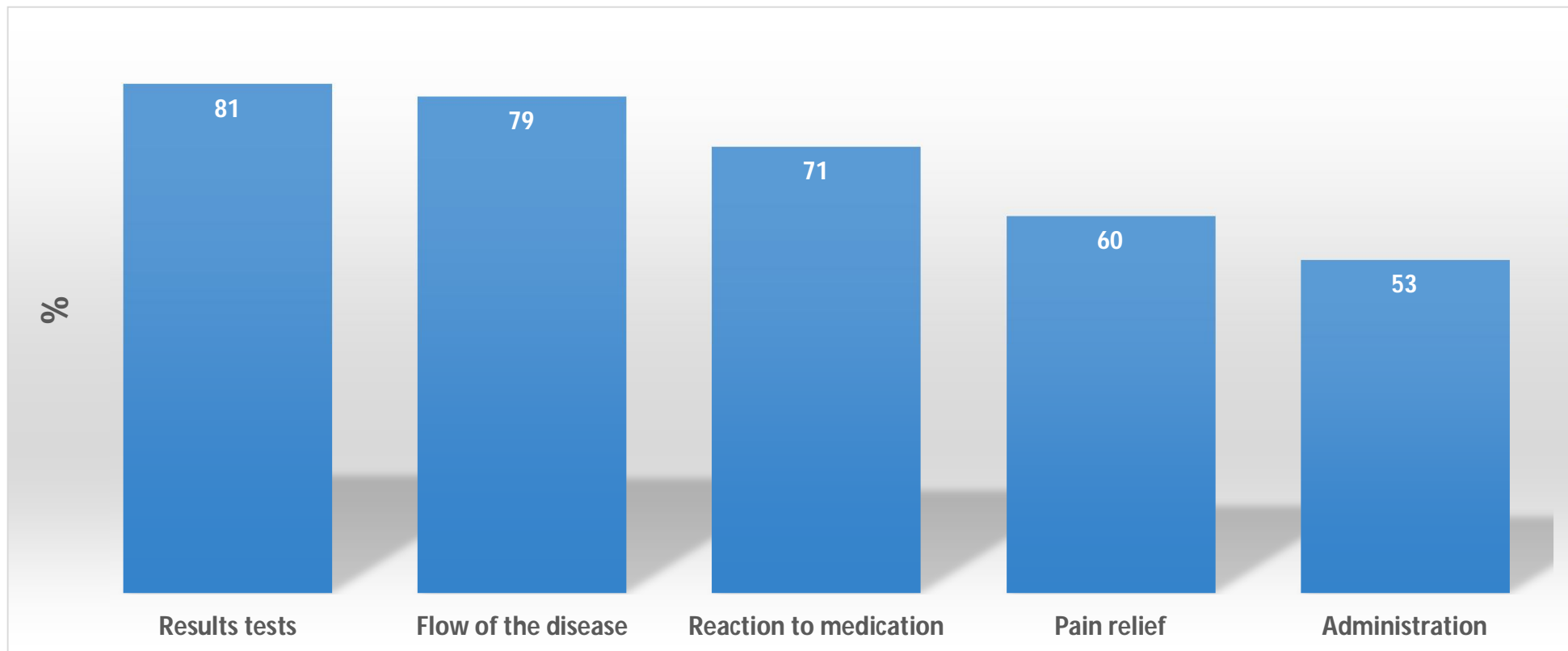
Does not listen enough
to stories/questions/
complaints/emotions of
pts

124 persons

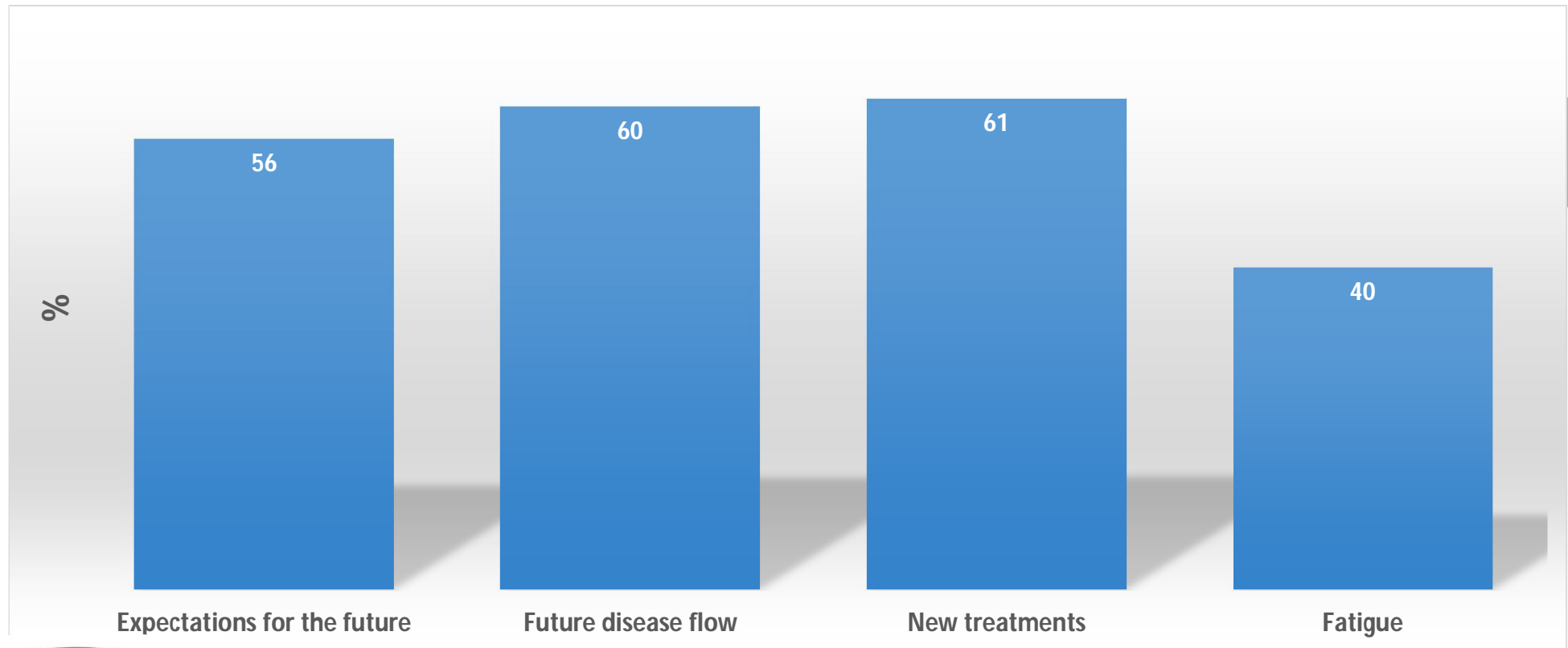
Too little time

50 persons

Which topics are being discussed during consultation?

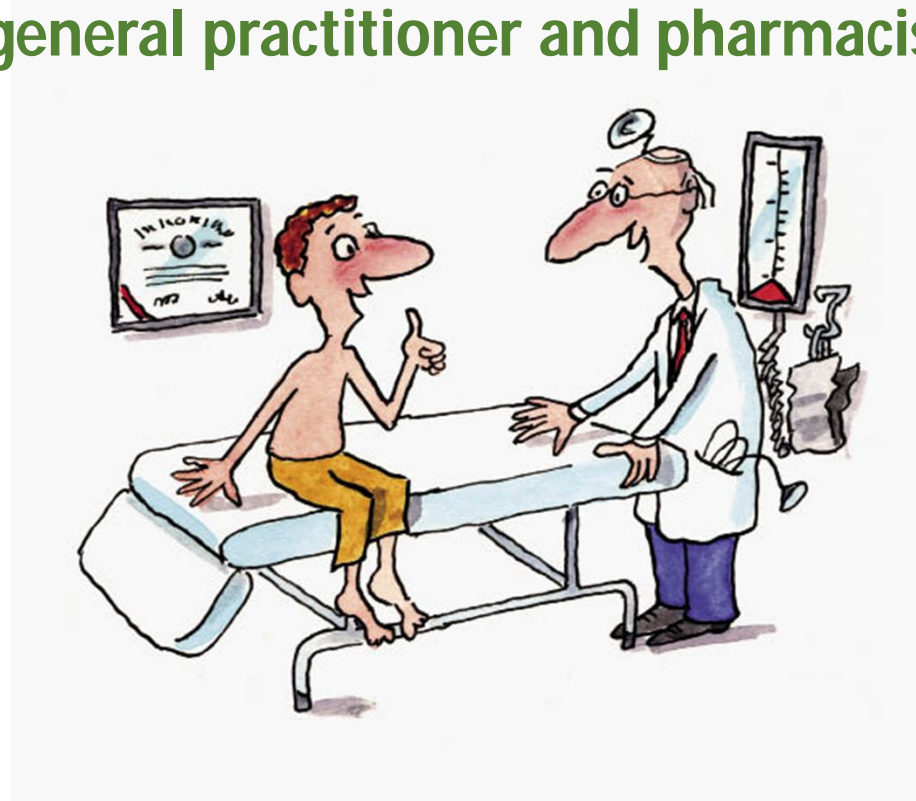


Which topics would you like to discuss?



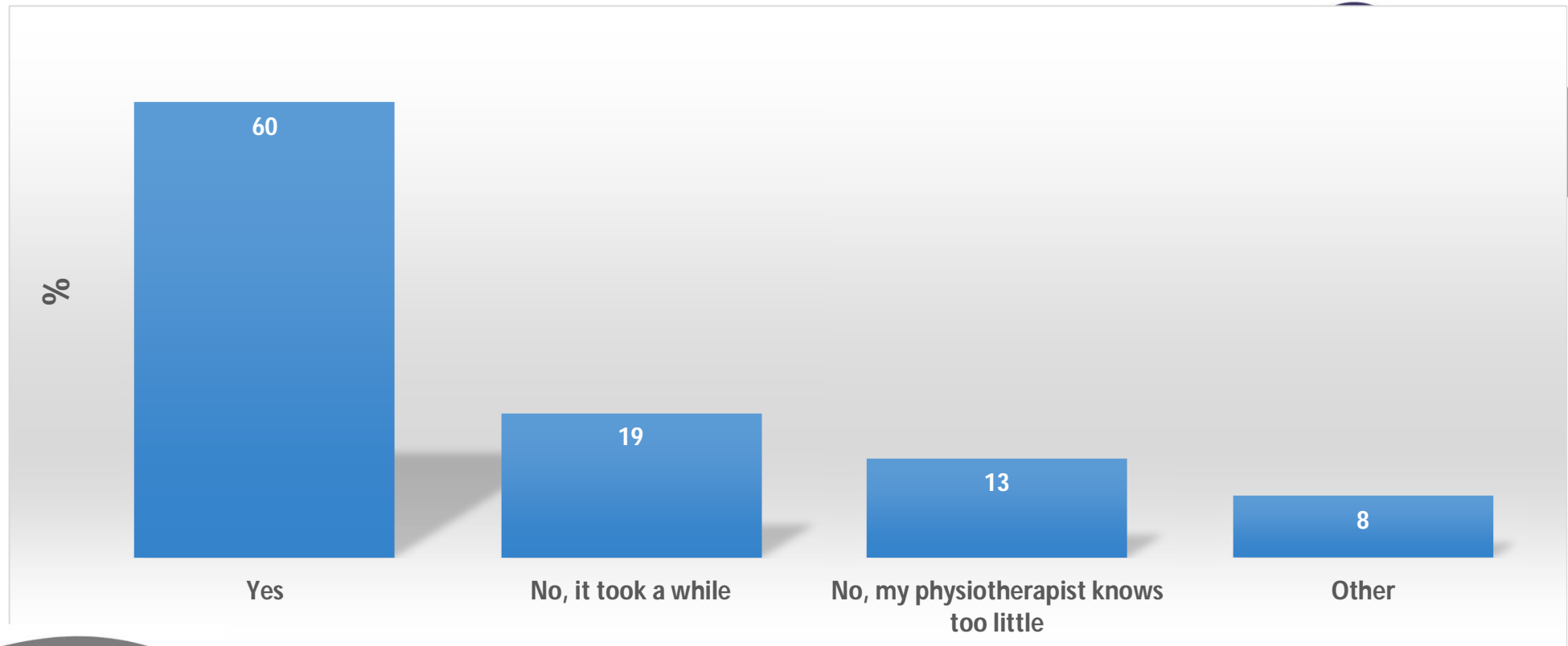
Part 5: You and the other health care providers

Questions about your relation with your physiotherapist, general practitioner and pharmacist

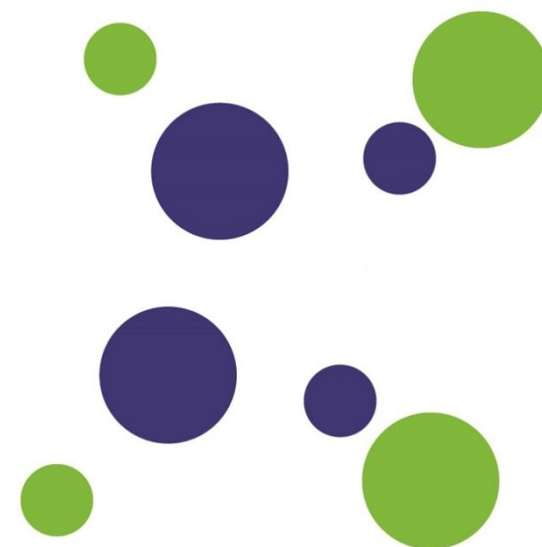


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Did you easily find a physiotherapist that knows enough about your condition?



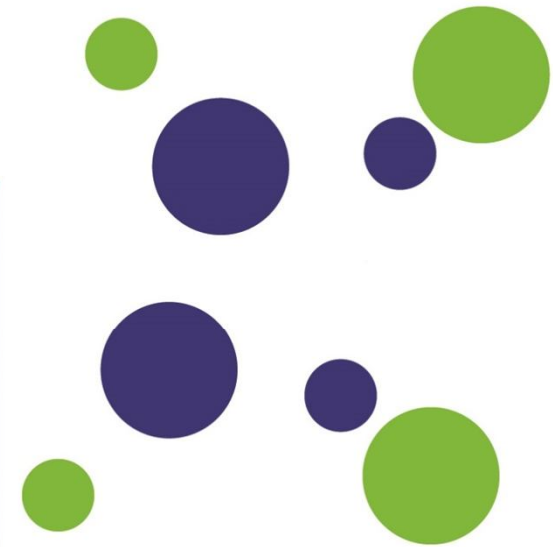
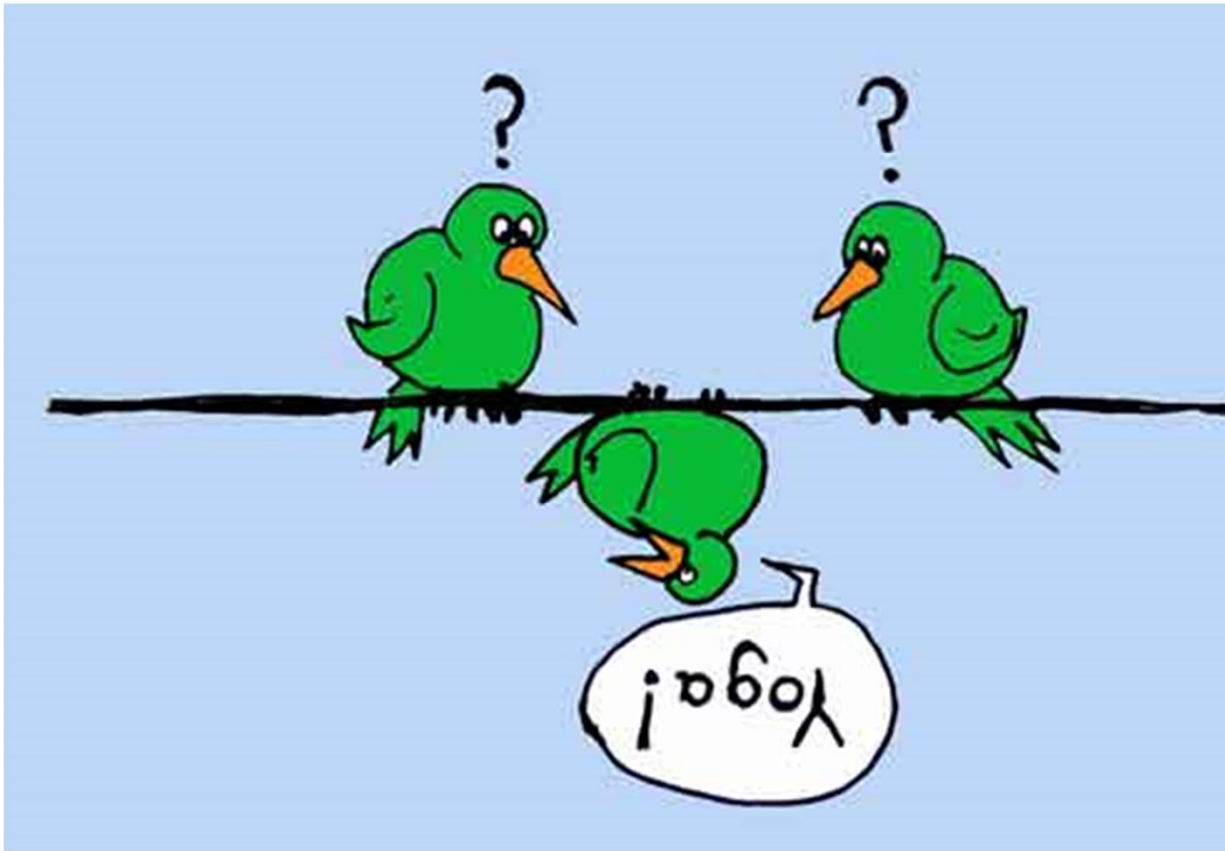
How satisfied are you with your physiotherapist?



Overall
8,1/10

16%
gives 10/10

5%
gives 5 or less

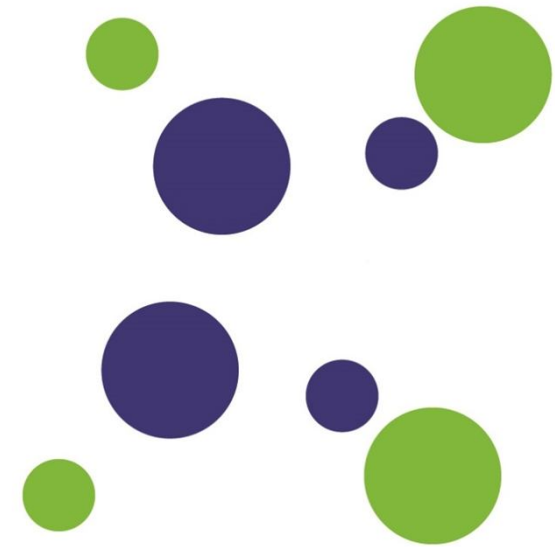


How satisfied are you with your GP?

Overall
8/10

17%
gives a 10/10

7%
gives a 5 or
less



What do doctors think?

**(n=95), survey by Mediplanet*

80% believe pts are more communicative than before

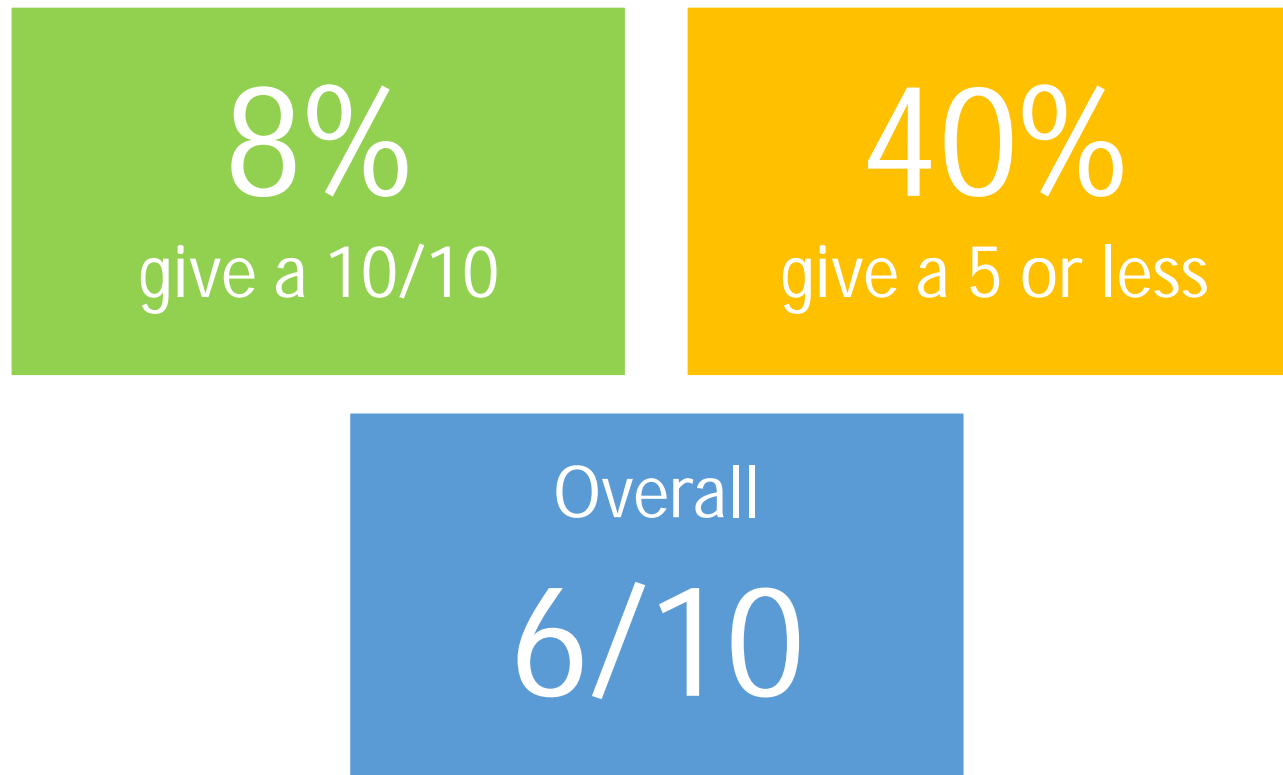
Doctors give themselves a score of **7,3/10** for communication

52% think pts are compliant to therapy
27% do not know

88% believe there is enough space and time to answer questions during consultations

44% think pts are well informed about their disease

How satisfied are you with the communication between your GP and rheumatologist?



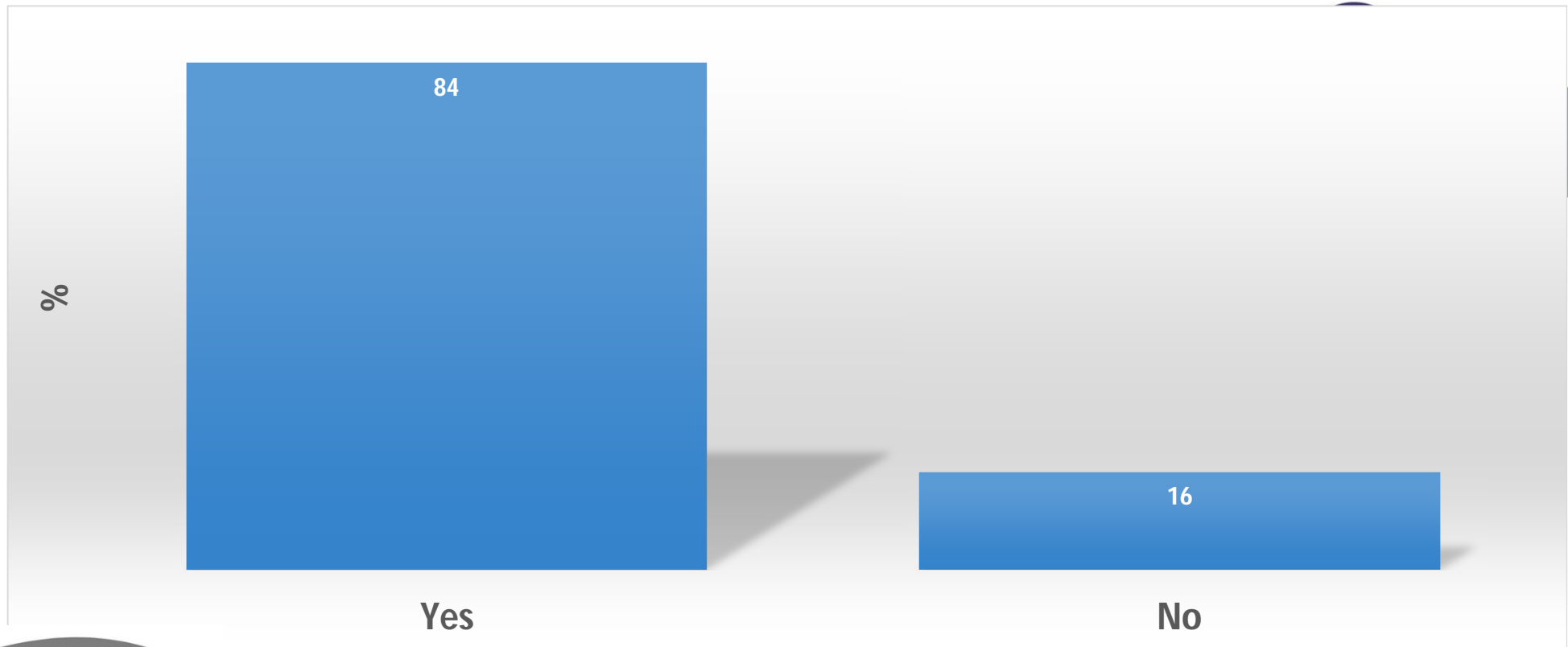
At the pharmacist's...

Prescriptions



**“I’ve been taking this medication for 50 years
and I’m going to sue! The side effects
made me wrinkled, fat and bald!”**

Does the pharmacist know about your condition(s)?



How satisfied are you with your pharmacist?

+65 pts are most satisfied (8,4/10)

Overall
8,1/10

Youth <26yrs are the least satisfied (7,5/10)

17%
give a 10/10

5%
give a score of 5
or less

What do pharmacists think?

**(n=139), survey by Mediplanet*

83% believe pts are more communicative than before

Pharmacists give themselves a score of **7,5/10** for communication

44% believe pts are compliant to therapy
27% do not know

84% believe there is enough space and time to discuss questions

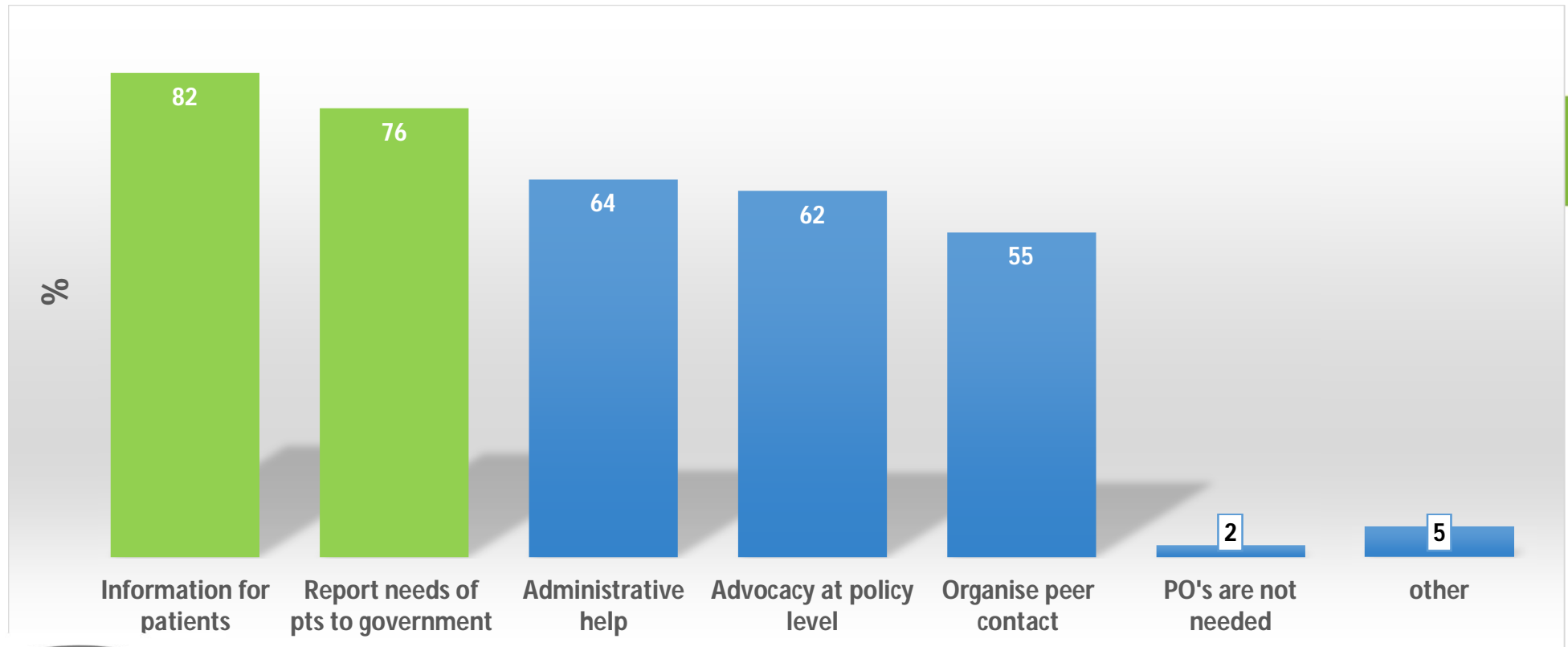
51% believe pts are well informed about their condition

Part 6: You and other patients

Questions about you and Patient Organisations



Why are patient organisations needed?



Conclusions:

- **People with RMD's...**
 - **Want more information and communication about treatment and medication**
 - **Want more information and communication about future disease expectations**
 - **Are afraid of side effects of medication**
 - **Do not need to be reminded to take medication**
 - **Want to see 'fatigue' on the research agenda**
 - **Are moderately satisfied with the rheumatologist (7,4/10) and satisfied with GP/Pharmacist/Physiotherapist (8/10)**
 - **Want more communication between GP and rheumatologist (6/10)**
 - **Believe PO's to be useful for spreading information among patients and for advocacy work towards policy makers**

THANK YOU FOR YOUR ATTENTION!

*A booklet has been published with more details on the results.
Please ask ReumaNet for a copy.*

