The Impact of Giant Cell Arteritis (GCA) Study

Arthritis Research UK Primary Care Centre

Instructions for completing this questionnaire

Thank you for taking part in **'The Impact of Giant Cell Arteritis (GCA)'** study.

We want to find out more about Giant Cell Arteritis (GCA) (also known as Temporal Arteritis) so that we can better understand what happens to people who have it. The following questions are about the GCA that you were previously diagnosed with, how it affects you and how you and your doctor manage it.

Please answer **all** of the questions, **even if you have no current problems with your health**. Unless stated, most questions can be answered by putting a cross in a box, like this: 

When you have finished, please check that all questions have been answered and then return the completed questionnaire back to us **as soon as you can**. A pre-paid envelope has been provided and you **do not** need a stamp.

The answers you give in the questionnaire will be treated in the strictest confidence. Whether you take part in this research or not, your right to use health services at your practice or elsewhere will not be affected.

Further details about this project are available in the Participant Information Sheet enclosed. If you have any more questions please contact the **Study Coordinator, Sarah Lawton** on **01782 734965** during office hours or email **s.a.lawton@keele.ac.uk** mentioning your name or ID number (which can be found on the back of your questionnaire).

Thank you for taking part in this study.

Section A: About your GCA diagnosis

1. How old were you when your doctor **first** said you had GCA?
(Don't worry if you are not sure, please try to give us a rough idea)

Age ☐ *years*

2. For approximately how long had you had your GCA symptoms when you **first** visited your doctor?
*(Please write in the total number of days, weeks **or** months)*

☐ ***Days***
☐ ***Weeks***
☐ ***Months***

*Please only enter a number in **one** of these boxes.*

3. Approximately how long did it take between visiting your doctor for the **first** time with your GCA symptoms and getting a **final** diagnosis of GCA?
*(Please write in the total number of days, weeks **or** months)*

☐ ***Days***
☐ ***Weeks***
☐ ***Months***

*Please only enter a number in **one** of these boxes.*

4. Who diagnosed your GCA?
(Please put a cross in as many boxes that apply to you)

a. GP..... ☐
b. Rheumatologist..... ☐
c. Ophthalmologist..... ☐
d. Geriatrician..... ☐
e. Other, please state;..... ☐

.....

5. How many times did you visit the various health professionals listed below about your GCA symptoms until you were diagnosed with GCA?
(Please put a cross in one box in each row)

	Health professional	Number of visits until your GCA diagnosis				
		Never	Once	Twice	3 times	4 or more times
a	GP	☐	☐	☐	☐	☐
b	Rheumatologist	☐	☐	☐	☐	☐
c	Ophthalmologist	☐	☐	☐	☐	☐
d	Geriatrician	☐	☐	☐	☐	☐
e	Vascular surgeon	☐	☐	☐	☐	☐
f	Other, please state…… ……....	☐	☐	☐	☐	☐

6. Which of the following tests did you have to help diagnose your GCA?
Please put a cross in as many boxes that apply to you)

a. Blood test..... ☐
b. Temporal artery biopsy..... ☐
c. Scalp ultrasound..... ☐
d. MRI……..... ☐
e. PET-Scan…….. ☐
f. Other, please state;..... ☐

.....

7. Have you experienced any of the symptoms listed below, **in relation to your GCA**, at the different times stated?
(Please put a cross in as many boxes that apply to you)

		Before diagnosis of GCA this symptom prompted me to see my doctor	**Currently** experiencing	**Ever** experienced since my GCA diagnosis
a	Headache / head pain	☐	☐	☐
b	Scalp tenderness e.g. when brushing hair	☐	☐	☐
c	Pain or difficulty chewing (e.g. when eating meat/bread)	☐	☐	☐
d	Double vision	☐	☐	☐
e	Temporary vision problems	☐	☐	☐
f	Permanent vision problems	☐	☐	☐
g	Shoulder pain or stiffness	☐	☐	☐
h	Hip pain or stiffness	☐	☐	☐
i	High temperature	☐	☐	☐
j	Weight loss	☐	☐	☐
k	Loss of appetite	☐	☐	☐
l	Tiredness/fatigue	☐	☐	☐
m	Pain in upper body when walking	☐	☐	☐
n	Pain in lower body when walking	☐	☐	☐
o	Ear pain	☐	☐	☐
p	Toothache	☐	☐	☐
q	Dry cough	☐	☐	☐
r	Hoarseness	☐	☐	☐
s	Other, please specify:	.....	.....	.....

8. Please list in rank-order the **three** most important symptoms to you **before** your GCA diagnosis.

1. ……

2. ……

3. ……

9. Please list in rank-order the **three** most important symptoms to you **after** your GCA diagnosis.

1. ……

2. ……

3. ……

Section B: About your GCA medication

1. Have you ever taken prednisolone (steroid medication) for your GCA?

Yes..... ☐ No..... ☐ If **'No'**, please go to question 7 on page 8.

2. Are you still taking prednisolone?

Yes..... ☐ If '**Yes**', what is your daily dose? _____ milligrams (mg)

No..... ☐ If '**No**', for about how long did you take prednisolone?

_____ months _____years

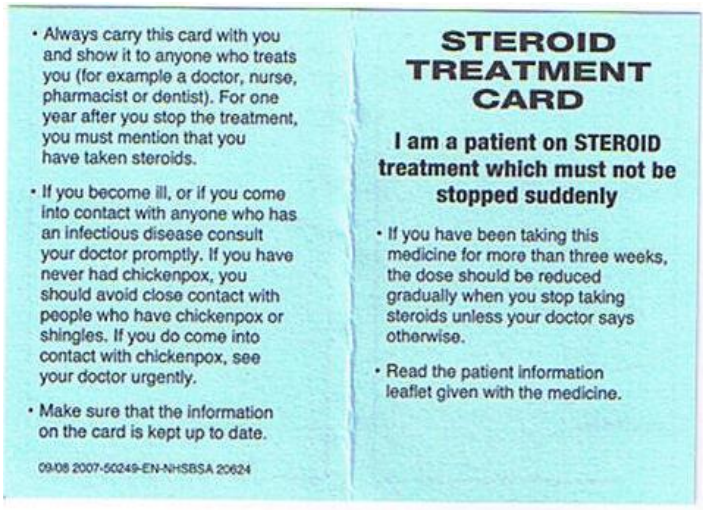
3. When you were first prescribed prednisolone for your GCA, what was your starting dose?
(Don't worry if you can't remember, please try to give us a rough idea)

☐ milligrams (mg)

4. After you first started taking prednisolone, how long did it take for your symptoms to improve?
(Please put a cross in one box only)

1 day	2-3 days	4-6 days	Within a week	Within 1-2 weeks	My symptoms did not improve
☐	☐	☐	☐	☐	☐

5. Have you ever been given a steroid card? It looks like this:



- Always carry this card with you and show it to anyone who treats you (for example a doctor, nurse, pharmacist or dentist). For one year after you stop the treatment, you must mention that you have taken steroids.
- If you become ill, or if you come into contact with anyone who has an infectious disease consult your doctor promptly. If you have never had chickenpox, you should avoid close contact with people who have chickenpox or shingles. If you do come into contact with chickenpox, see your doctor urgently.
- Make sure that the information on the card is kept up to date.

09/08 2007-50249-EN-NHSBSA 20624

STEROID TREATMENT CARD

I am a patient on STEROID treatment which must not be stopped suddenly

- If you have been taking this medicine for more than three weeks, the dose should be reduced gradually when you stop taking steroids unless your doctor says otherwise.
- Read the patient information leaflet given with the medicine.

Yes..... ☐ No..... ☐

6. Have you ever increased or decreased your steroid dose yourself without going to see your doctor?

Yes..... ☐ No..... ☐

If '**Yes**', please specify how you altered your steroid dose;

Increased dose..... ☐

Decreased dose..... ☐

by ☐ milligrams (mg)

Please specify why you altered your dose.....

.....

7. We are interested in some of the other medications you may take **in connection** with your GCA.

Please put a cross in the first column if you took any of the listed products **before** you were diagnosed with GCA and put a cross in the second column to indicate if you take any of the products listed **now**.
(Please put a cross in as many boxes that apply to you)

	Medication	Took before GCA diagnosis	Taking Now
a	Paracetamol	☐	☐
b	Paracetamol and codeine (e.g. co-codamol)	☐	☐
c	Non-steroidal anti-inflammatories (e.g. ibuprofen, diclofenac)	☐	☐
d	Strong painkillers on prescription (e.g. tramadol)	☐	☐
e	Medicine to protect your stomach and digestive system (e.g.omeprazole, lansoprazole)	☐	☐
f	Calcium supplements	☐	☐
g	Vitamin D supplements	☐	☐
h	Medicines for osteoporosis (e.g. alendronate, risedronate, strontium)	☐	☐
i	Azathioprine	☐	☐
j	Methotrexate	☐	☐
k	Leflunomide	☐	☐
l	Cyclophosphamide	☐	☐
m	Tocilizumab	☐	☐
n	Other, please specify:……...	☐	☐
	…….	☐	☐

8. Please indicate below whether you have ever experienced any of these since you started medication for your GCA?
(Please put a cross in as many boxes that apply to you)

a Weight gain..... ☐
b Bruising..... ☐
c Osteoporosis and/or fractures..…….. ☐
d Thinning of the skin..... ☐
e Bruising more easily..... ☐
f Muscle weakness..... ☐
g Depression..... ☐
h Moodiness..... ☐
i Change in shape of face..... ☐
j Change in shape of body..... ☐
k Sleep disturbance..... ☐
l Indigestion..... ☐
m Ankle swelling..... ☐
n Thrush..... ☐
o Infections..... ☐
p Increased body hair..... ☐
q Tremor/shaking..... ☐

Section C: About your other treatments for GCA

1. Have you tried any other treatments for your GCA?
(Please put a cross in the box for any treatments you have tried)

a Acupuncture..... ☐

b Aromatherapy..... ☐

c Herbal medicine……..…….. ☐

d Homeopathy..... ☐

e Hydrotherapy..... ☐

f Massage..... ☐

2. Have you tried any treatments, other than those mentioned above, for your GCA?

Yes..... ☐ No..... ☐

If '**Yes**', please specify:……..……

……

……

3. Are there any treatments that you think might have helped, or you would like to try, for your GCA?

Yes..... ☐ No..... ☐

If '**Yes**', please specify:……..……

……

……

4. Have you ever had a bone density/DEXA scan?

Yes..... ☐ No..... ☐

If '**Yes**', was this...

Before GCA diagnosis..... ☐ After GCA diagnosis..... ☐

I've had one before and after GCA diagnosis..... ☐

Section D: Information you received about GCA

1. Has your doctor ever given you any written information about GCA?

Yes..... ☐ No..... ☐

If '**Yes**'**,** did you find this useful?

Yes..... ☐ No..... ☐

2. Have you (or a friend or family member) searched on the internet for information about GCA?

Yes..... ☐ No..... ☐ I don't have access to the internet..... ☐

If **'Yes',** which websites did you look at?
(Please put a cross in as many boxes that apply to you)

Arthritis Research UK	Arthritis Care	NHS Choices	Patient.co.uk	PMRGCAuk .com	Netdoctor	Other
☐	☐	☐	☐	☐	☐	☐

If '**Other**', please specify:……...…….

……..

3. Have you ever contacted a patient support group e.g. PMR-GCA uk?

Yes..... ☐ No..... ☐

4. How often do you need someone to help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
(Please put a cross in one box only)

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐

Section E: Your general health

Please answer every question in this section. Some questions may look similar to others but each one is different. Please take the time to read and answer each question carefully by placing a **cross in the box** of your choice.

1. In general, would you say your health is……
(Please put a cross in one box only)

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

2. The following questions are about activities you might do during a typical day. **Does your GCA now limit you** in these activities? If so, how much? (Please put a cross in one box in each row)

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a	**Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
b	Climbing **several** flights of stairs	☐	☐	☐

3. During the **past 4 weeks,** how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?
(Please put a cross in one box in each row)

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	**Accomplished less** than you would like	☐	☐	☐	☐	☐
b	Were **limited** in the kind of work or other activities you could do	☐	☐	☐	☐	☐

4. During the **past 4 weeks,** how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
(Please put a cross in one box in each row)

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	**Accomplished less** than you would like	☐	☐	☐	☐	☐
b	Did work or other activities less carefully than usual	☐	☐	☐	☐	☐

5. During the **past 4 weeks,** how much did **pain** interfere with your normal work (including both work outside the home and housework)?
(Please put a cross in one box only)

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

6. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.
(Please put a cross in one box in each row)

How much of the time during the past 4 weeks…

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	Have you felt calm and peaceful?	☐	☐	☐	☐	☐
b	Did you have a lot of energy?	☐	☐	☐	☐	☐
c	Have you felt downhearted and low?	☐	☐	☐	☐	☐

7. During the **past 4 weeks,** how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?
(Please put a cross in one box only)

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

8. Over the **last 2 weeks** how often have you been bothered by the following problems?
(Please put a cross in one box in each row)

		Not at all	On several days	On more than half the days	Nearly every day
a	Feel nervous, anxious or on the edge	☐	☐	☐	☐
b	Not being able to stop or control worrying	☐	☐	☐	☐
c	Worrying too much about different things	☐	☐	☐	☐
d	Trouble relaxing	☐	☐	☐	☐
e	Being so restless that it is hard to sit still	☐	☐	☐	☐
f	Becoming easily annoyed or irritable	☐	☐	☐	☐
g	Feeling afraid as if something awful might happen	☐	☐	☐	☐

9. Still thinking about the **last 2 weeks**, how often have you been bothered by any of the following problems?
(Please put a cross in one box in each row)

		Not at all	Several days	More than half of the days	Nearly every day
a	Little interest or pleasure in doing things…….	☐	☐	☐	☐
b	Feeling down, depressed, or hopeless.	☐	☐	☐	☐
c	Trouble falling or staying asleep, or sleeping too much……	☐	☐	☐	☐
d	Feeling tired or having little energy…	☐	☐	☐	☐
e	Poor appetite or overeating……	☐	☐	☐	☐
f	Feeling bad about yourself or that you are a failure or have let yourself or your family down……..	☐	☐	☐	☐
g	Trouble concentrating on things, such as reading the newspaper or watching television……	☐	☐	☐	☐
h	Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual…….	☐	☐	☐	☐
i	Thoughts that you would be better off dead or of hurting yourself in some way……	☐	☐	☐	☐

10. How true do you find each statement below. In the **past 4 weeks** I have found that...

(Please put a cross in one box in each row)

		Not at all	A little bit	Some what	Quite a bit	Very Much
a	I feel fatigued……..	☐	☐	☐	☐	☐
b	I feel weak all over……..	☐	☐	☐	☐	☐
c	I feel listless (“washed out”)……..	☐	☐	☐	☐	☐
d	I feel tired…….	☐	☐	☐	☐	☐
e	I have trouble ***starting*** things because I’m tired…….	☐	☐	☐	☐	☐
f	I have trouble ***finishing*** things because I’m tired…….	☐	☐	☐	☐	☐
g	I have energy……..	☐	☐	☐	☐	☐
h	I am able to do my usual activities...	☐	☐	☐	☐	☐
i	I need to sleep during the day……..	☐	☐	☐	☐	☐
j	I am too tired to eat…….	☐	☐	☐	☐	☐
k	I need help doing my usual activities……	☐	☐	☐	☐	☐
l	I am frustrated by being too tired to do the things I want to do……..	☐	☐	☐	☐	☐
m	I have to limit my social activity because I’m tired…….	☐	☐	☐	☐	☐

11. In the last 4 weeks, because of your vision, how much difficulty do you have with the following activities? is difficult to…
(Please put a cross in the box that best describes how much difficulty you have, even with glasses. If you do not perform the activity for reasons unrelated to your vision, cross the "n/a" box).

		n/a	None	A little	Moderate	Great deal	Unable to do
1	Reading small print, such as medicine bottle labels, a telephone book or food labels	☐	☐	☐	☐	☐	☐
2	Reading a newspaper or a book	☐	☐	☐	☐	☐	☐
3	Reading a large-print book or large-print newspaper or numbers on a telephone	☐	☐	☐	☐	☐	☐
4	Recognising people when they are close to	☐	☐	☐	☐	☐	☐
5	Seeing steps, stairs or curbs	☐	☐	☐	☐	☐	☐
6	Reading traffic signs, street signs or store	☐	☐	☐	☐	☐	☐
7	Doing fine handwork like sewing, knitting, crocheting, carpentry	☐	☐	☐	☐	☐	☐
8	Writing cheques or filling out forms	☐	☐	☐	☐	☐	☐
9	Playing games such as bingo, dominos or card games	☐	☐	☐	☐	☐	☐
10	Taking part in sports like bowling, tennis, golf	☐	☐	☐	☐	☐	☐
11	Cooking	☐	☐	☐	☐	☐	☐
12	Watching television	☐	☐	☐	☐	☐	☐
13	Driving during the day	☐	☐	☐	☐	☐	☐
14	Driving at night	☐	☐	☐	☐	☐	☐

12. Has a doctor ever told you that you have any of the following…..
(Please put a cross in as many boxes that apply to you)

a Acid reflux / indigestion / stomach ulcer..... ☐
b Diabetes..... ☐
c Polymyalgia rheumatica (PMR)..... ☐
d Heart disease..... ☐
e High blood pressure..... ☐
f High cholesterol..... ☐
g Osteoporosis..... ☐
h Stroke..... ☐
i Cataracts..... ☐
j Glaucoma..... ☐
k Heart attack..... ☐
l Cancer…..... ☐
m Osteoarthritis..... ☐

Section F: Questions about your priorities for GCA research

This section is about what you think are the most important things that should be researched in GCA.

1. What in your opinion are the most important things that should be researched in GCA?
*(Please put a cross next to your **3** most important.)*

a Accurate and timely diagnosis ☐
b Steroid Management ☐
c How giant cell arteritis develops ☐
d Pain, stiffness and fatigue ☐
e Avoiding steroid complications ☐
f Alternative and complementary therapies ☐
g Roles of health professionals ☐
h Things patients with GCA can do for their condition ☐
i Multiple health conditions ☐
j Other, please specify..... ☐

……

Section G: Questions about you

This section contains some questions about you.

1. What is your date of birth?
(e.g. 1st March 1930 would be 01 / 03 / 1930)

☐☐ / ☐☐ / **19** ☐☐

2a. What is your weight now?

☐☐ stones ☐☐ lbs **or** ☐☐☐ kgs

2b What is your height?

☐ feet ☐☐ inches **or** ☐☐☐ cms

3. Are you:

Male..... ☐ Female..... ☐

4. Which ethnic group do you consider yourself to belong to?
(Please put a cross in one box only)

White..... ☐ Black/African/Caribbean/Black British... ☐

Asian/Asian British..... ☐ Mixed/multiple ethnic groups..... ☐

Other..... ☐

5. What is your current employment status?
(Please put a cross in one box only)

Employed.....	☐	Unemployed or seeking work.....	☐	Housewife/ Husband.....	☐
Retired.....	☐	Not working due to ill health.....	☐	Other.....	☐

6. If you are working, what is your job title, or if you are not working, or are retired, what job did you do for most of your working life?

.....

7. What is your current smoking status?
(Please put a cross in one box only)

Never smoked	Previously smoked	Currently smoking
☐	☐	☐

8. About how often do you drink alcohol?
(Please put a cross in one box only)

Daily or almost daily	3 or 4 times a week	Once or twice a week	1 to 3 times a month	Special occasions only	Never
☐	☐	☐	☐	☐	☐

9. Do you currently live alone?

Yes..... ☐ No..... ☐

10. What is your current marital status?
(Please put a cross in one box only)

Married	Separated	Divorced	Widowed	Cohabiting	Single
☐	☐	☐	☐	☐	☐

11. In the last month, how much did your GCA symptoms affect your intimate or sexual relationships?
(Please put a cross in one box only)

Does not apply to me	Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐	☐

This is the end of the questions

Thank you for taking the time to fill in this questionnaire.

We assure you that any information will be held in the strictest confidence.

Please return this questionnaire and signed consent form (Section H) in the prepaid envelope provided. **You do not need a stamp.** If you have any questions about this questionnaire or the study in general, please contact the **Study Coordinator, Sarah Lawton** on **01782 734965** during office hours or email **s.a.lawton@keele.ac.uk**

Thank you very much for your help.

ID number:

Section H: Continuing to help with this study

Thank you for completing this questionnaire.

Please ensure that you have read the enclosed Participant Information Sheet (version 1.0, dated 10/10/14) that explains the study in detail.

Please read and complete the following consent form, and then sign below.

Consent form

Please answer each statement by putting a cross in the appropriate box on each line.

	Yes	No
I confirm that I have read and understood the study Participant Information Sheet (version 1.0, dated 10/10/14), and I am willing to take part in the study.	☐	☐
I understand that I can withdraw from the study at any time, and that this will not affect the care I receive in any way.	☐	☐
I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Keele University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐	☐
I understand that I can withdraw from the study at any time, and that this will not affect the care I receive in any way.	☐	☐
I give my consent to be contacted again about related studies.	☐	☐

Signed……..... Date……..…

Please print your name and address

Title _____ First name _____ Last name _____

Address line 1 _____

Address line 2 _____

Town _____ County _____

Postcode _____ Telephone number _____

Even if you would prefer us not to review your medical records, the answers you have given in this questionnaire will still be very important to us.

Please return your questionnaire in the FREEPOST (no stamp needed) envelope provided.

Thank you for your help with this research project.

ID number: