Item S1. Patient Survey

Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)

A Patient Survey

Thank you for considering taking part in this survey. The survey is focused on finding out how patients with vasculitis feel about the treatments they may be offered.

OPTIONS Vasculitis is being organized by researchers and patients from Canada, Switzerland, the United Kingdom, and the United States. We are trying to understand how patients with ANCA associated vasculitis (sometimes called granulomatosis with polyangiitis [GPA], Wegener's granulomatosis, or microscopic polyangiitis [MPA]) make decisions about treatments they might be offered.

Patients from around the world with vasculitis and patients with other kidney diseases are participating in OPTIONS Vasculitis. OPTIONS Vasculitis can only be completed online. Participating in OPTIONS Vasculitis is completely voluntary.

If you are eligible and agree to complete this survey, you will first answer a few questions about yourself and your past medical treatment.

In the next part of the survey, you will be asked to imagine that you have just been diagnosed with ANCA associated vasculitis and that your doctor is explaining the potential harms and benefits of a treatment called plasma exchange. After the explanation, you will decide whether you would choose plasma exchange or not.

After you answer, you will be given the same imaginary scenario but with the harms and benefits changed slightly. You will then, once again, be asked whether you would choose plasma exchange or not again.

There are five imaginary scenarios in total.

The survey takes about 15 minutes to complete.

Your answers will be used anonymously to help researchers and health care providers understand how patients make choices about treatments. No one will be able to identify you from your answers. Because the survey is anonymous, once you submit your answers, we cannot change or remove them. By completing this survey, your consent to participate is implied.

Only the study researchers have access to the data on SurveyMonkey, a platform which has high standards for security. Data is encrypted in transit and will not be disclosed to any third parties. All personal health information is confidential and private.

OPTIONS Vasculitis was reviewed and approved by the Hamilton Integrated Research Ethics Board, REB #2170. If you have any questions about the survey, you can email us at optionsvasculitis@gmail.com or call 204-632-3664.

Sincerely,

Dr. Mark Little, Dr. Reem Mustafa, Dr. Lynn Fussner, Dr. Alexa Meara, Dr. Gordon Guyatt, Dr. David Jayne, Dr. Peter Merkel, Dr. Michael Walsh
* 1. I am interested in participating in this study.
Yes
○ No
* 2. I understand and agree that my answers will be used anonymously for research purposes only.
Yes
○ No
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)
A Patient Survey
* 3. You may only participate in OPTIONS Vasculitis once. Is this the first time that you are completing the survey?
Yes
O No
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)
PART 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES
4. How old are you?
18

Dr. David Collister, Mark Farrar, Lesha Farrar, Paul Brown, Michelle Booth, Tracy Firth, Dr. Alfred Mahr,

* 5. \	What best describes you?
	Male
	Female
\bigcirc	Other
\bigcirc	Prefer not to say
* 6. \	What country do you live in?
	Canada
	United States
	United Kingdom
\bigcirc	Other (please specify)
	tions and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis
	tions and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis PTIONS Vasculitis)
(O	
(O PART	PTIONS Vasculitis)
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours):
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis Granulomatosis with polyangiitis (also called GPA or Wegener's granulomatosis)
(O PART	1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis Granulomatosis with polyangiitis (also called GPA or Wegener's granulomatosis) Microscopic polyangitis (also called MPA)
(O PART	1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis Granulomatosis with polyangiitis (also called GPA or Wegener's granulomatosis) Microscopic polyangiitis (also called MPA) Eosinophilic granulomatosis with polyangiitis (also called EGPA or Churg Strauss syndrome)
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis Granulomatosis with polyangiitis (also called GPA or Wegener's granulomatosis) Microscopic polyangitis (also called MPA) Eosinophilic granulomatosis with polyangiitis (also called EGPA or Churg Strauss syndrome) I am not certain what my vasculitis is called
(O PART	PTIONS Vasculitis) 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES have the following type of vasculitis (choose the diagnosis closest to yours): ANCA associated vasculitis Granulomatosis with polyangiitis (also called GPA or Wegener's granulomatosis) Microscopic polyangiitis (also called MPA) Eosinophilic granulomatosis with polyangiitis (also called EGPA or Churg Strauss syndrome) I am not certain what my vasculitis is called I do not have vasculitis

Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)

PART 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES

* 8. Has your vasculitis ever involved your kidneys?
Yes
○ No
☐ I don't know
* 9. Have you ever been on dialysis because of your vasculitis?
Yes
○ No
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)
PART 1: PARTICIPANT DEMOGRAPHICS AND DISEASE EXPERIENCES
* 10. Do you currently receive dialysis or have a kidney transplant?
Yes
○ No
* 11. Have you ever received plasma exchange? (sometimes also called PLEX, apheresis, pheresis, plasmapheresis or therapeutic plasma exchange)
Yes
○ No
☐ I don't know
* 12. Have you ever had an infection that required intravenous antibiotics?
Yes
○ No
☐ I don't know
* 13. Have you ever had an infection that required a hospitalization?
Yes
○ No
I don't know

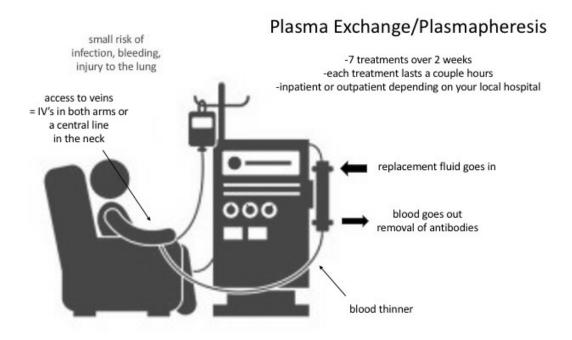
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)

PART 2: VALUES AND PREFERENCES REGARDING PLASMA EXCHANGE

Imagine you have been recently diagnosed with ANCA associated vasculitis. Your doctor explains that the disease is caused by your immune system attacking your own body and the attack causes inflammation that damages your organs. Your doctor says you should be treated with an immune suppressing drug and anti-inflammatory steroids and that most patients do well with this combination of treatments.

An additional treatment called plasma exchange is also available. Plasma exchange is a procedure that uses a machine to remove antibodies from your blood that might be contributing to your vasculitis. The machine replaces your plasma with a replacement fluid that does not have antibodies. You will get 7 treatments with the machine over the next 2 weeks.

Additional information regarding plasma exchange is shown in the picture below.



Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, but **no plasma exchange**, within 1 year:

2 will go on to develop kidney failure requiring permanent dialysis9 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

1 will go on to develop kidney failure requiring permanent dialysis (that is 1 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 1 patient from needing dialysis for the rest of her or his life)

11 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 2 more patients will suffer a serious infection; in other words plasma exchange will cause 2 people in 100 to have an serious infection that they would not have had without the plasma exchange)

For more information about what life on dialysis is like, please visit:

https://www.nhs.uk/conditions/dialysis/

In particular, see the section on side effects (https://www.nhs.uk/conditions/dialysis/side-effects/) so you can consider the potential consequences of being on dialysis versus the potential harms of plasma exchange.



kidney failure = dialysis or transplant



no kidney failure no serious infection



serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 2/100

	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	•	0	•	0	•	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
9	0	0	•	0	0	0	•	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

Plasma exchange

Chance of kidney failure over 1 year 1/100

0	0	0	0	0	0	0	0	9	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	•	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

1 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year 9/100

	0	0	0	0		0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	•	0	0
0	0	0	0	9	0	0	0	0	0
0	0	0	•	0	0	0	0	0	•

Plasma exchange

Chance of serious infection over 1 year
2 11/100

0			0					0	0
	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

an additional
2 in 100
patients will
experience a
serious
infection with
plasma
exchange

* 14.	Based on the information above, would you choose to receive treatment with plasma exchange?
\bigcirc	Yes
\bigcirc	No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

8 will go on to develop kidney failure requiring permanent dialysis 18 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

5 will go on to develop kidney failure requiring permanent dialysis (that is 3 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 3 patients from needing dialysis for the rest of her or his life)

23 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 5 more patients will suffer a serious infection; in other words plasma exchange will cause 5 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

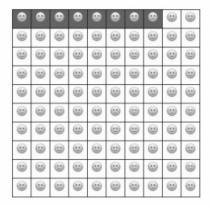


no kidney failure no serious infection



serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 8/100



Plasma exchange

Chance of kidney failure over 1 year \$\frac{1}{2}\$ 5/100

0	0	0	0		0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	9	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

3 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

18/100

	0	0	0	0	0	0		0	0
								0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	•	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	•	0	•	0	0	0	0	0	•
0	0	0	0	9	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

Plasma exchange

Chance of serious infection over 1 year 23/100

									0
			0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	9	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	9	0	0	0	9	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	•	0	0	0	0	0	0	0	0

an additional 5 in 100 patients will experience a serious infection with plasma exchange

* 15	. Based on the information above, would you choose to receive treatment with plasma exchange?
\Box	Yes
) No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

15 will go on to develop kidney failure requiring permanent dialysis 27 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

9 will go on to develop kidney failure requiring permanent dialysis (that is 6 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 6 patients from needing dialysis for the rest of her or his life)

34 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 7 more patients will suffer a serious infection; in other words plasma exchange will cause 7 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

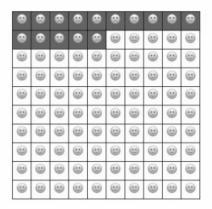


no kidney failure no serious infection



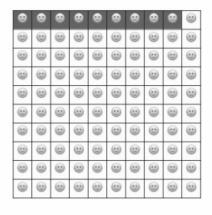
serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 15/100



Plasma exchange

Chance of kidney failure over 1 year 9/100

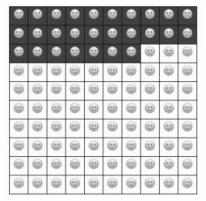


6 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection

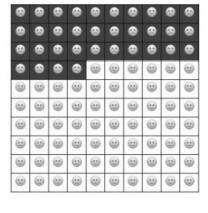
over 1 year 27/100



Plasma exchange

Chance of serious infection over 1 year

34/100



an additional 7 in 100 patients will experience a serious infection with plasma exchange

* 16	. Based on the information above, would you choose to receive treatment with plasma exchange?
\bigcirc	Yes
	No No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

28 will go on to develop kidney failure requiring permanent dialysis 36 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

17 will go on to develop kidney failure requiring permanent dialysis (that is 11 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 11 patients from needing dialysis for the rest of her or his life)

46 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 12 more patients will suffer a serious infection; in other words plasma exchange will cause 12 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

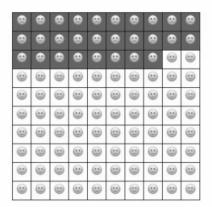


no kidney failure no serious infection



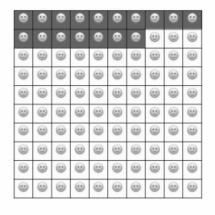
serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 28/100



Plasma exchange

Chance of kidney failure over 1 year 17/100

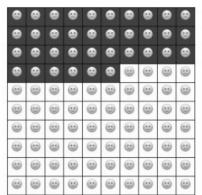


11 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

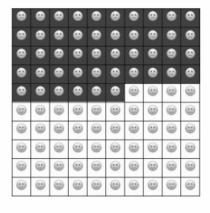
<u>9</u> 36/100



Plasma exchange

Chance of serious infection over 1 year

46/100



an additional 10 in 100 patients will experience a serious infection with plasma exchange

* 17	. Based on the information above, would you choose to receive treatment with plasma exchange?
\subset	Yes
\Box	No No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

40 will go on to develop kidney failure requiring permanent dialysis 50 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

25 will go on to develop kidney failure requiring permanent dialysis (that is 15 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 15 patients from needing dialysis for the rest of her or his life)

64 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 14 more patients will suffer a serious infection; in other words plasma exchange will cause 14 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

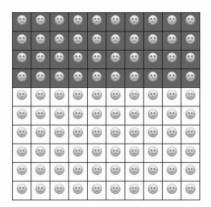


no kidney failure no serious infection



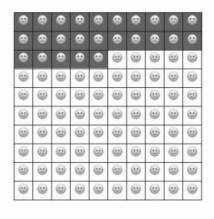
serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year
40/100



Plasma exchange

Chance of kidney failure over 1 year 25/100

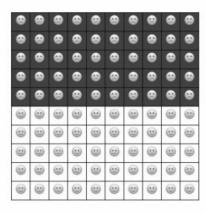


15 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

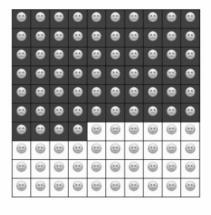
50/100



Plasma exchange

Chance of serious infection over 1 year

64/100



an additional
14 in 100
patients will
experience a
serious
infection with
plasma
exchange

* 18	Based on the information above, would you choose to receive treatment with plasma exchange?
\bigcirc	Yes
	\ No

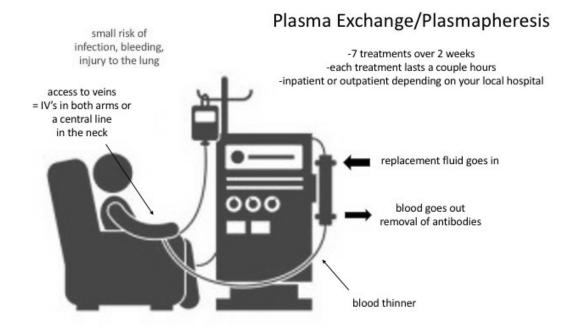
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis (OPTIONS Vasculitis)

PART 2: VALUES AND PREFERENCES REGARDING PLASMA EXCHANGE

Imagine you have been recently diagnosed with ANCA associated vasculitis. Your doctor explains that the disease is caused by your immune system attacking your own body and the attack causes inflammation that damages your organs. Your doctor says you should be treated with an immune suppressing drug and anti-inflammatory steroids and that most patients do well with this combination of treatments.

An additional treatment called plasma exchange is also available. Plasma exchange is a procedure that uses a machine to remove antibodies from your blood that might be contributing to your vasculitis. The machine replaces your plasma with a replacement fluid that does not have antibodies. You will get 7 treatments with the machine over the next 2 weeks.

Additional information regarding plasma exchange is shown in the picture below.



Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange.** within 1 year:

40 will go on to develop kidney failure requiring permanent dialysis 50 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

25 will go on to develop kidney failure requiring permanent dialysis (that is 15 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 15 patients from needing dialysis for the rest of her or his life)

64 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 14 more patients will suffer a serious infection; in other words plasma exchange will cause 14 people in 100 to have an serious infection that they would not have had without the plasma exchange)

For more information about what life on dialysis is like, please visit:

https://www.nhs.uk/conditions/dialysis/

In particular, see the section on side effects (https://www.nhs.uk/conditions/dialysis/side-effects/) so you can consider the potential consequences of being on dialysis versus the potential harms of plasma exchange.



kidney failure = dialysis or transplant

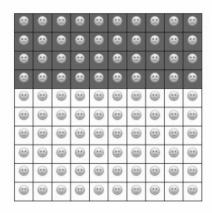


no kidney failure no serious infection



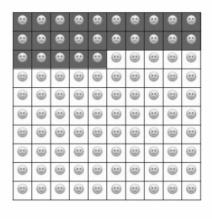
serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year
40/100



Plasma exchange

Chance of kidney failure over 1 year 25/100

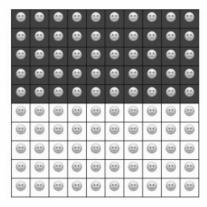


15 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

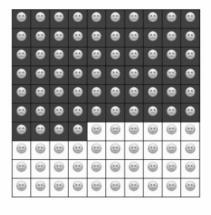
50/100



Plasma exchange

Chance of serious infection over 1 year

64/100



an additional
14 in 100
patients will
experience a
serious
infection with
plasma
exchange

* 19	. Based on the information above, would you choose to receive treatment with plasma exchange?
\bigcirc	Yes
	No No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

28 will go on to develop kidney failure requiring permanent dialysis 36 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

17 will go on to develop kidney failure requiring permanent dialysis (that is 11 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 11 patients from needing dialysis for the rest of her or his life)

46 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 10 more patients will suffer a serious infection; in other words plasma exchange will cause 10 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant



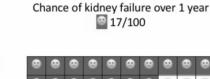
no kidney failure no serious infection



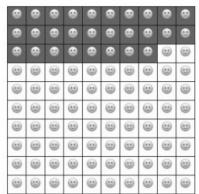
serious infection = admission to hospital or IV antibiotics

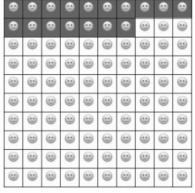
No plasma exchange

Chance of kidney failure over 1 year 28/100



Plasma exchange





11 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

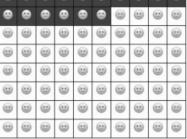
Chance of serious infection over 1 year

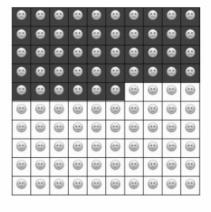
over 1 year 36/100

Plasma exchange

Chance of serious infection over 1 year

46/100





an additional 10 in 100 patients will experience a serious infection with plasma exchange

* 20. Base	ed on the information abo	ve, would you choose to	receive treatment with	plasma exchange?
Yes				
O No				

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, but no plasma exchange, within 1 year:

15 will go on to develop kidney failure requiring permanent dialysis 27 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

9 will go on to develop kidney failure requiring permanent dialysis (that is 6 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 6 patients from needing dialysis for the rest of her or his life)

34 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 7 more patients will suffer a serious infection; in other words plasma exchange will cause 7 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

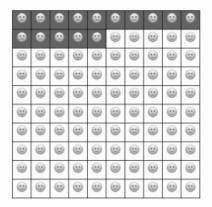


no kidney failure no serious infection



serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 15/100



Plasma exchange

Chance of kidney failure over 1 year 9/100

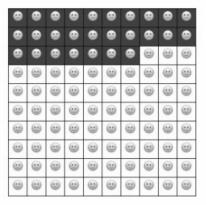
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0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

6 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

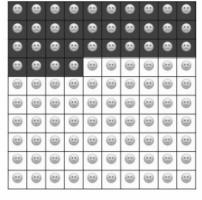
27/100



Plasma exchange

Chance of serious infection over 1 year

34/100



an additional 7 in 100 patients will experience a serious infection with plasma exchange

* 21. Based on the information above, would you choose to receive	treatment with plasma exchange?
Yes	
○ No	

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

8 will go on to develop kidney failure requiring permanent dialysis 18 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

5 will go on to develop kidney failure requiring permanent dialysis (that is 3 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 3 patients from needing dialysis for the rest of her or his life)

23 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 5 more patients will suffer a serious infection; in other words plasma exchange will cause 5 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

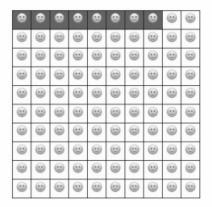


no kidney failure no serious infection



serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 8/100



Plasma exchange

Chance of kidney failure over 1 year \$\frac{1}{2}\$ 5/100

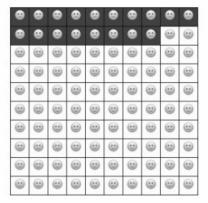
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0	0	0	0	0	0	0	0	0	0
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0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

3 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year

2 18/100



Plasma exchange

Chance of serious infection over 1 year 23/100

			0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	9	0	0	0	0	0
9	0	0	0	9	0	0	0	9	0
0	0	0	0	9	0	0	0	9	0
0	0	0	0	0	0	0	0	0	•
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

an additional 5 in 100 patients will experience a serious infection with plasma exchange

* 22.	. Based on the information above, would you choose to receive treatment with plasma exchange?
	Yes
	No No

Your doctor tells you that if 100 patients, just like you, are treated with an immune suppressing drug and anti-inflammatory steroids, **but no plasma exchange**, within 1 year:

2 will go on to develop kidney failure requiring permanent dialysis9 will have a serious infection requiring intravenous antibiotics or hospitalization

With plasma exchange, within 1 year:

1 will go on to develop kidney failure requiring permanent dialysis (that is 1 in 100 patients who would have required permanent dialysis will not require permanent dialysis – the treatment prevents 1 patient from needing dialysis for the rest of her or his life)

11 will have a serious infection requiring intravenous antibiotics or hospitalization (that is, 2 more patients will suffer a serious infection; in other words plasma exchange will cause 2 people in 100 to have an serious infection that they would not have had without the plasma exchange)



kidney failure = dialysis or transplant

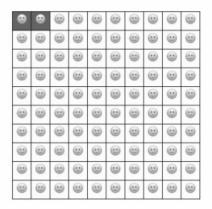


no kidney failure no serious infection



serious infection = admission to hospital or IV antibiotics

Chance of kidney failure over 1 year 2/100



Plasma exchange

Chance of kidney failure over 1 year 1/100

0	0	0	0	0	0	0	0	9	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	•	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

1 in 100 patients no longer need dialysis for the rest of their lives with plasma exchange

No plasma exchange

Chance of serious infection over 1 year 9/100

0	0	0	0	0	0	0	0	0	0
0	•	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

Plasma exchange

Chance of serious infection over 1 year 11/100

									0
	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0

an additional
2 in 100
patients will
experience a
serious
infection with
plasma
exchange

* 23. Based on the information above, would you choose to receive treatment with plasma exchange?
Yes
○ No
Options and Preferences for Treatments Informing recOmmendatioNs Study in Vasculitis
(OPTIONS Vasculitis)
End of survey
24. Thank you for participating in our survey.
We will communicate our its results with vasculitis patient organizations from Canada, the United States and
the United Kingdom via email and social media when the study is completed.
Please provide us with any additional comments if necessary.

Table S1: Multilevel multivariable logistic regression model for choosing PLEX using previous kidney disease instead of dialysis as a predictor

	OR	95% CI	95% CI	p value
Age				
(per 1 year increase)	0.97	0.96	0.99	< 0.01
Male sex	1.23	0.72	2.10	0.46
Country				
(reference = Canada)				
Other	0.74	0.20	2.74	0.66
United Kingdom	2.73	1.15	6.51	0.02
United States	1.04	0.51	2.11	0.92
Previous kidney disease	1.86	1.09	3.15	0.02
Previous PLEX	6.74	3.46	13.10	< 0.01
Previous infection	1.18	0.73	1.90	0.51
Scenario				
(reference=1)				
2	1.08	0.76	1.54	0.65
3	1.93	1.35	2.77	< 0.01
4	1.61	1.13	2.29	< 0.01
5	1.25	0.88	1.79	0.21

Note: OR=odds ratio, CI=confidence interval, AAV=ANCA associated vasculitis, PLEX= plasma exchange, scenarios 1,2,3,4,5 are the 5 different cases with increasing baseline risks of dialysis and serious infection

Table S2: Multilevel multivariable logistic regression model for choosing PLEX using current dialysis or transplant instead of previous dialysis as a predictor

diarysis of transplant instead of previous diarysis as a predictor						
	OR	95% CI	95% CI	p value		
Age						
(per 1 year increase)	0.98	0.96	0.99	< 0.01		
Male sex	1.28	0.75	2.19	0.37		
Country						
(reference = Canada)						
Other	0.70	0.19	2.58	0.59		
United Kingdom	2.58	1.08	6.15	0.03		
United States	0.96	0.47	1.94	0.90		
Current dialysis or						
transplant	3.78	1.21	11.80	0.02		
Previous PLEX	6.85	3.53	13.29	< 0.01		
Previous infection	1.15	0.71	1.86	0.57		
Scenario						
(reference=1)						
2	1.08	0.76	1.54	0.65		
3	1.93	1.35	2.77	< 0.01		
4	1.61	1.13	2.30	< 0.01		
5	1.26	0.88	1.79	0.21		

Note: OR=odds ratio, CI=confidence interval, AAV=ANCA-associated vasculitis,
PLEX= plasma exchange, scenarios 1,2,3,4,5 are the 5 different cases with increasing baseline risks of dialysis and serious infection