

# NRAS Patient Experience Survey

## May 2021

Developed with an educational grant from medac Pharma



**nras**  
National Rheumatoid  
Arthritis Society

# Contents

<b>Patient Demographics</b>	<b>1</b>
<b>Impact of Adult JIA/RA</b>	<b>2</b>
<b>Consultation Experience</b>	<b>3</b>
<b>First Treatment Outcomes</b>	<b>4</b>
<b>The Methotrexate Experience</b>	<b>5</b>
<b>Impact of the COVID-19 Pandemic</b>	<b>6</b>
<b>Switching from Oral to Injectable Methotrexate</b>	<b>7</b>
<b>Comparisons with the 2015 Survey</b>	<b>8</b>

# “If a newly diagnosed patient asked you about methotrexate, what would you tell them?”

## Detractors (15%)

It might not work or takes too much time to work

Unpleasant drug

A very toxic drug that did nothing for my condition

It has unpleasant side effects and wasn't that effective for me. I felt very sick on injections and felt it as poisonous

Don't take it. It made my life a misery

DONT DO IT!!!!!!

Also including patients who reported a lack of symptom improvement and/or a reduction in QoL (22%)

## Passive (20%)

It is worth a try, it did not work with me but many do benefit

It helps RA but made me feel sick and toxic at the start

Try taking it since for some people it can be very effective with the effectiveness outweighing the side effects but be aware that for others the opposite is true

It is the gold standard and works well for many people but it didn't work for me as a sole medication

Also including patients who reported slight symptom improvement and/or a slight change in in QoL (22%)

## Promoters (65%)

It is a proven gold standard treatment providing relief for millions worldwide

Give it a go. It's worth trying

It will change your life for the better in spite of some minor side effects. Definitely my gold elixir!

Please try it as I wish I'd tried it earlier

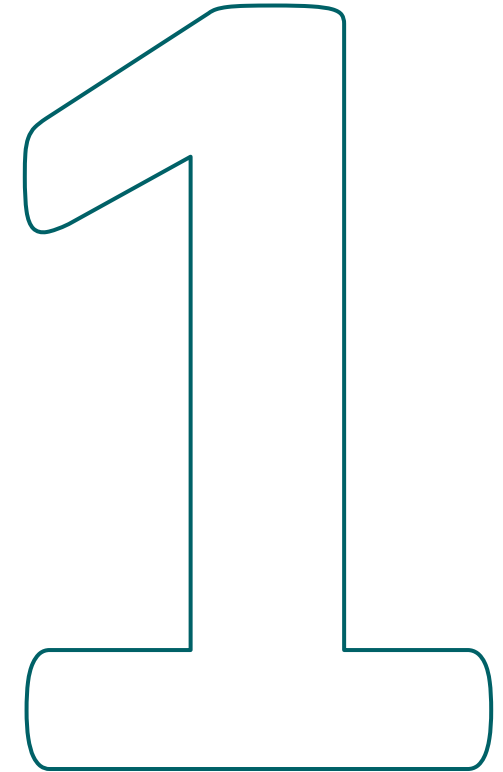
Try it, does work and side effects get better with time

It's the most effective drug to treat RA and important to start it asap

Also including patients who reported a positive effect on symptoms and/or an improvement in QoL (57%)

CHAPTER ONE

# Patient Demographics

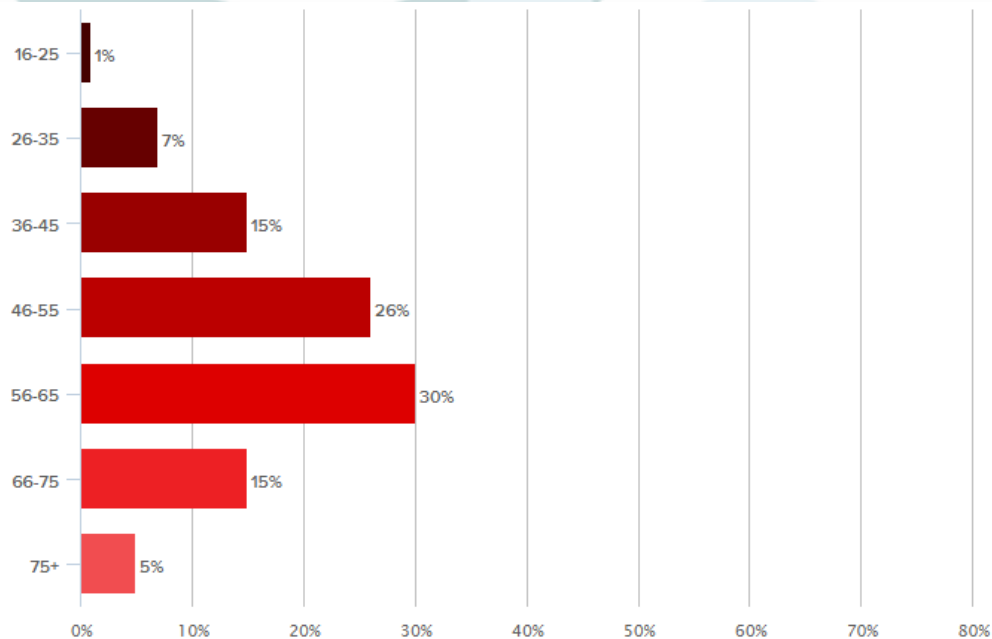


## Patient Demographics

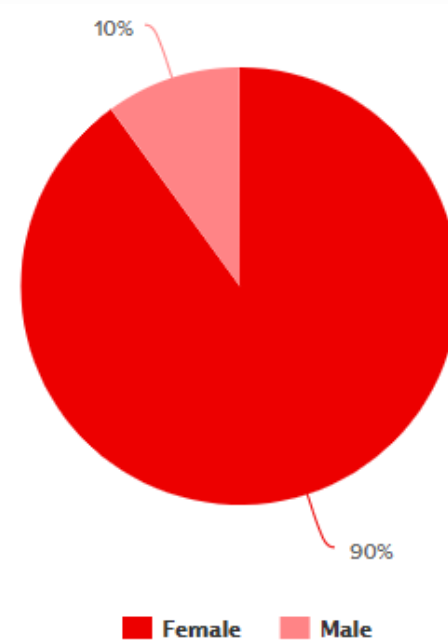
- 732 participants took part in the online survey between the 21<sup>st</sup> April to the 14<sup>th</sup> May 2021
- Conducted by medac in collaboration with NRAS
- LOI: 20-25 minutes

143 participants were excluded due to having been diagnosed with JIA/RA in excess of 5 years ago

Age N = 732



Gender N = 728



Ethnicity	Total
White British	92%
White Irish	1%
Any other white background	3%
Asian or Asian British Indian	1%
Black or Black British Caribbean	1%
N =	716

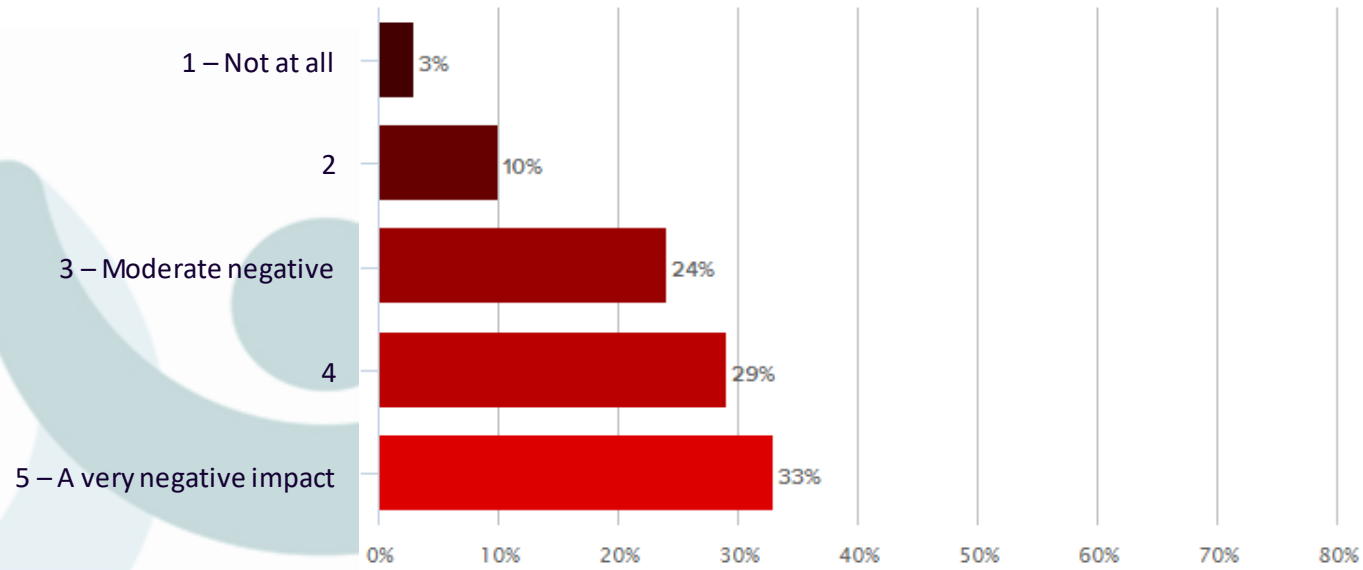
Location	Total
South East England	19%
London	6%
North West England	12%
South West England	15%
East of England	10%
East Midlands	6%
West Midlands	7%
North East England	9%
Scotland	9%
Wales	4%
Northern Ireland	1%
N =	723

CHAPTER TWO

# Impact of Adult JIA/RA



“Before diagnosis, how much of an effect on your **quality of life** would you consider your RA/JIA symptoms to have had?”



**Other areas affected:**  
32% Relationships with friends or family  
29% Relationship with partner/spouse  
3% Education

46% of these were affected to a significant degree

“What **areas** of your life were negatively affected?”

**89%**  
Activity/Fitness Levels

**71%**  
Mobility

**54%**  
Employment

**64%**  
Recreational Hobbies

**66%**  
Mental Health/Mood

CHAPTER THREE

# First Consultation Experience

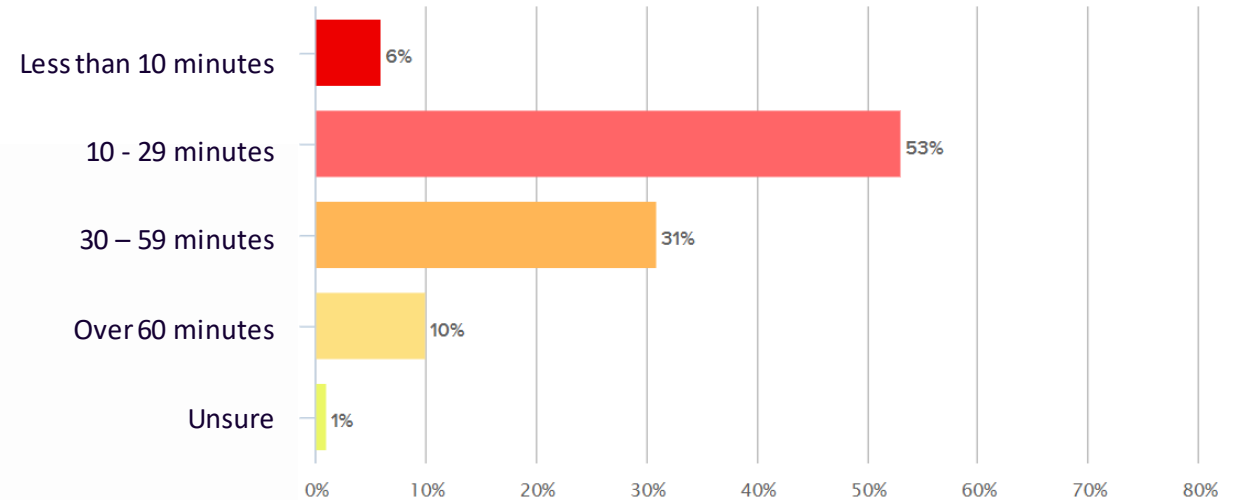




## Duration and Information Level

For most respondents, 61%, their first consultation lasted for less than 29 minutes.

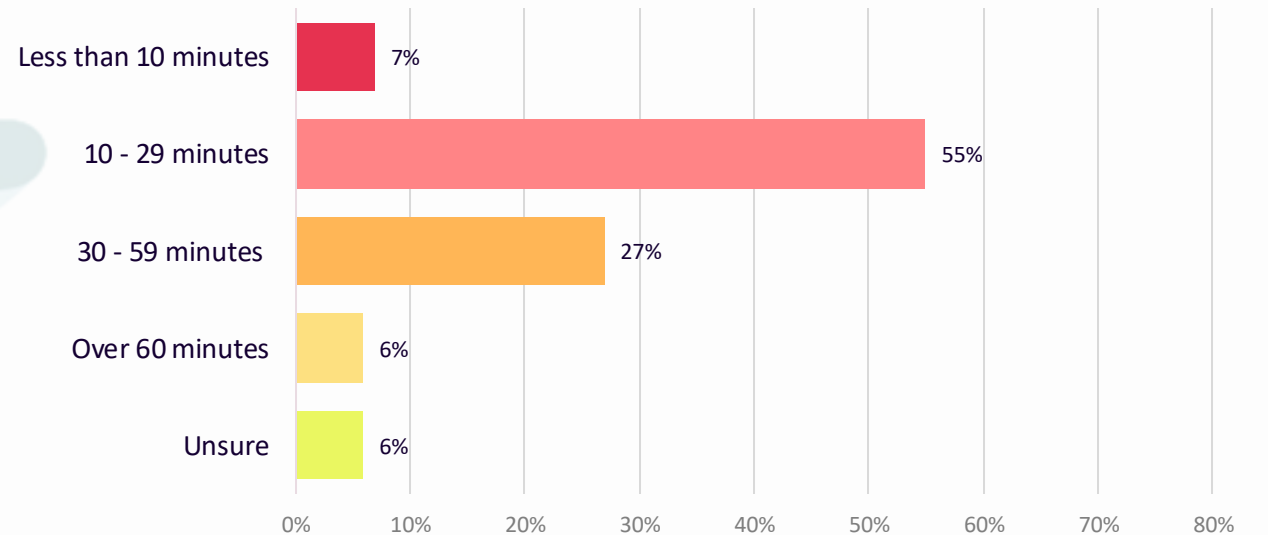
6% lasted less than 10 minutes.  
41% over 30 minutes.



### 2015 comparison

Patterns within consultation duration have maintained relatively consistent since the 2015 survey.

Consultation times lasting between 30-59 minutes, and over 60 minutes, have both **increased by 4%** over the past 5 years, suggesting slightly longer consultations this year compared to 2015.



## Duration and Information Level

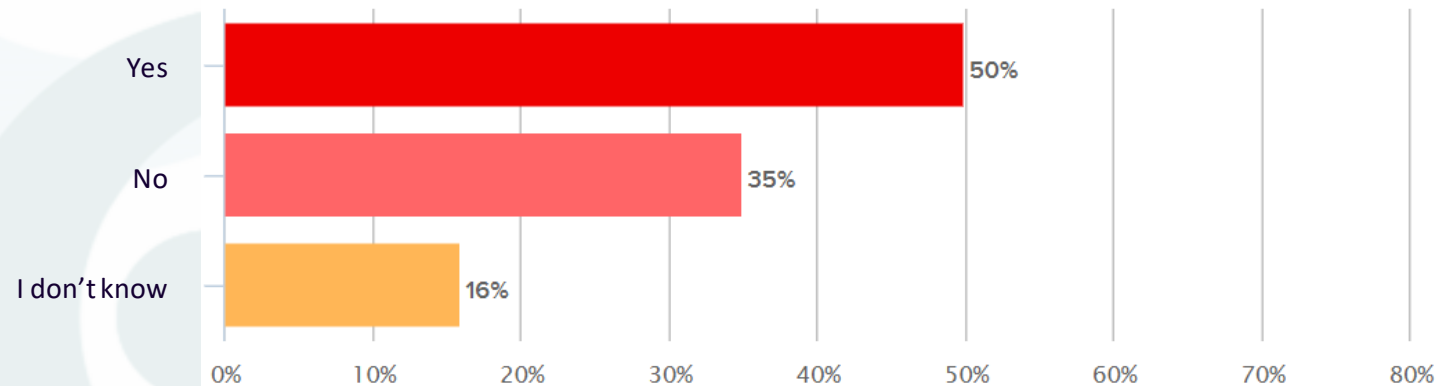
At this first consultation, **47% of patients were only given information on the specific medications they were going to start on.**

22% didn't receive any information about treatment options at this stage, whilst 31% were given information on a range of future treatment options.

“When treatment options were first discussed, would you have liked more information about the proposed treatment from your rheumatologist?”

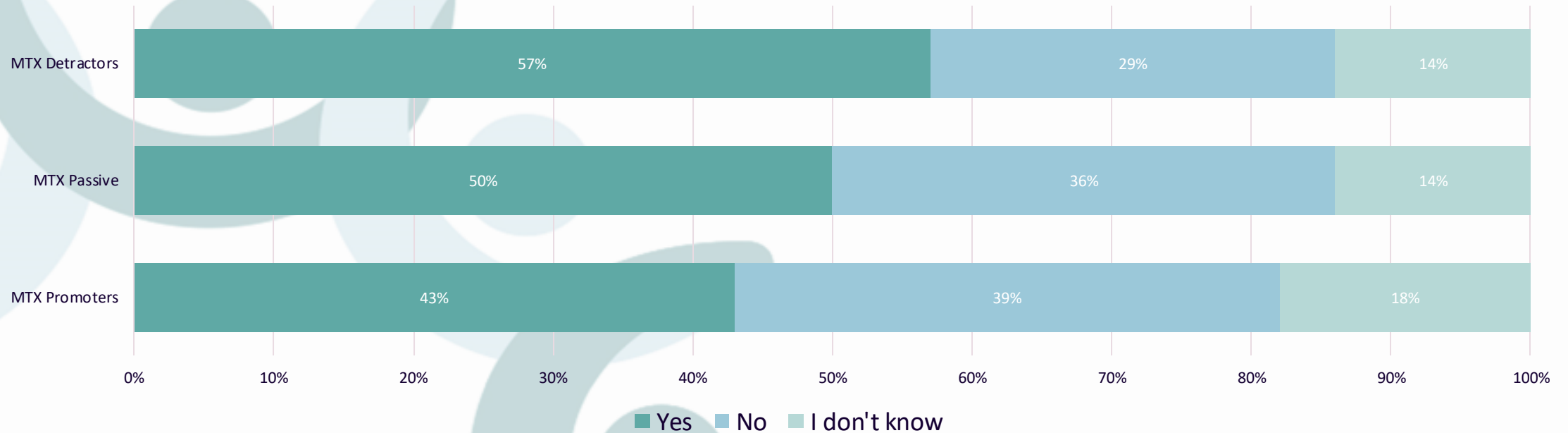
**50% would have liked more information about their proposed treatment from their rheumatologist.**

35% felt that they had enough information.  
16% were unsure.



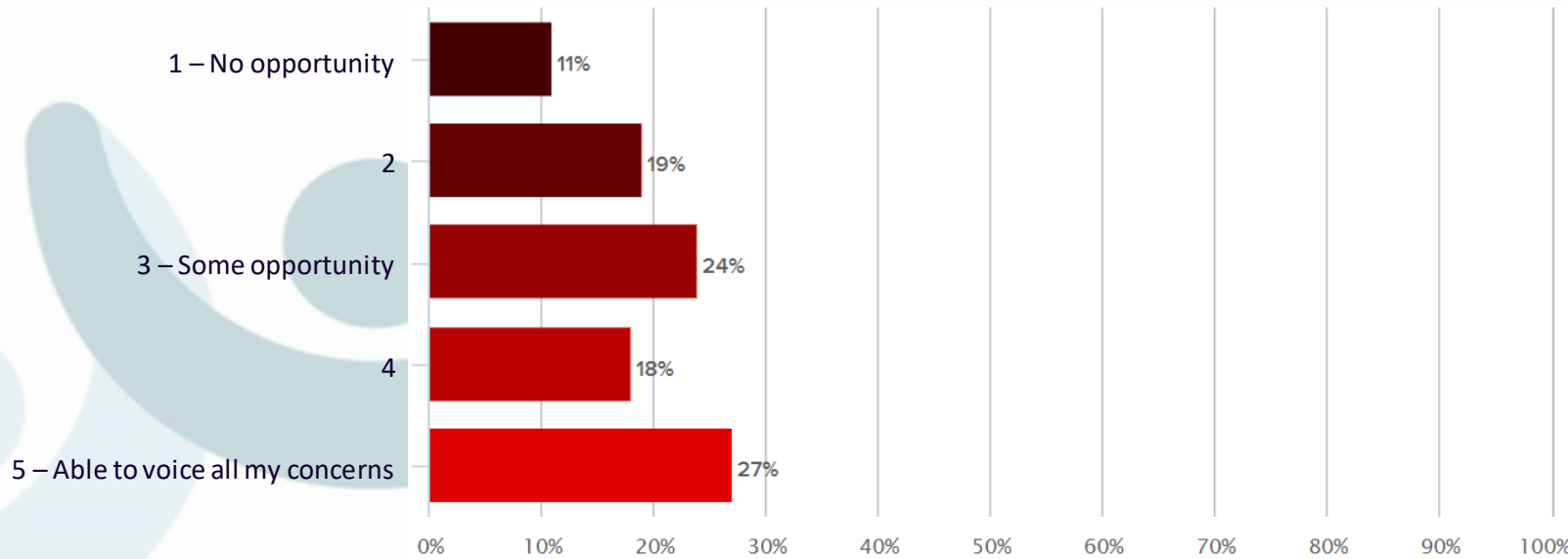
# Duration and Information Level

Whilst there doesn't seem to be any correlation between consultation length and MTX perspectives, **MTX negative responders report to a higher degree having liked more information about the proposed treatment option, 57% compared to 43%.**



# Shared Decision Making

“Did you feel you were able to voice your opinion/concerns about the suggested treatment(s)?”



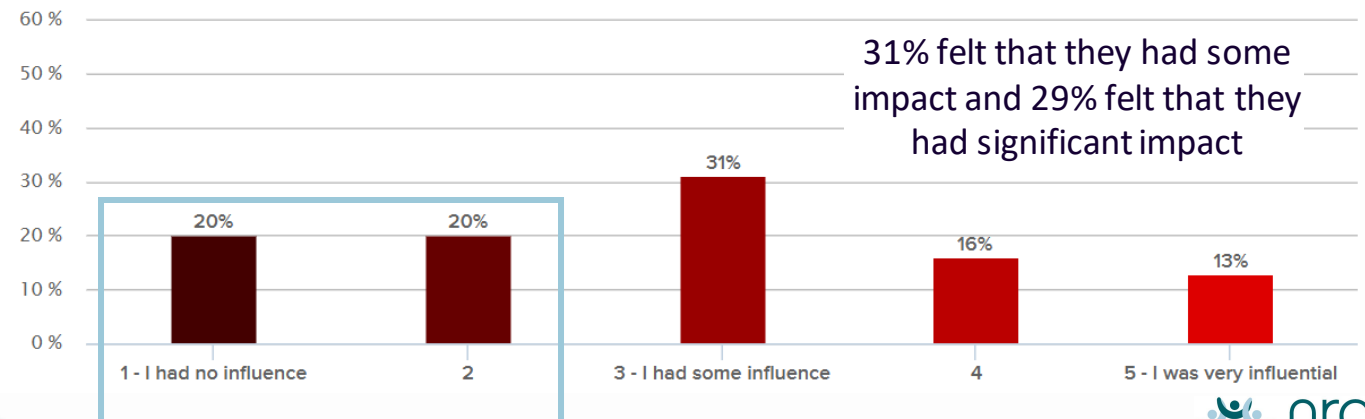
**2015 comparison**

Since the 2015 survey, perceptions of shared decision making have decreased. In 2015, 34% felt that they were able to voice all their concerns, reduced to 27% this year. However, fewer patients, 32%, felt that they had little to no influence on the treatment decision in 2015.

On the whole, patients in this survey did feel as though they had some opportunity to voice their concerns about the proposed treatment

However...

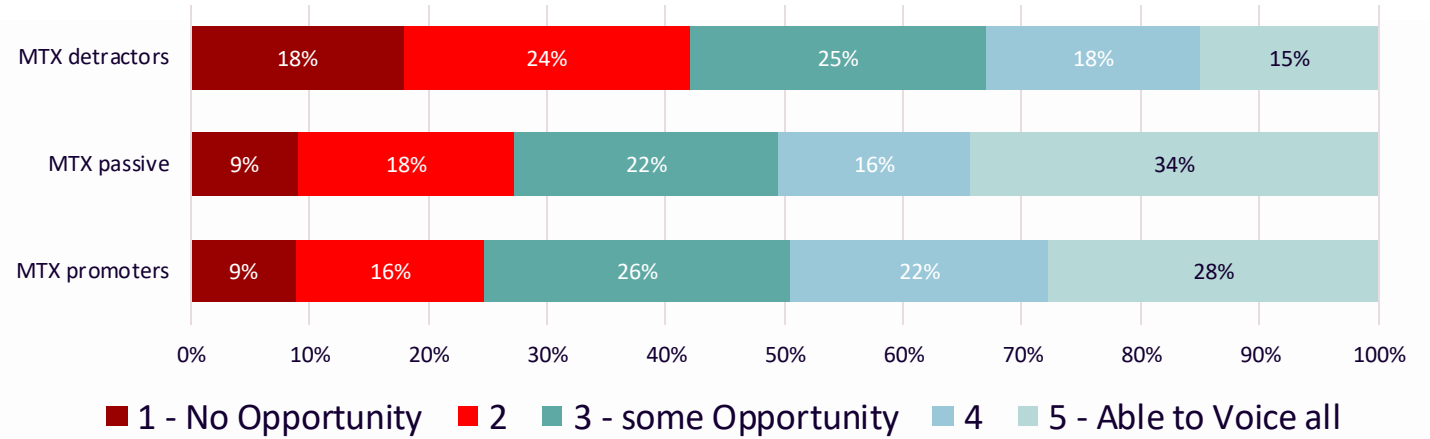
**40%**  
Felt they had **little to no** influence on the treatment decision



# Shared Decision Making

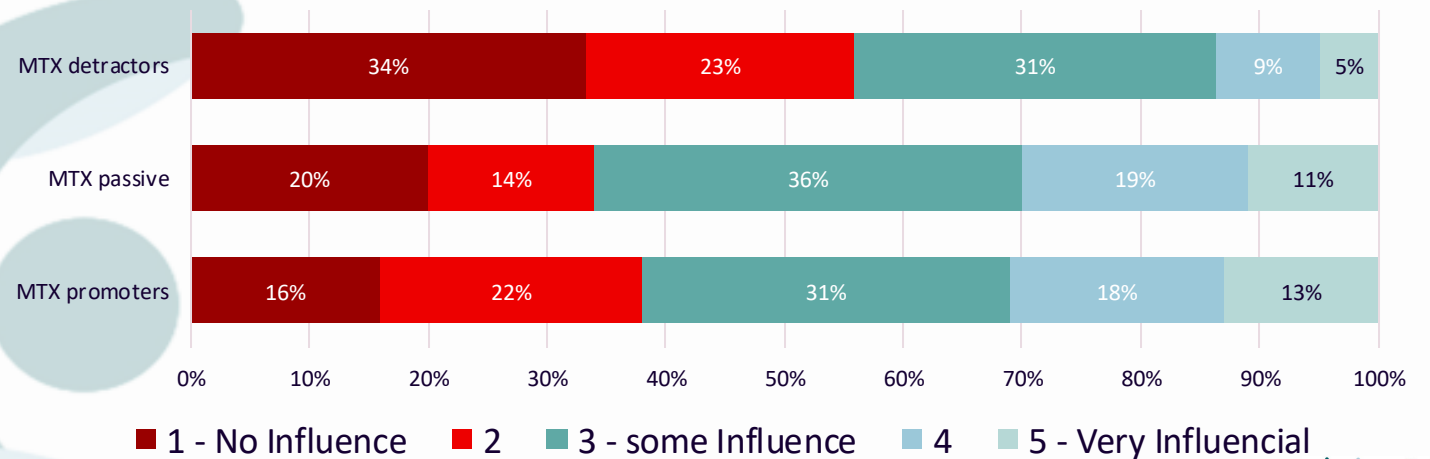
## Ability to voice concerns

**MTX promoters report to a greater degree feeling able to voice their opinions.**  
 28% report being able to voice all their concerns, compared to 15% of MTX detractors.



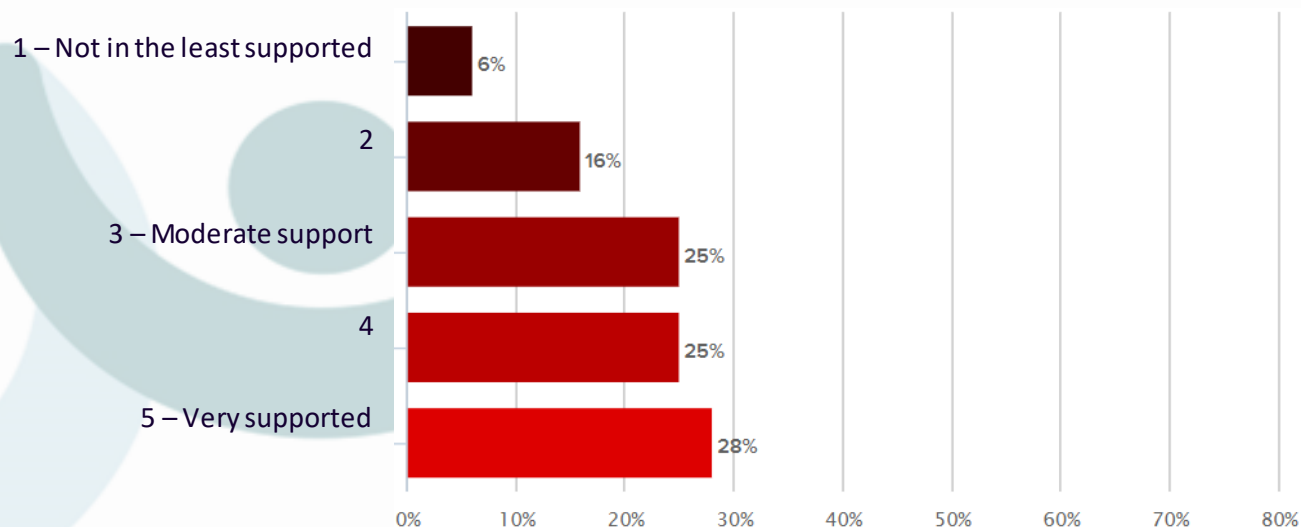
## Concerns taken into consideration

**MTX detractors report to a greater degree feeling as though their opinions were NOT taken into consideration.**  
 34% felt as though they had no influence, compared to 16% of MTX promoters.



# Patient Empowerment

“If your initial treatment was not working as you would like, do you feel you had sufficient support from your Rheumatology Care Team to review and change your treatment?”



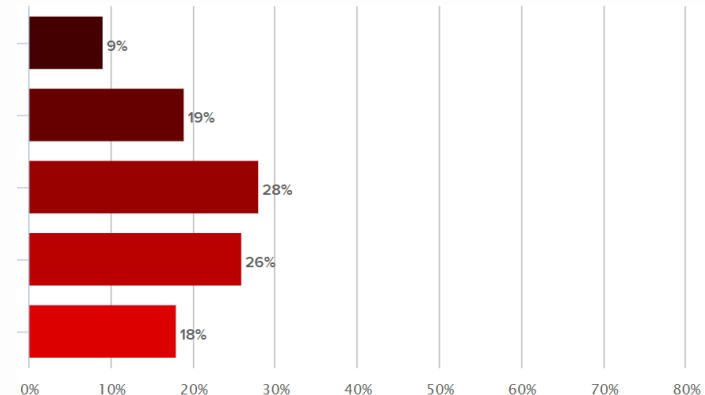
On the whole, patients in this survey did feel as though they had some support from their rheumatology team to review and change their treatment if it was not working as they would like.

However...

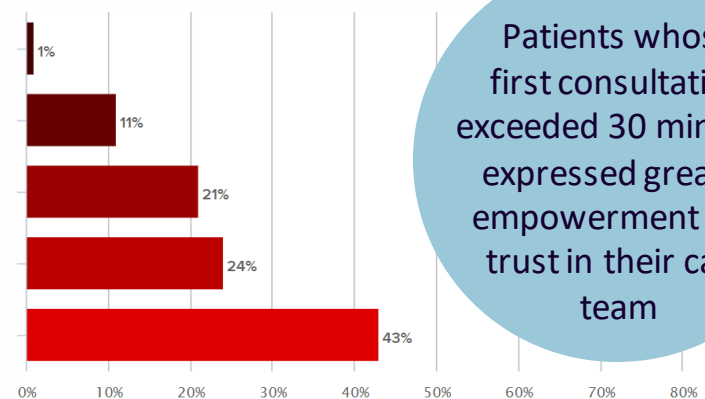
**15% of MTX detractors felt ‘not in the least’ supported, compared to only 4% of MTX promoters.**

## Impact of first consultation duration

### LESS than 30 minutes



### LONGER than 30 minutes



Patients whose first consultation exceeded 30 minutes expressed greater empowerment and trust in their care team

## In conclusion...

First consultation duration **doesn't** have a significant effect on treatment outcomes, however **the level of information provided does**. 50% of patients would have liked more information from their consultation, this is higher amongst people who go on to respond **negatively** to methotrexate.

Similarly, people who feel more empowered to voice their concerns, and that these concerns are taken into consideration, are more likely to respond **positively** to methotrexate.

CHAPTER FOUR

# First Treatment Outcomes





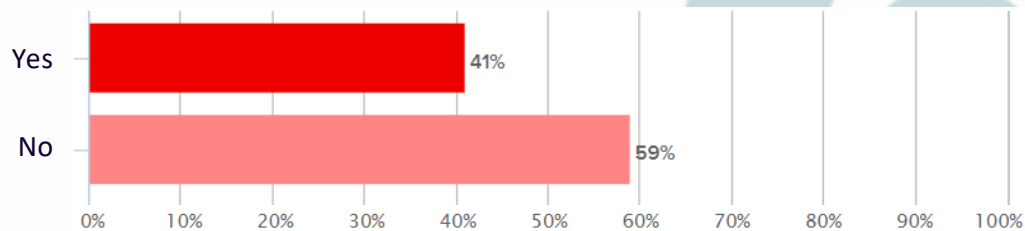
# First Prescribed Treatment Outcomes

First Prescribed Treatment	Total
Pain relief	18%
Anti-inflammatory drugs	31%
Steroids	59%
Oral methotrexate	56%
Injectable methotrexate	3%
Hydroxychloroquine	33%
Sulfasalazine	17%
Leflunomide	1%
Other	4%

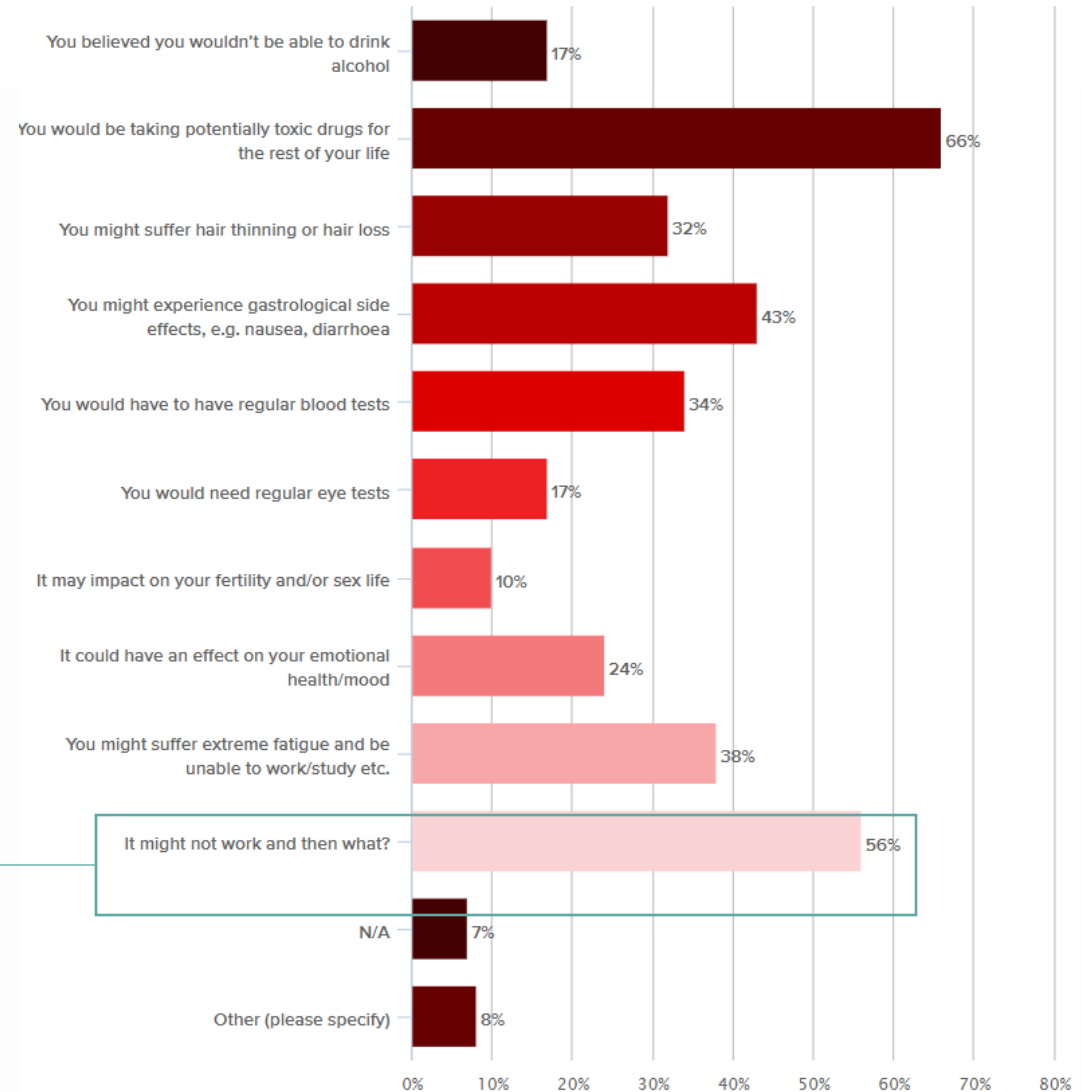
The percentage of people first prescribed oral and injectable MTX has not changed since the 2015 survey.

45% started their treatment immediately following their first consultation, and a further 24% started within 2 weeks.

“Did your consultant discuss what the next treatment option(s) would be if your initial therapy failed to bring your RA/ JIA under control?”



“If you had concerns about the suggested treatment, what were they?”



CHAPTER FIVE

# The Methotrexate Experience



## 503 participants are, or have been at some point, treated with methotrexate

“When you were initially prescribed methotrexate, were you given a choice of having it as oral tablets, oral liquid or an injection?”

**91%** said no

**95%** Were then initially prescribed **Oral** methotrexate

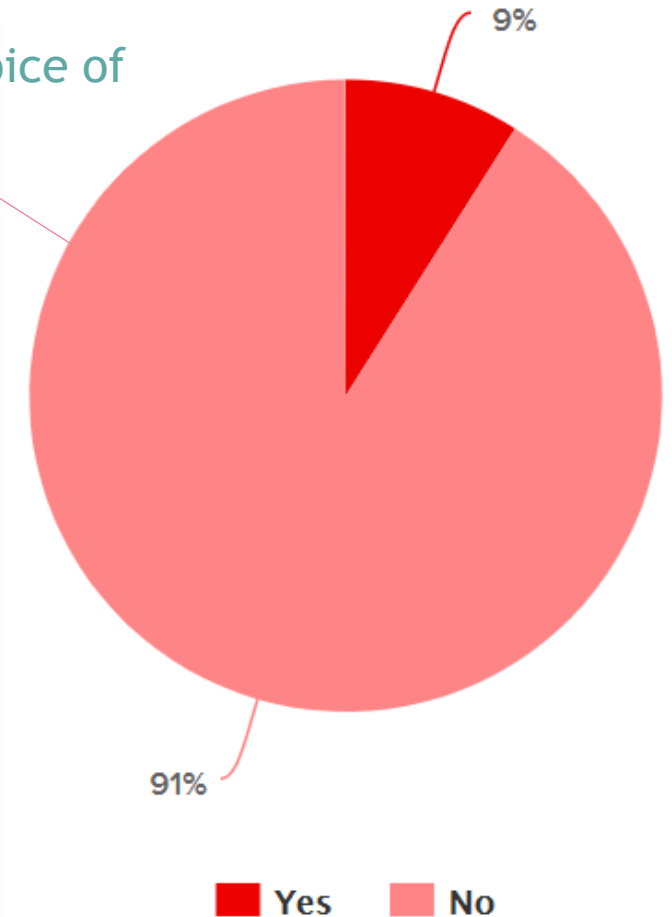
### 2015 comparison

In the 2015 survey...

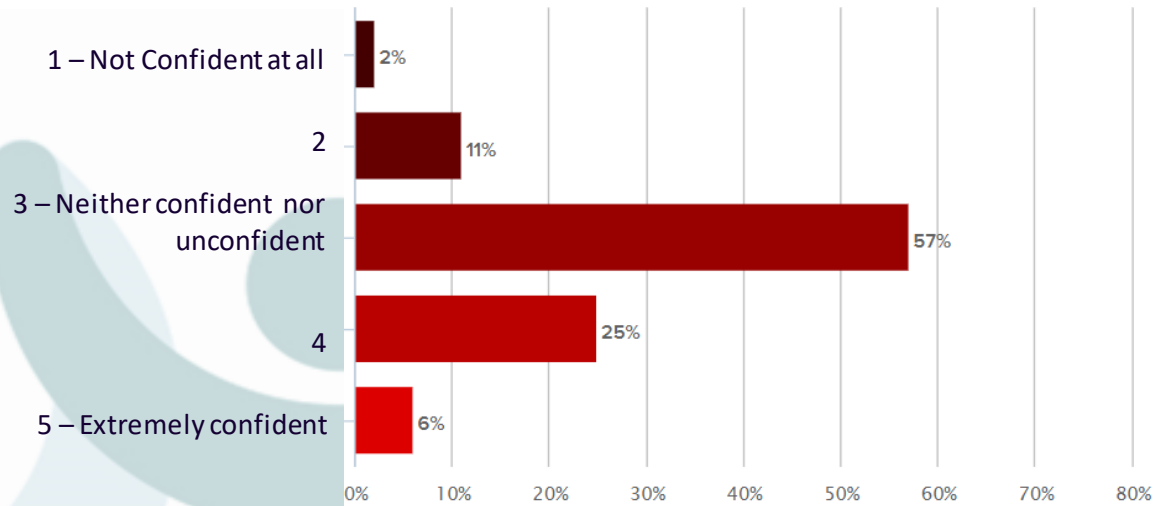
**93%** Of patients were not given a choice between oral or injectable methotrexate

**98%** Were then prescribed oral methotrexate

This suggests a slight (2%) increase in patients being given a treatment choice in the first consultation, and a very small increase (3%) in likelihood to be prescribed injectable methotrexate, in recent years.

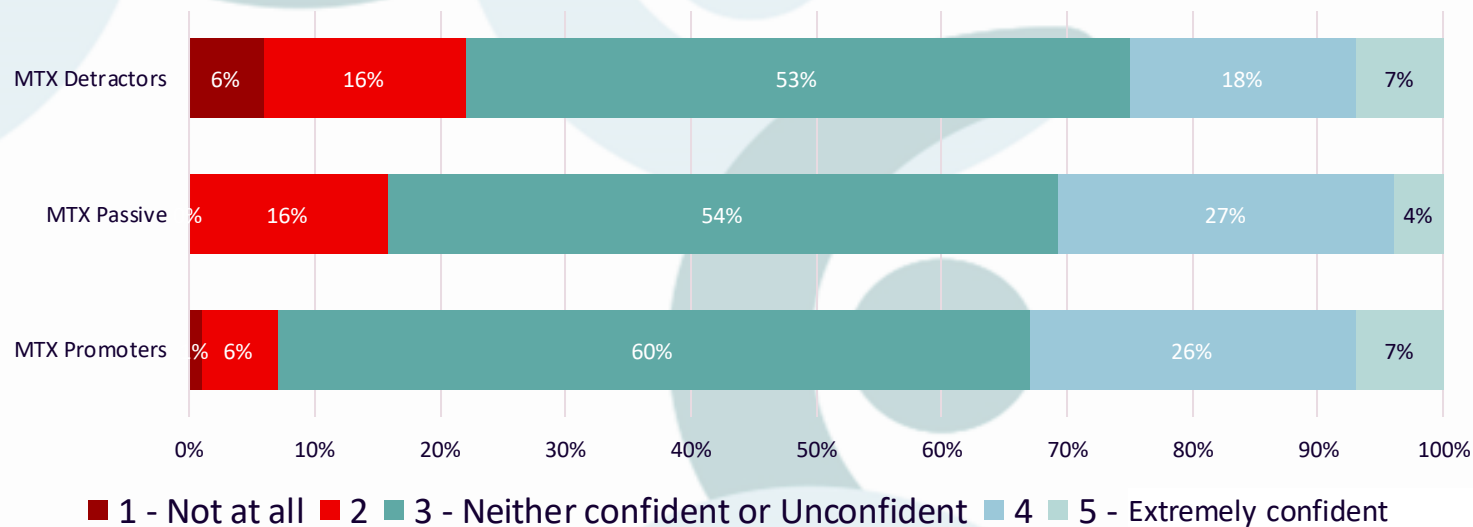


# “When you were prescribed methotrexate for the first time, were you confident that it would work?”



The majority (57%) report feeling neither confident nor unconfident about the treatment efficacy. 25% report some confidence. This is higher amongst MTX Promoters. A lack of confidence is more likely amongst people who go on to respond negatively towards MTX.

Having been informed about the next treatment options, should methotrexate fail, does **not** have a significant impact on patient’s confidence in the treatment. Similarly, having undertaken personal research does **not** have statistically significant impact on treatment confidence.



## 2015 comparison

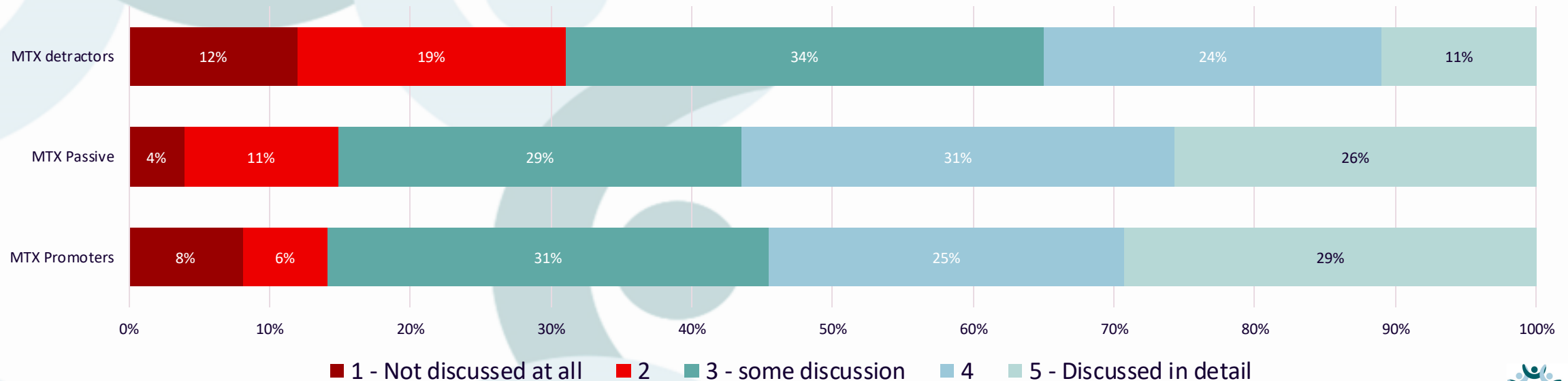
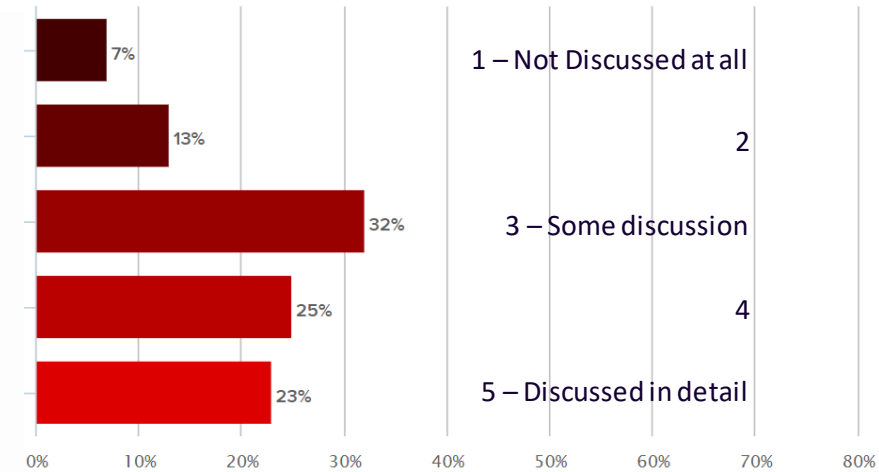
Patients in the 2015 survey showed a greater level of confidence in their prescribed methotrexate treatment, with **13%** being ‘extremely confident’. **15%** had low or no confidence in their MTX treatment.

# “Did your consultant/nurse discuss the benefits of methotrexate before prescribing it?”

20% of patients report that the benefits of MTX treatment received little to no discussion.

**2015 Comparison:** Information level regarding MTX benefits has increased over the past 6 years. In 2015, 36% reported receiving little to no information on benefits, and 37% considerable to detailed information.

Particularly MTX promoters state that their consultant did discuss about the benefits of treatment options, with 31% describing a significant level of discussion, compared to 14% of those with a negative perception of MTX.

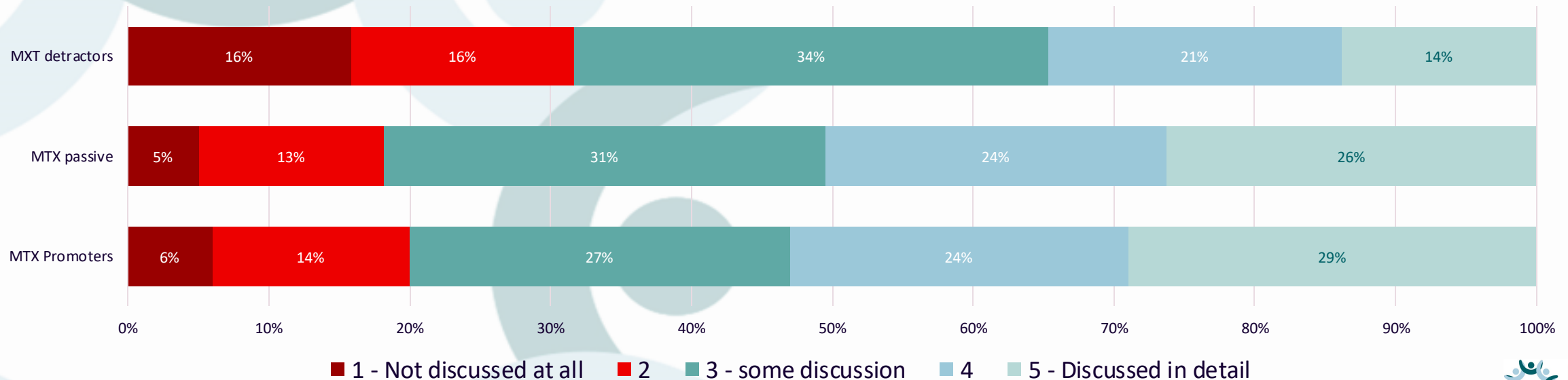
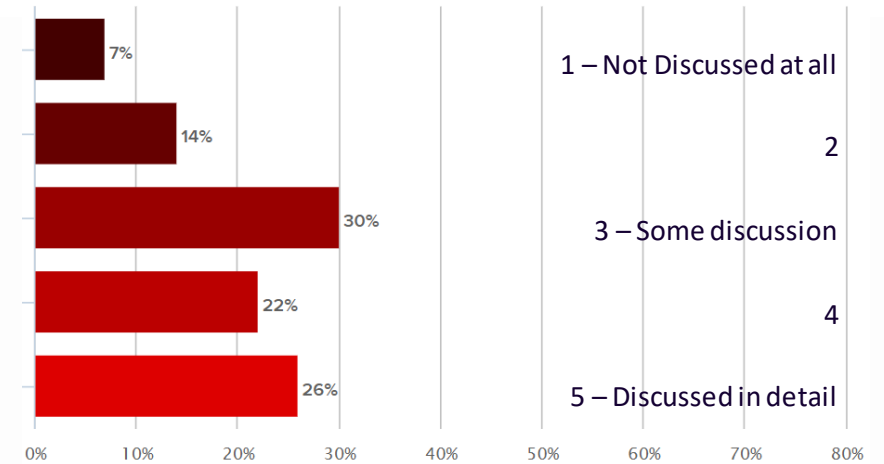


# “Did your consultant/nurse discuss the possible side effects of methotrexate before prescribing it?”

**21%** of patients report that the side effects of MTX treatment received little to no discussion. **26%** of responders report that side effects were discussed in detail.

**2015 Comparison:** Information level regarding MTX side effects has increased over the past 6 years. In 2015, **47%** reported receiving little to no information, with **21%** having had detailed discussion.

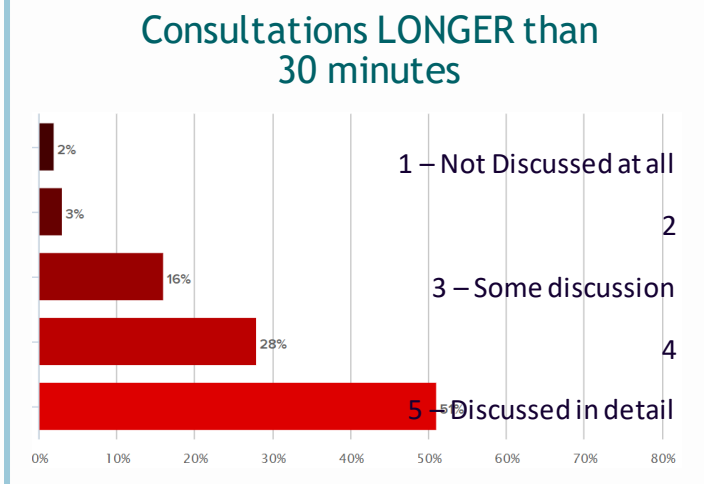
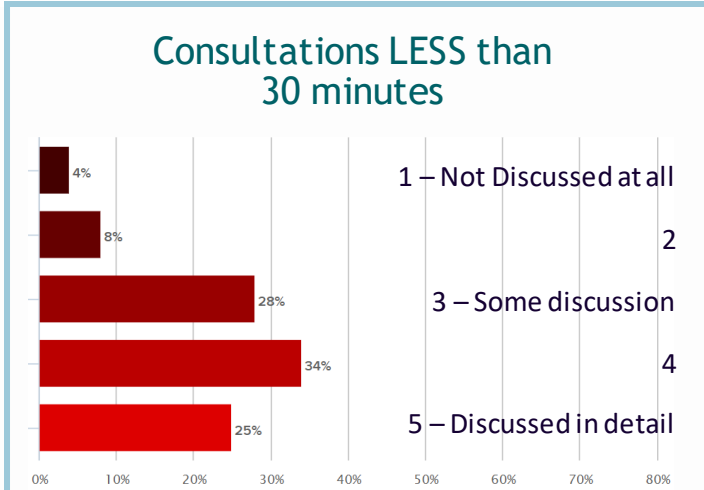
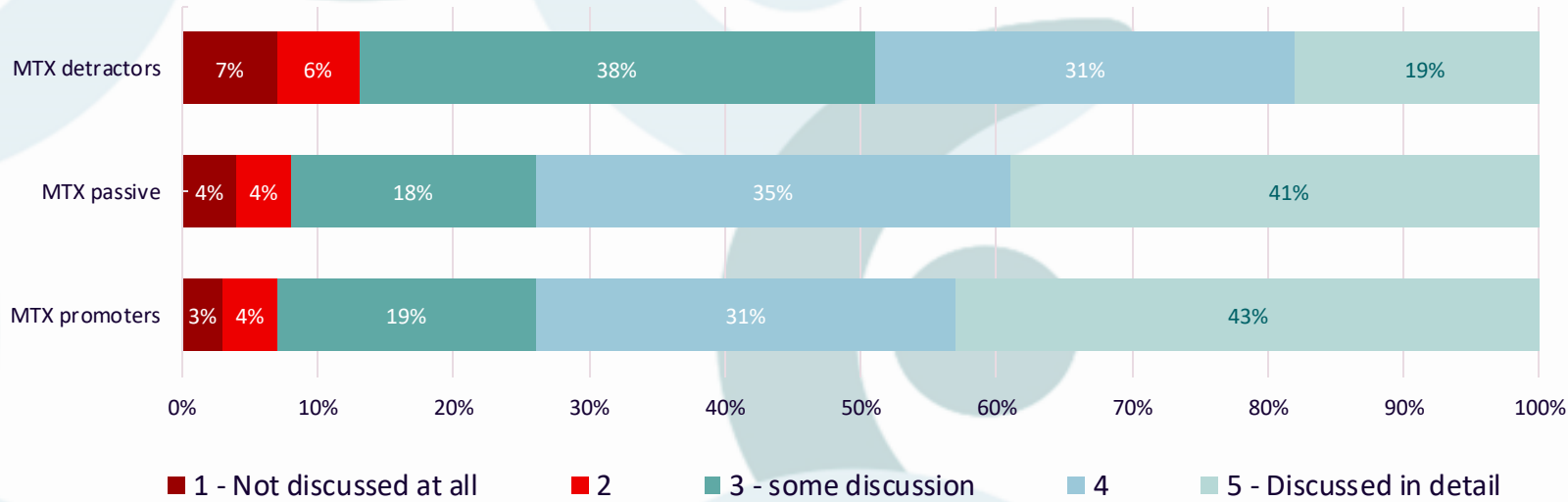
**More MTX promoters state that their consultant discussed the side effects of treatment in detail, 29% in comparison to 14% of those with a negative perceptive of MTX.**



# “Did your consultant/nurse discuss when prescribing methotrexate, the possible length of time that methotrexate may take to work/before you may expect to experience symptom improvement?”

On the whole, patients report receiving comprehensive information about the length of time taken to work, with 68% reporting significant to detailed discussion. The likelihood of detailed discussion increases with consultation duration. Only 9% report little to no discussion.

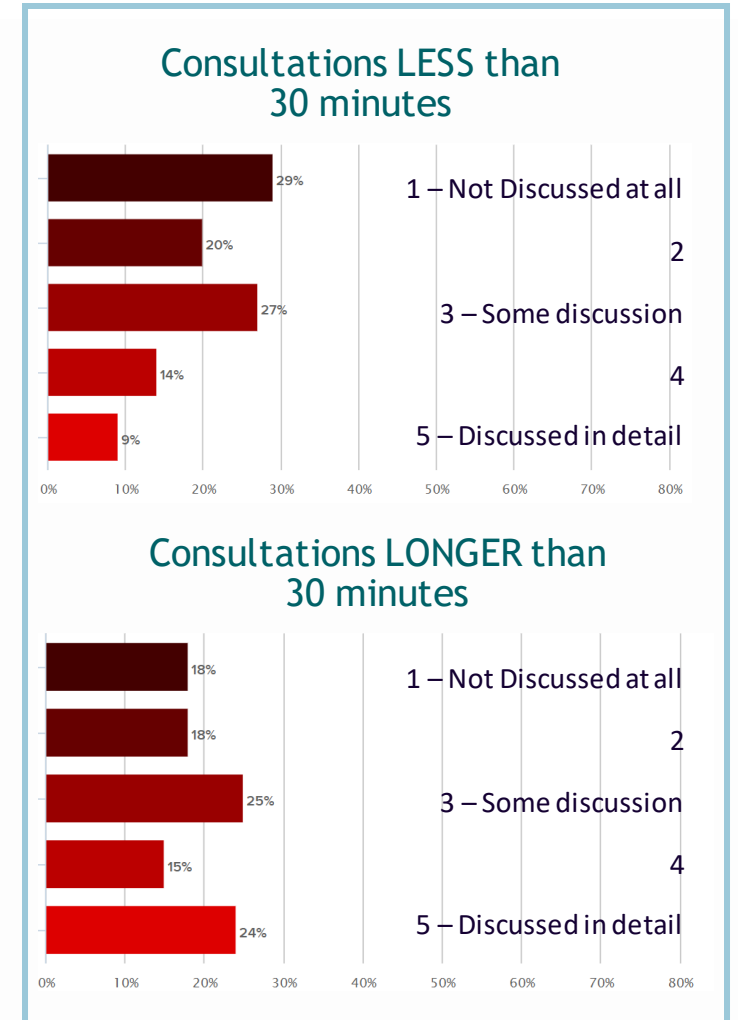
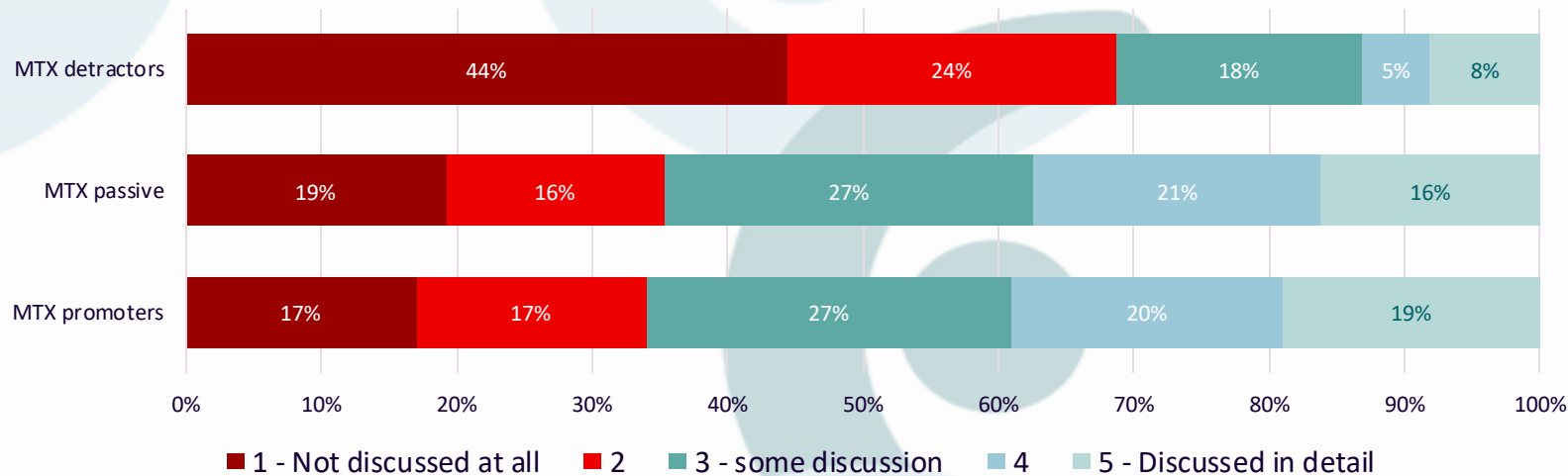
**Significantly more MTX promoters state that their consultant discussed the length taken for treatment to work in detail - 43% in comparison to 19% of those with a negative perceptive of MTX.**



# “Did your consultant/nurse discuss the impact of missed doses on the effectiveness of methotrexate before prescribing it?”

Overall, 25% of patients report receiving NO information regarding the impact of missed doses on methotrexate effectiveness. This is twice as likely to occur in a consultation lasting less than 30 minutes in duration. In total, 16% report receiving detailed information, and 15% significant information.

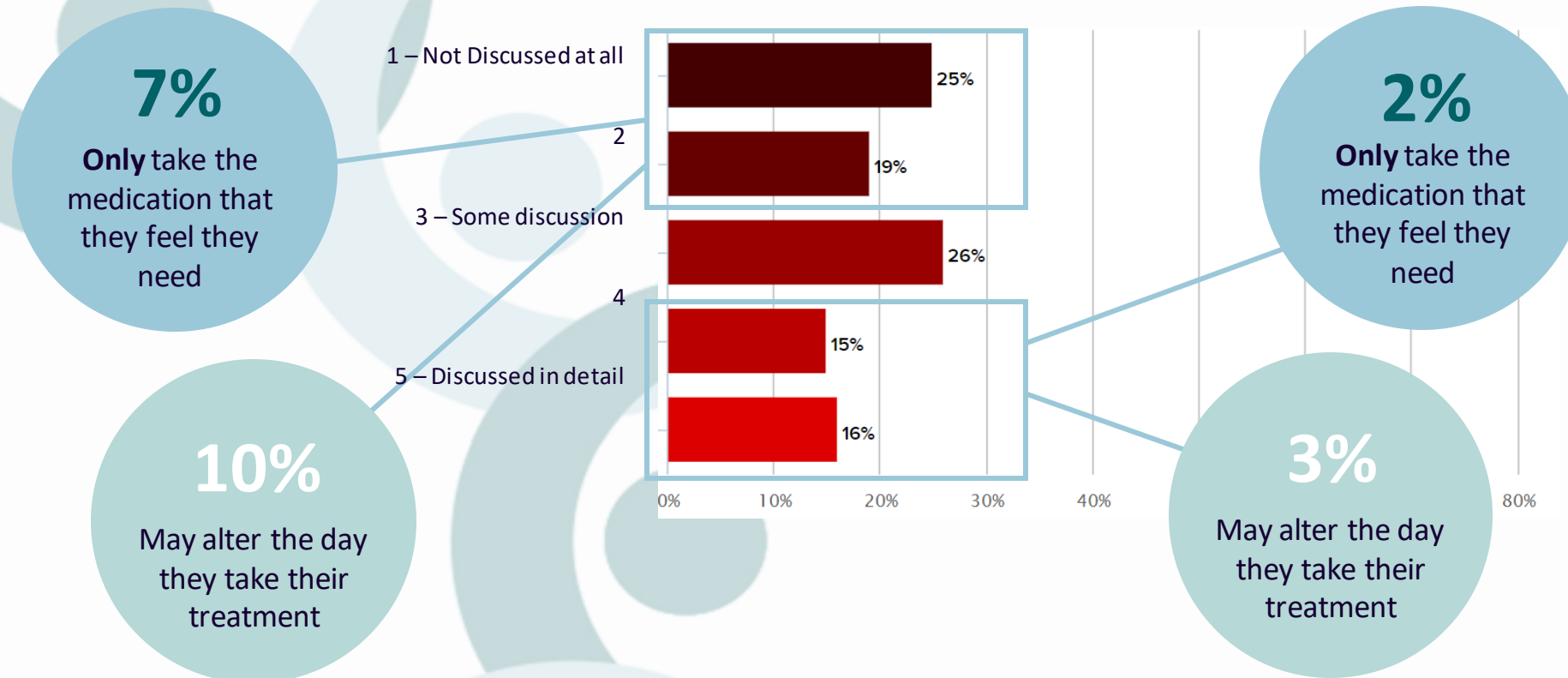
MTX detractors are over twice as likely to have received no information about the impact of missed doses on Methotrexate effectiveness – 44% compared to 17% of methotrexate promoters.





# “Did your consultant/nurse discuss the impact of missed doses on the effectiveness of methotrexate before prescribing it?”

The level of information provided at the first consultation has a knock-on effect on the way patients take their medications. **Patients who received little to no information about the impact of missed doses report a higher level of deviation from prescribed treatment.**



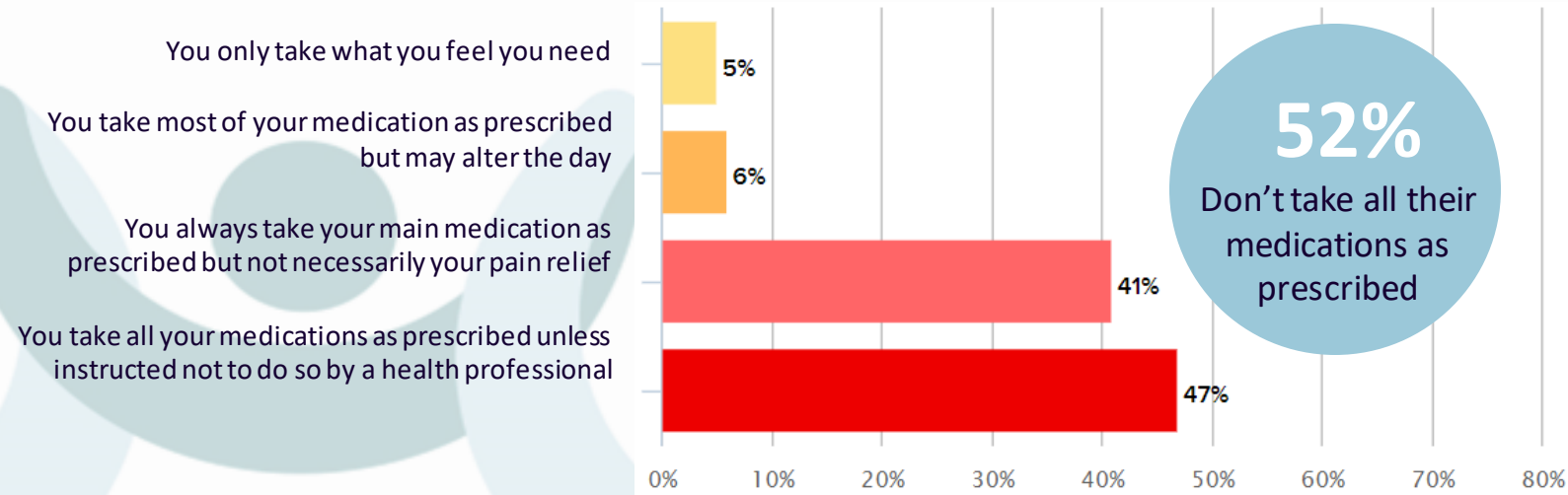
## In conclusion...

Patients who receive detailed information about the **benefits, side effects and time taken to work** are more likely to respond positively to methotrexate. **More information results in better adherence.**

Patients who receive little/no information about the **impact of missed doses** are more likely to not directly follow their prescribing advice and are also more likely to respond negatively to methotrexate.

# Adherence Issues

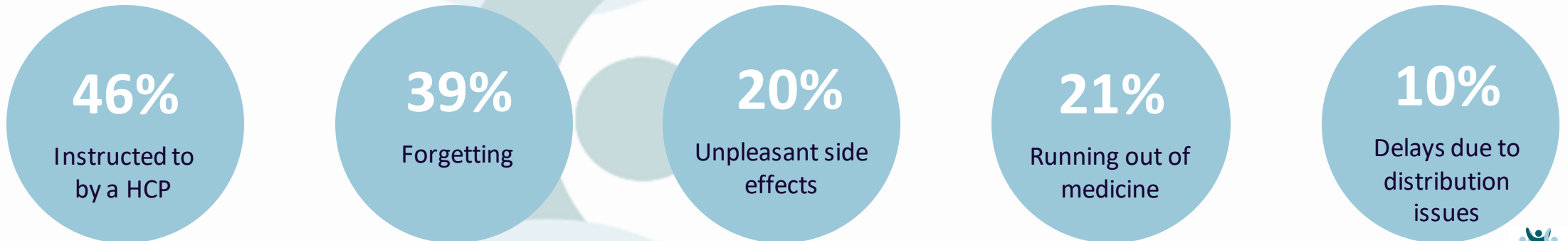
“Which of the following statements best describes how you take your medications now?”



**Other causes:**

- 4% Work or social commitment
- 4% Going on holiday
- 5% Reducing medication intake by increasing intervals
- 6% Starting on another medication
- 1% Difficulty using autoinjector due to painful hands
- 2% Not wanting to reduce alcohol intake

“What would be the main reason(s) you would MISS/SKIP a dose?”

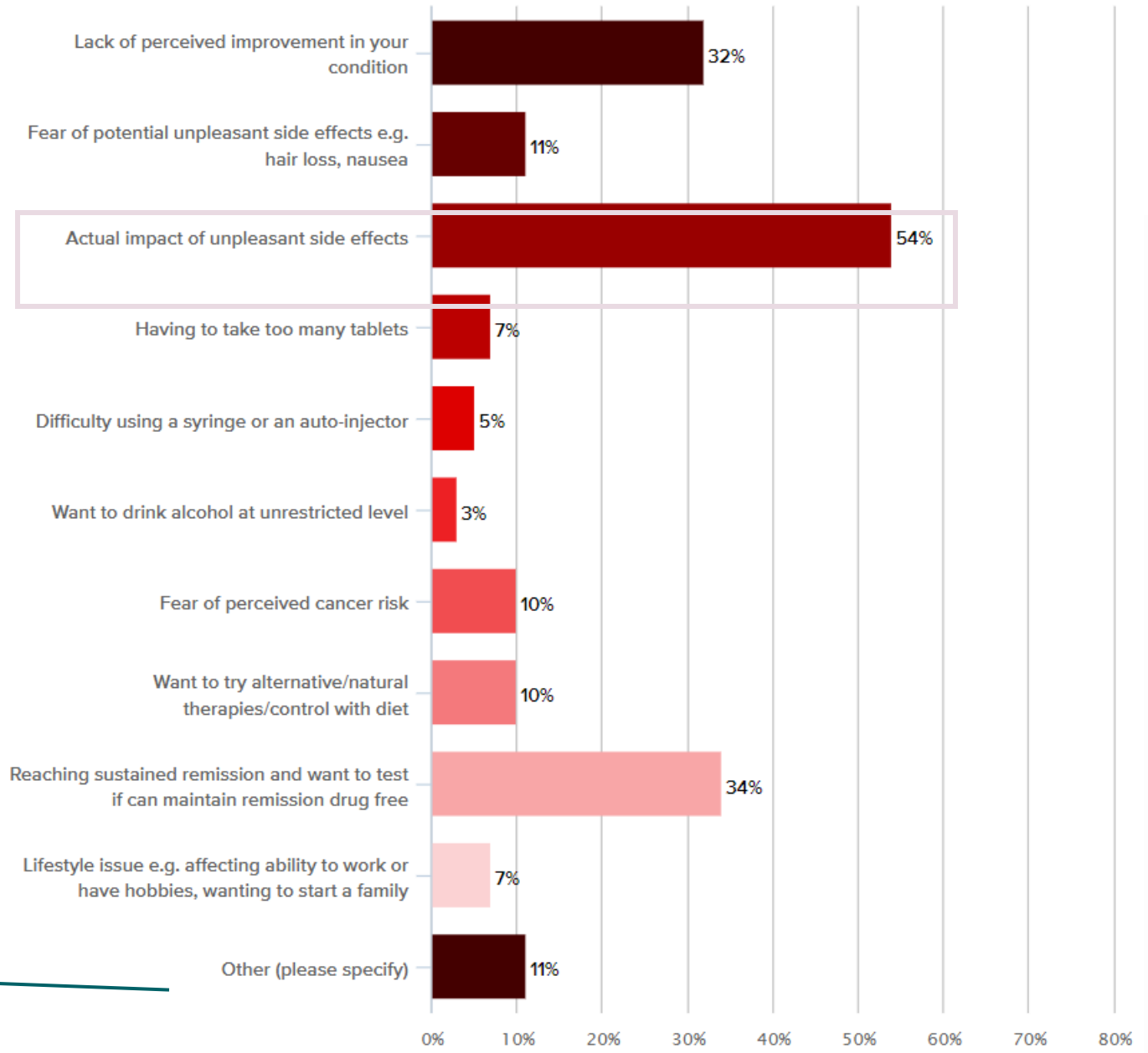


# Adherence Issues

“What would be the main reason that you would stop treatment all together?”

The majority of patients, 54%, cite unpleasant side effects as a main reason for stopping a treatment all together.

There does not seem to be any correlation between these people and the topics or level of information received during the consultation.



“Wanting to start a family”

“Breathlessness”

“Affecting ability to work”

“Lack of resources abroad”

“Problem’s socialising”

## Methotrexate Research

**78%** of methotrexate patients surveyed researched for more information on methotrexate before they committed to taking it. This is up a little bit from 73% in 2015.

### Main sources used:

**75%** Google/internet search

**71%** Hospital leaflet/booklet

**53%** NHS choices

**30%** Social media – up from just 6% in 2015

**21%** Patient organisations

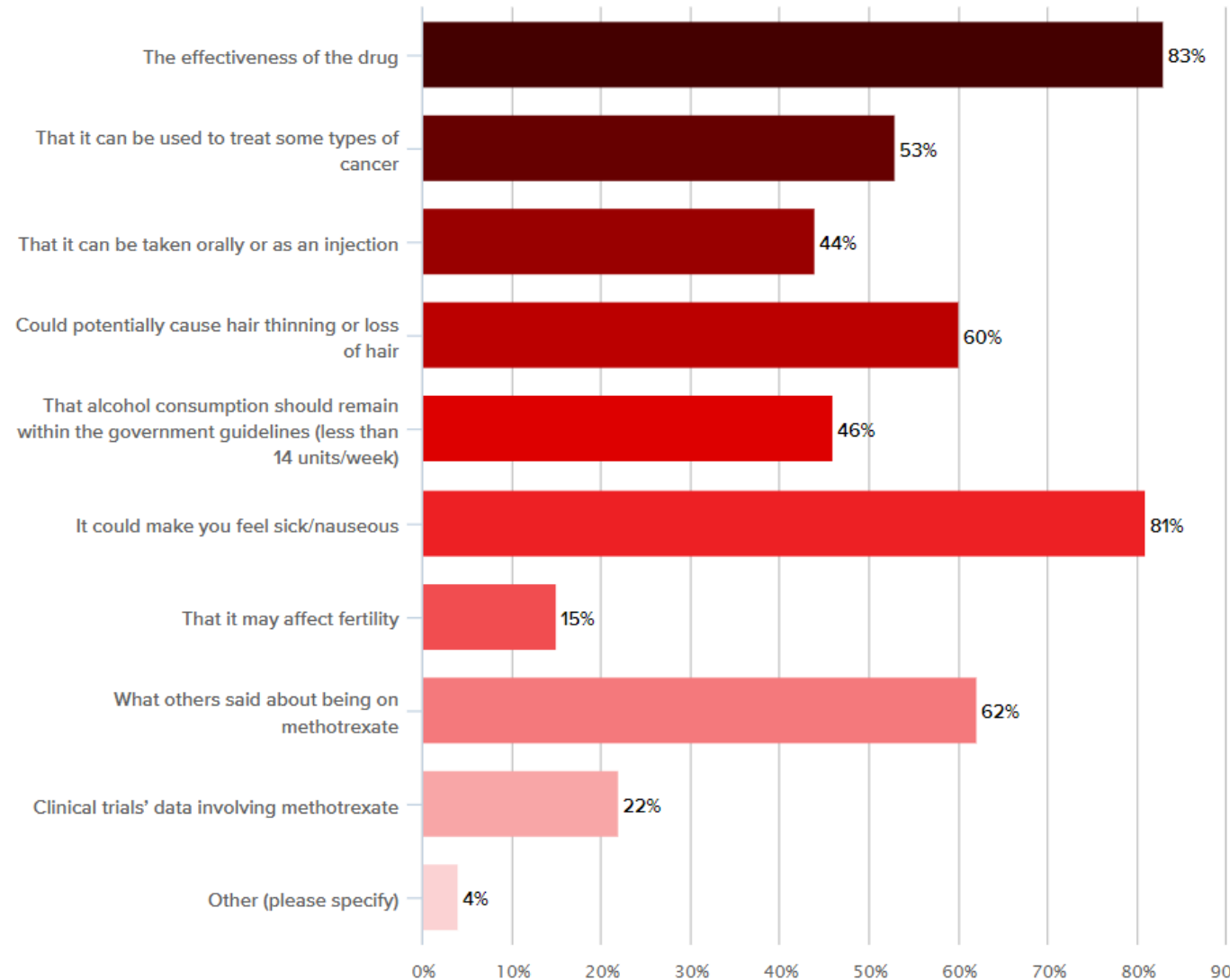
**21%** Patient.co.uk

**20%** Manufacturer's websites

**11%** Friends and family

**7%** Printed press

### Areas researched:



## Methotrexate Concerns

“How concerned were/are you about the following statements relating to methotrexate?”

	1 - Not concerned at all	2	3 - Somewhat concerned	4	5 - Extremely concerned
Higher dose Methotrexate can be used to treat some types of cancer	20%	15%	33%	18%	14%
Alcohol consumption should remain within the recommended guidelines (less than 14 units/week) whilst being treated with methotrexate	47%	25%	14%	9%	6%
Some people may experience hair thinning/loss whilst being treated with methotrexate	9%	14%	35%	22%	20%
You should not fall pregnant/or father a child whilst being treated with methotrexate	75%	7%	8%	3%	7%
Methotrexate can impact liver function	1%	6%	33%	32%	27%

## Alcohol consumption

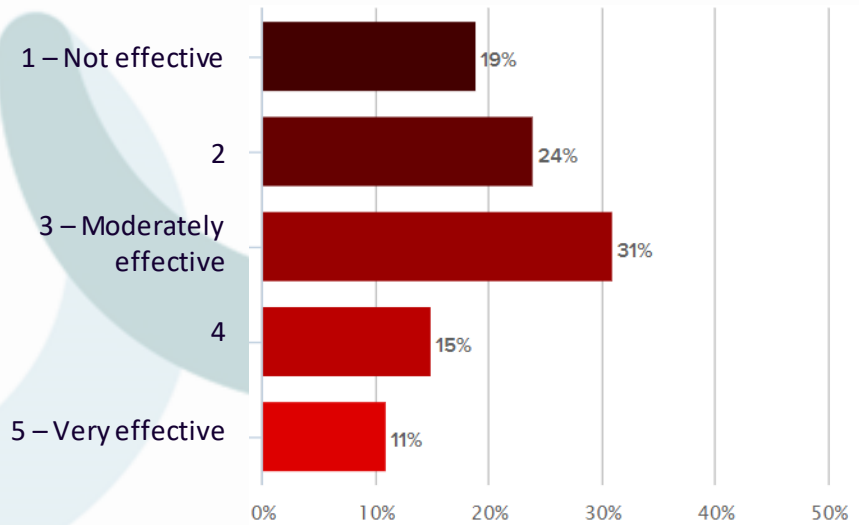
“Approximately how many units of alcohol do/did you consume per week?”

Units	Before Methotrexate	Whilst on Methotrexate
None	31%	51%
1 - 5	35%	28%
6 - 10	13%	12%
11 - 15	10%	6%
16 - 20	8%	2%
More than 20	4%	1%

Overall, alcohol consumption dropped whilst on methotrexate, with 51% drinking no alcohol at all during treatment.

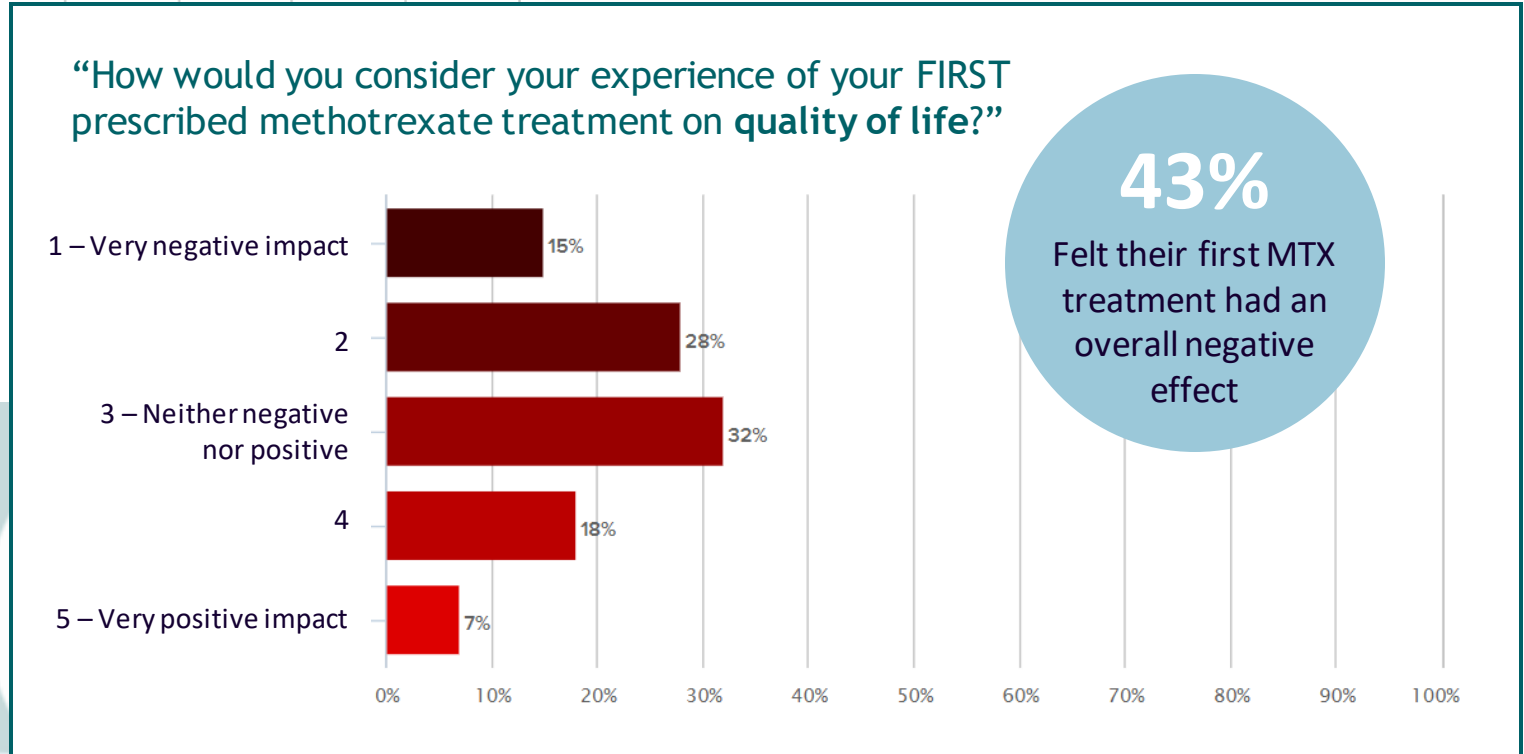
# Methotrexate Impact

“How would you consider the effectiveness of your first prescribed methotrexate treatment in relieving symptoms?”



**43%** Felt little to no improvement to their symptoms

**26%** Felt that their symptoms were improved

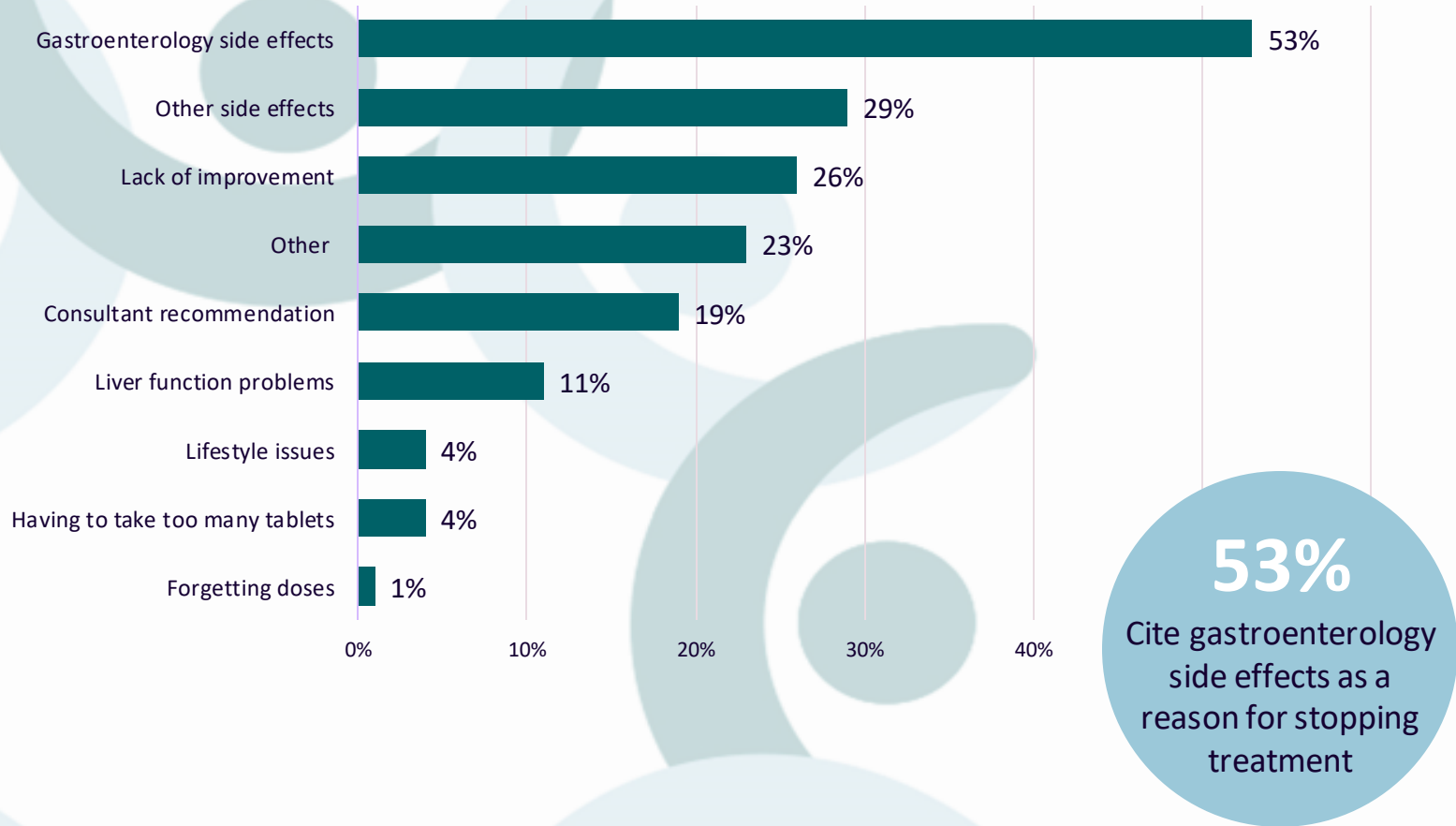




# Stopping Oral Methotrexate

358 participants had initially been prescribed oral methotrexate but later stopped - 71% of the total

“If initially prescribed oral methotrexate but no longer taking it, why did you stop?”



## Specified lifestyle issues

“I had no life I was like a zombie and always poorly”

“Extreme fatigue effecting social life”

“Struggled with time off due to side effects”

“Wanting to start a family”

“Unable to function for two days after dose”

## In conclusion...

Only **25%** of patients who are first prescribed methotrexate feel as though it has had a **positive** impact on their quality of life.

**53%** of those who stop taking oral methotrexate cite gastroenterology side effects as a main reason for stopping treatment.

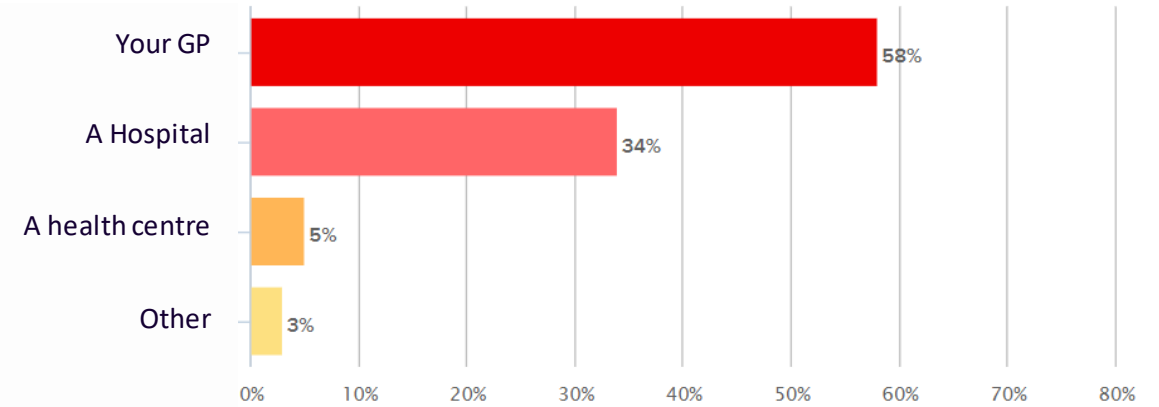
CHAPTER SIX

# The Impact of the COVID-19 Pandemic



# Blood Monitoring

“Whilst being treated with methotrexate, where did/do you go to receive your blood monitoring tests?”

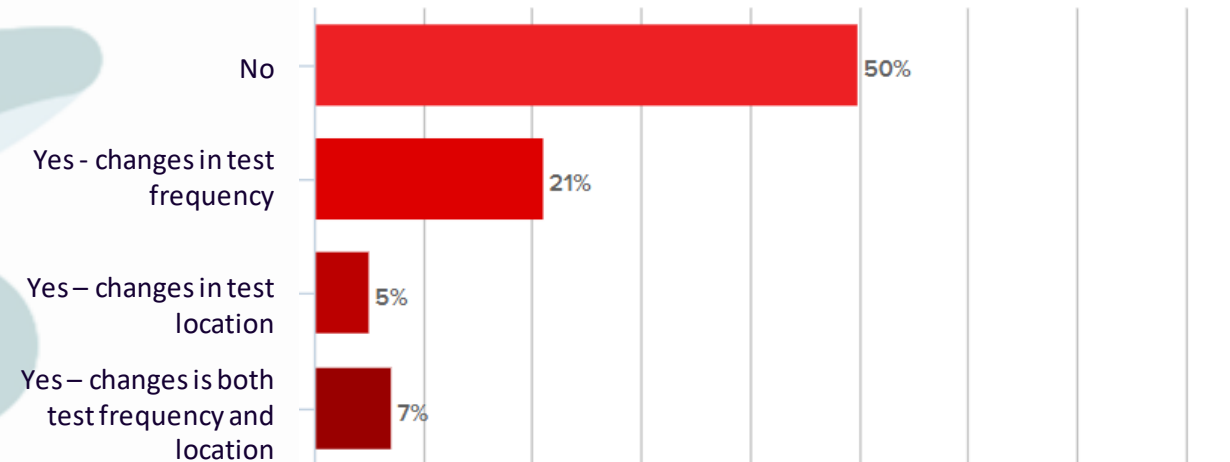


“If treated with methotrexate during the past year, has/had your blood monitoring changed as a result of the COVID-19 pandemic?”

16% of respondents had not been treated with methotrexate during the COVID-19 pandemic

Additional responses include:

- Delays in starting blood tests
- Delay/difficulty receiving results



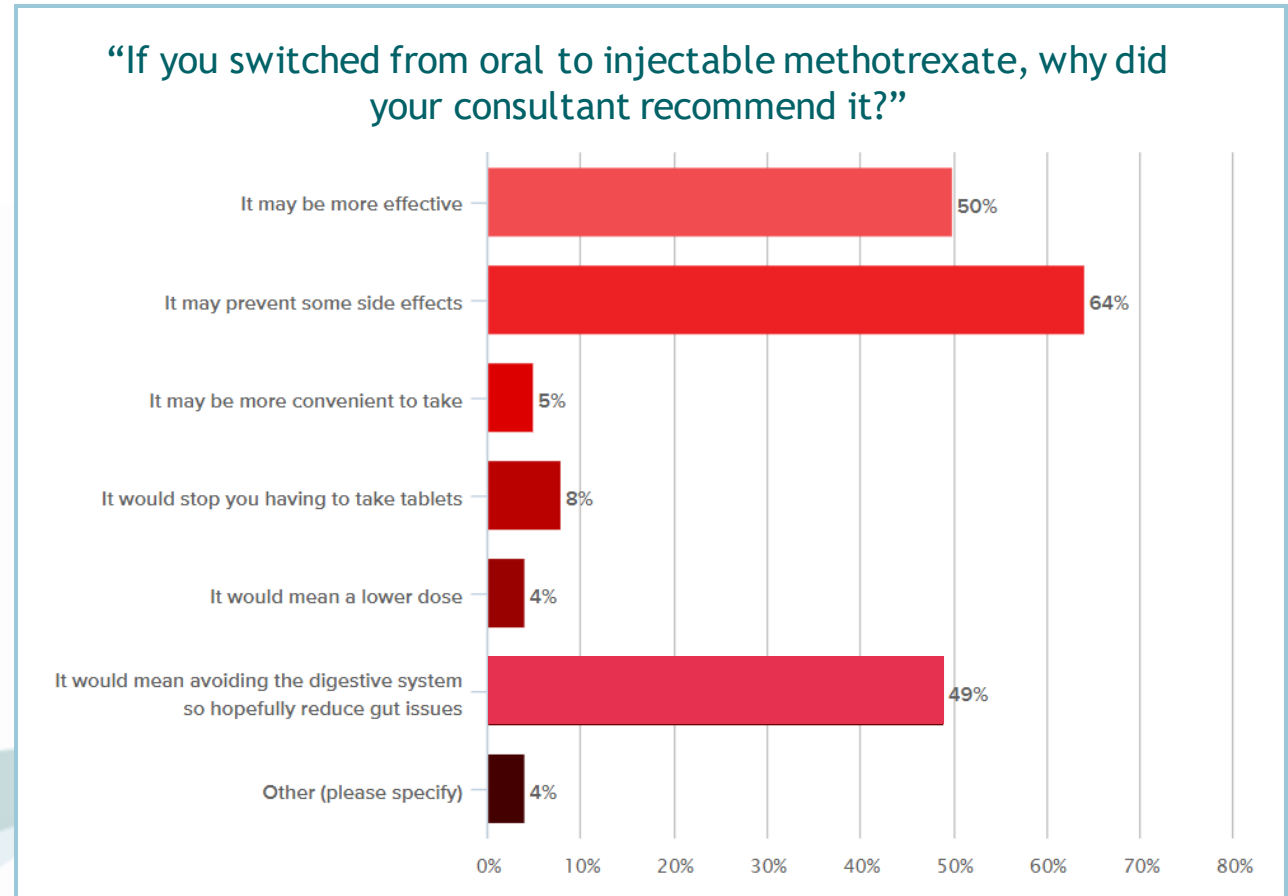
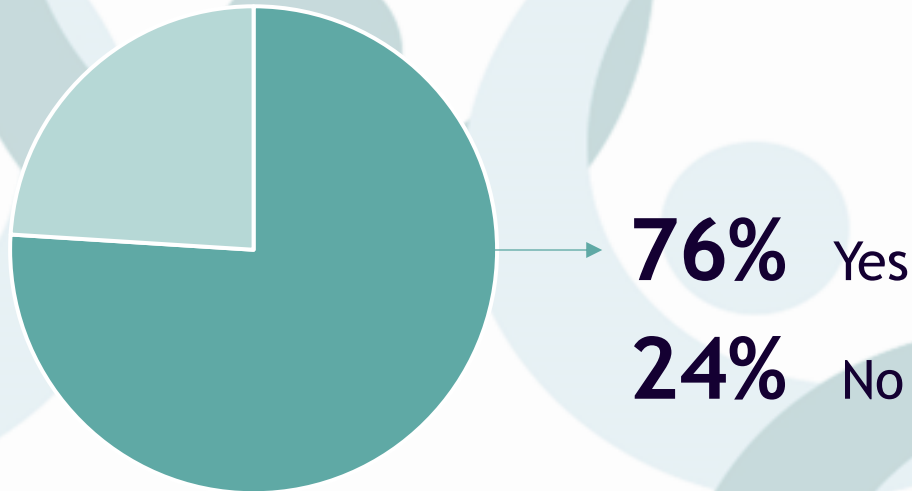
CHAPTER SEVEN

# Switching from Oral to Injectable Methotrexate



## Stopping Oral Methotrexate

“If you were first prescribed oral methotrexate but later stopped, were you given the choice to go onto Injectable methotrexate?”



**2015 comparison** In the 2015 survey...

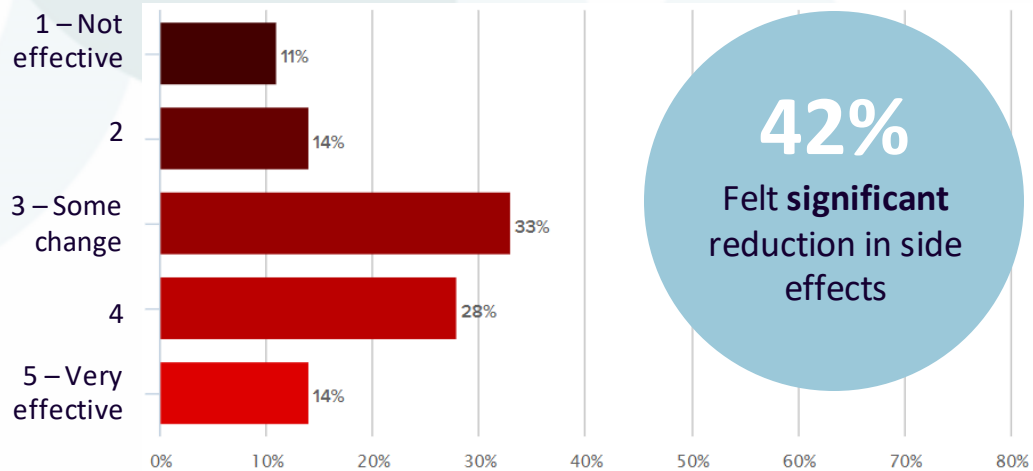
**64%** Of patients in the 2015 survey **were given the choice to switch** to injectable methotrexate. This shows a slight increase in the likelihood of HCPs to prescribe alternative treatment routes in recent years.

# Switching from oral to injectable methotrexate

224 participants then switched to injectable methotrexate

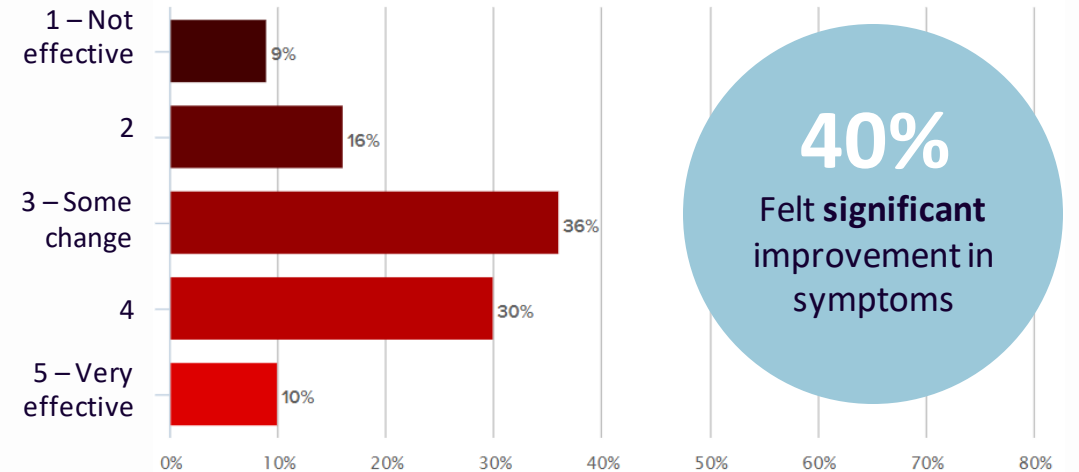
## Side Effect Reduction

“Having switched from oral methotrexate, how would you consider the effectiveness of Injectable methotrexate treatment in **reducing some side effects?**”



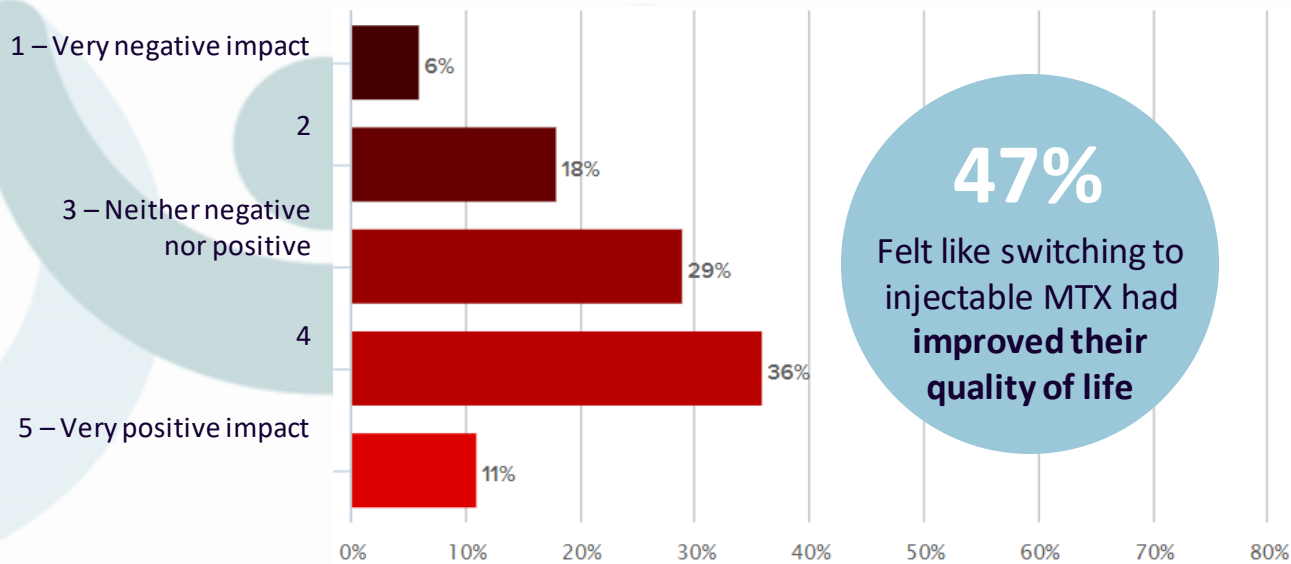
## Symptom Improvement

“Having switched from oral methotrexate, how would you consider the effectiveness of Injectable methotrexate treatment in **relieving your symptoms?**”



# Switching from oral to injectable methotrexate

“Having switched from oral methotrexate, how would you consider your experience of your Injectable methotrexate treatment on quality of life?”

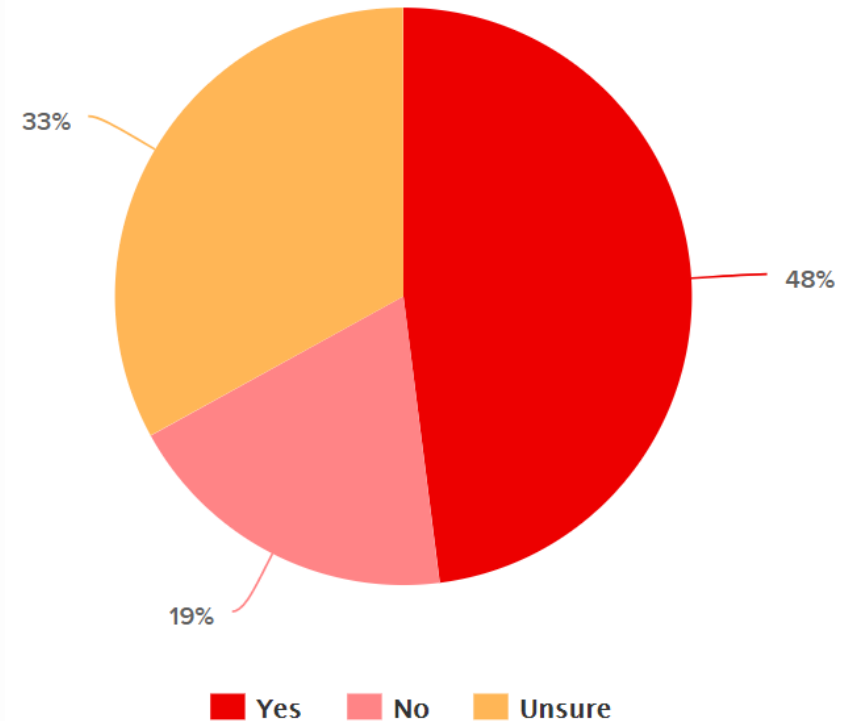


**48%**

Would have initially chosen an injectable treatment route if given the choice

**2015 Comparison:**  
This is a significant increase, from 28% of patients surveyed within the 2015 survey.

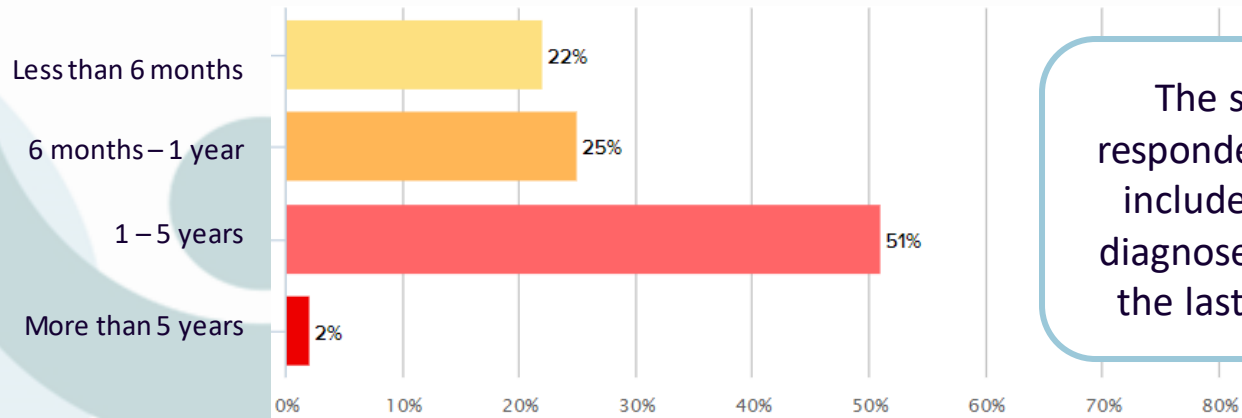
“If you had known about the option of Injectable methotrexate at the start of your treatment, would you have chosen this route rather than oral methotrexate initially?”





## Receiving injectable methotrexate

“How long have you been/were you taking injectable methotrexate?”

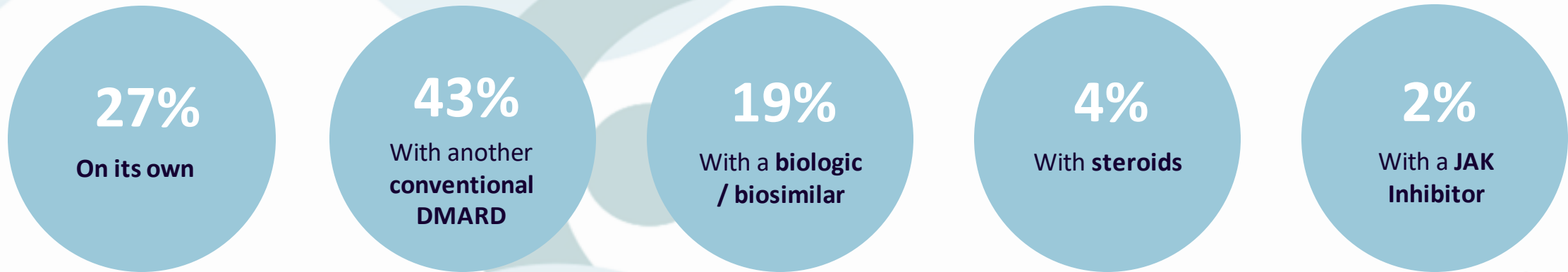


The survey respondents only includes those diagnosed within the last 5 years

“By which distribution method did/do you receive your methotrexate injection prescription?”

- 28%** Homecare delivery
- 18%** Hospital pharmacy
- 51%** Local pharmacy
- 1%** Administered in hospital
- 2%** Other

“How are/were you taking injectable methotrexate?”



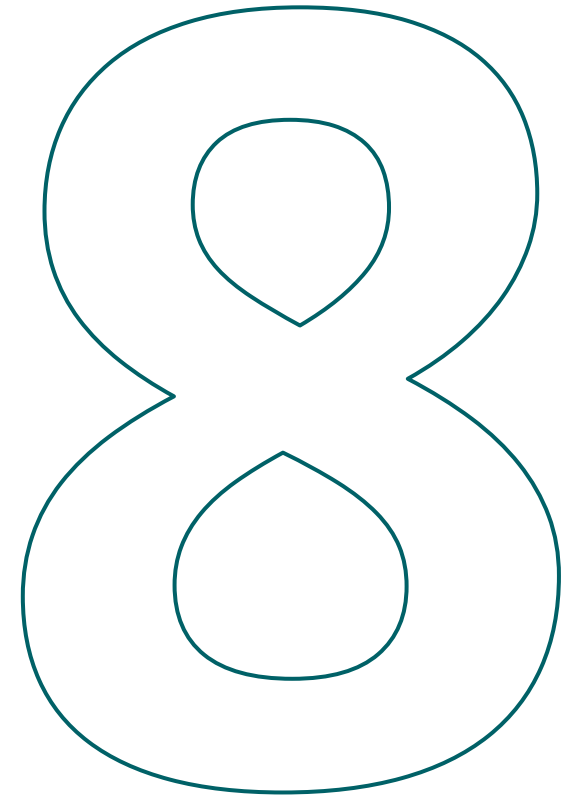
## In conclusion...

Over 40% of patients who switched from oral to injectable methotrexate felt as though it had a **positive** impact on the reduction of their side effects, as well as improving their symptoms.

**47%** feel as though it had a positive impact on their quality of life, and **48%** would have chosen this route initially if given the choice.

CHAPTER EIGHT

# Comparisons with the 2015 survey



# Then and Now – What has changed since the 2015 survey?

Overall, RA patients are less confident about their MTX treatment and express a reduction in shared decision making, than in 2015. Patients do however now receive more information in their consultations about MTX benefits and side effects. Whilst slightly more consultants are recommending switching to injectable after oral failure, far more patients would have preferred to start on injectable MTX initially.

2015 Survey Outcomes	2021 Survey Outcomes
A higher level of shared decision making was reported, with <b>34%</b> able to express all of their concerns.	This has reduced to <b>27%</b> , with more patients feeling as though they had little to no influence on the decision.
<b>13%</b> of patients prescribed MTX were “extremely confident” that their treatment would work in 2015.	This has reduced to just <b>6%</b> in this recent survey, showing a reduction in methotrexate confidence.
Fewer patients reported receiving significant information about MTX benefits and side effects, <b>37%</b> and <b>29%</b> respectively.	Both having risen to <b>48%</b> suggests an increase in information level discussed at consultation.
<b>64%</b> of patients who stopped oral methotrexate were given a choice to switch to injectable.	This has increased slightly to <b>76%</b> , showing more HCPs considering treatment administration routes.
<b>28%</b> of patients would have chosen the injectable route if they had been given the choice.	A significant increase has taken place over 6 years, to <b>48%</b> in this recent survey.

# THANK YOU!

**Developed with an educational grant from medac Pharma**

For more information about this survey or for press enquiries, please contact Sophie Hulf, at [Sophie.hulf@emotiveagency.com](mailto:Sophie.hulf@emotiveagency.com)



**nrAS**  
National Rheumatoid  
Arthritis Society