

Wegener's Granulomatosis Association

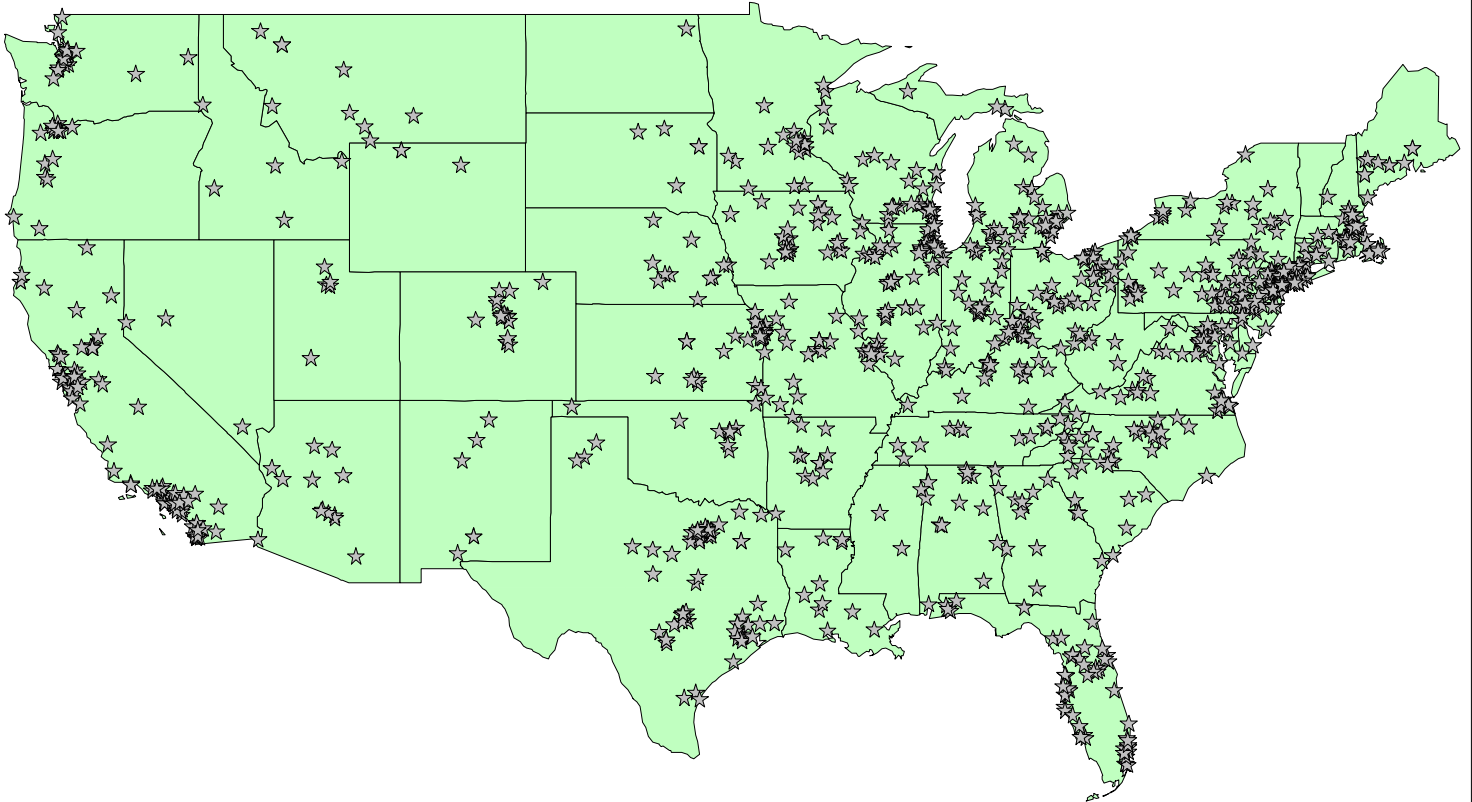
Formerly the: Wegener's Granulomatosis Support Group, Inc.

P. O. Box 28660

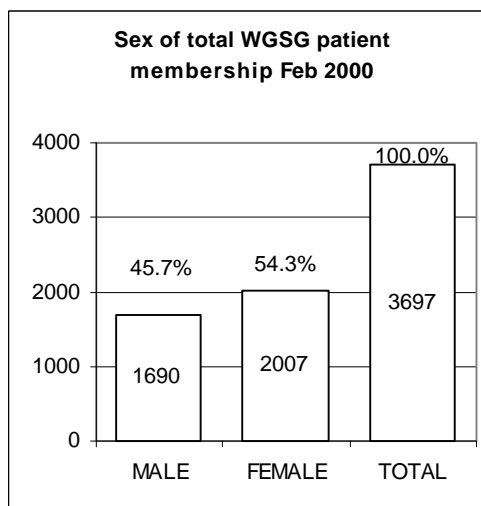
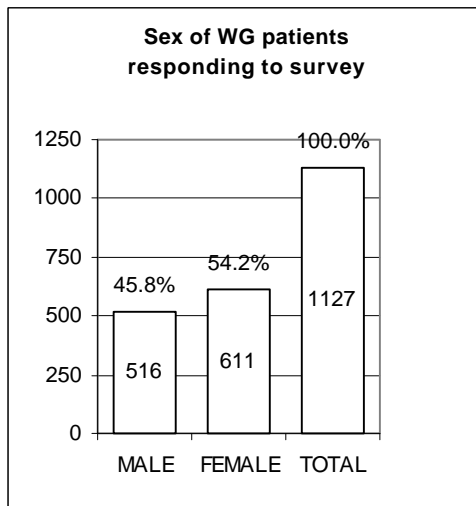
Kansas City, MO 64188-8660 phone 800-277-9474

Results of survey questionnaire sent in Oct. 1997 WGSG newsletter

Zip code location of 1059 Wegener's Granulomatosis patients completing survey questionnaire.

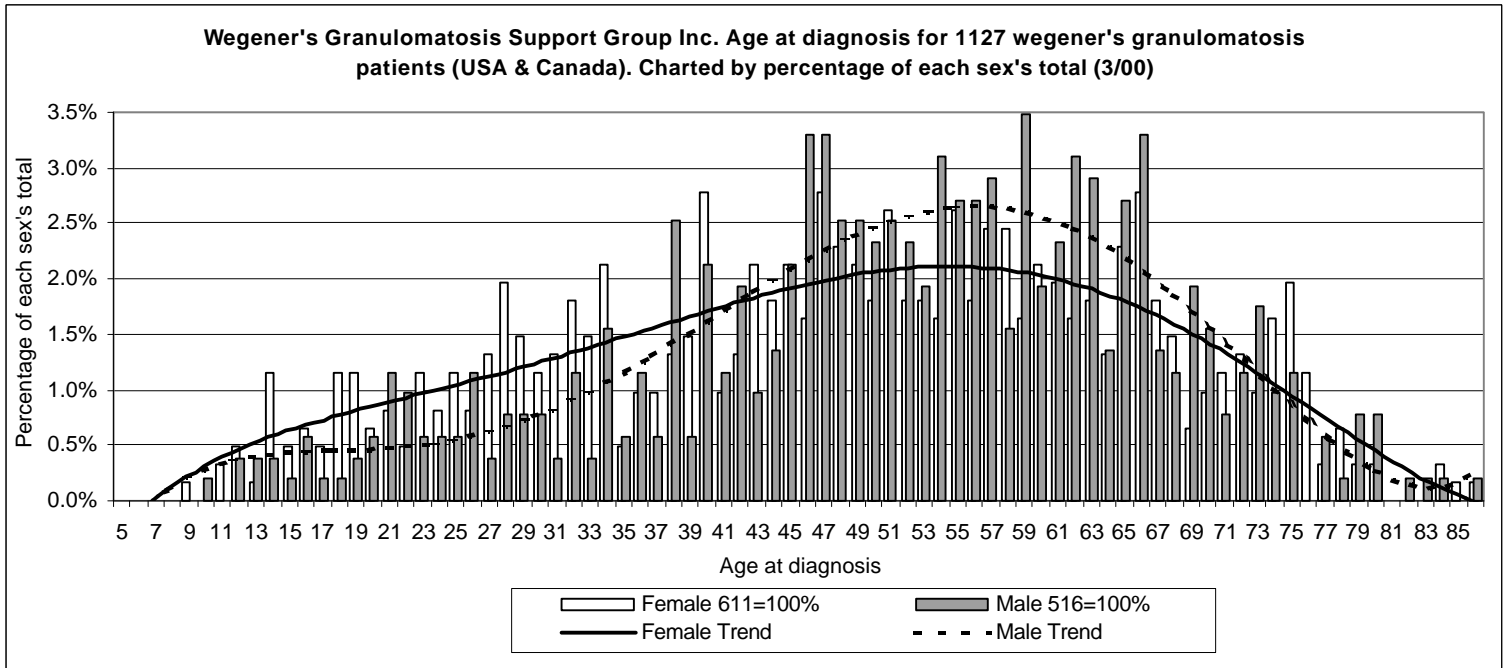


Question 1. Female _____ Male _____

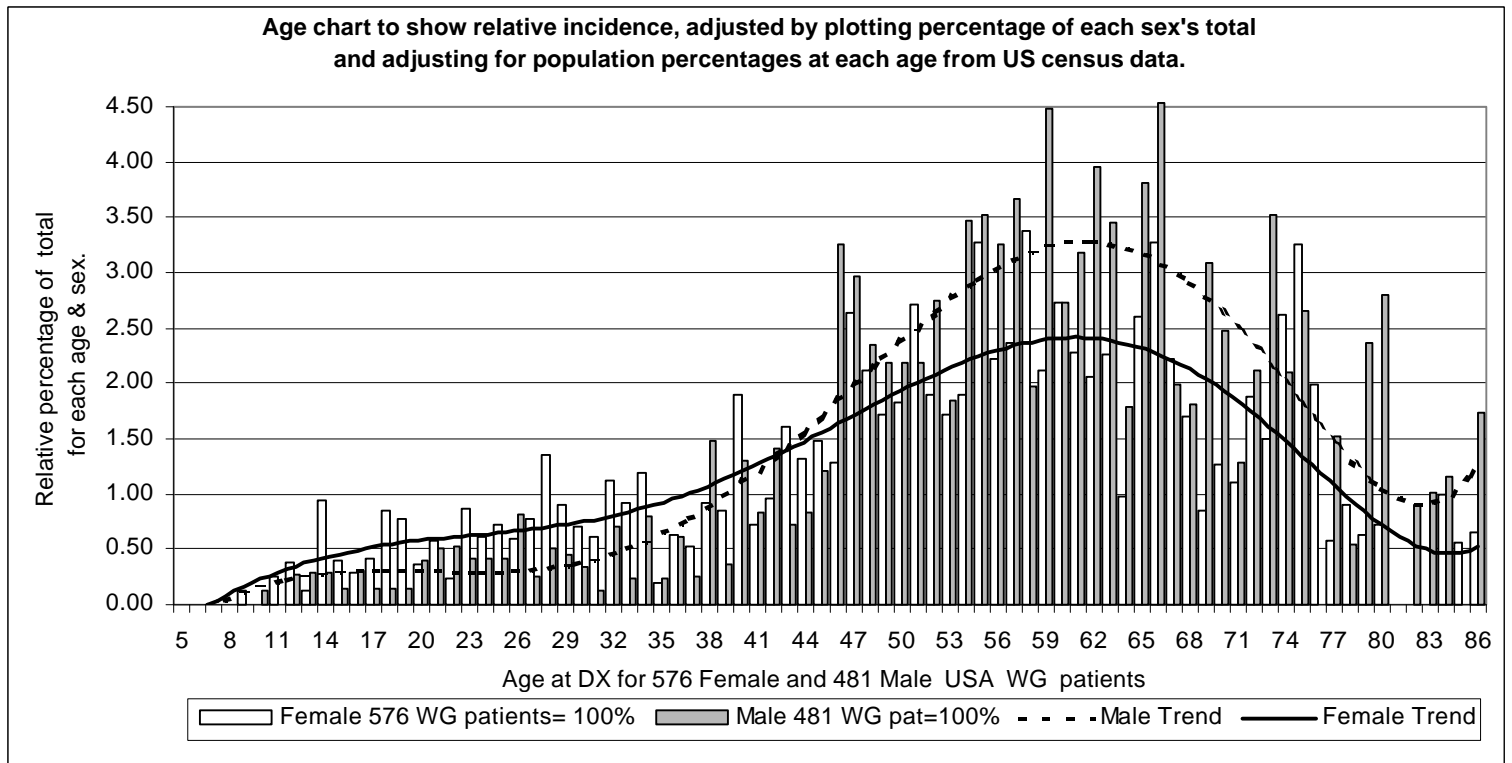


Question 2a. Birthyear 19__ __ **2b. Age when diagnosed** with Wegener's granulomatosis...__ __

Since there were an unequal number of men and women in the survey the following chart uses the percentage of each sex's total to adjust the incidence for comparison. Note until the age of 41 women have a higher incidence. Above that age men have a higher incidence.



The following chart is experimental. A correction factor has been calculated for each year of age Since there were an unequal number of men and women the percentage for each group's total was plotted to equalize the chart. Also a correction factor calculated from US census data was used to adjust for the decrease in population as age increases. For instance since the population of 70 year old males has decreased by a factor of 1.5 the number of males at that age is multiplied by that factor to chart the relative incidence of Wegener's at that age. Note since there are fewer men as age increases it indicates a higher incidence for those men over 42 years old.



Question 3. How would you classify your *race*?

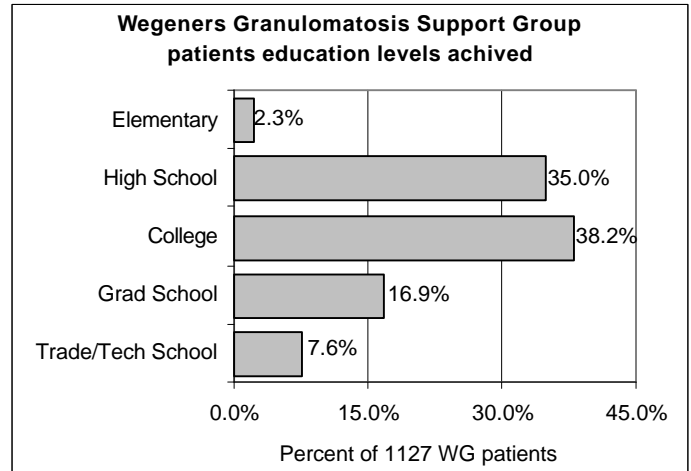
Please circle one of the numbers:

- 1.....White 2.....African American
 3.....Hispanic 4.....Pacific Islander
 5.....Asian 6.....Native American

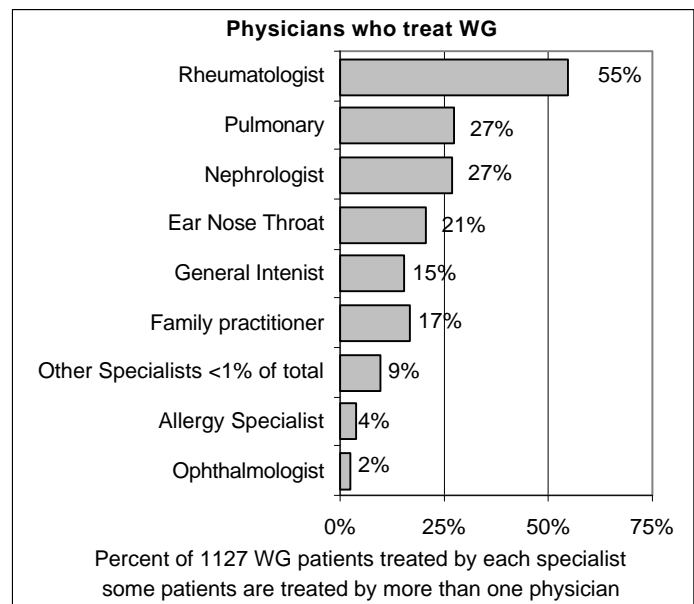
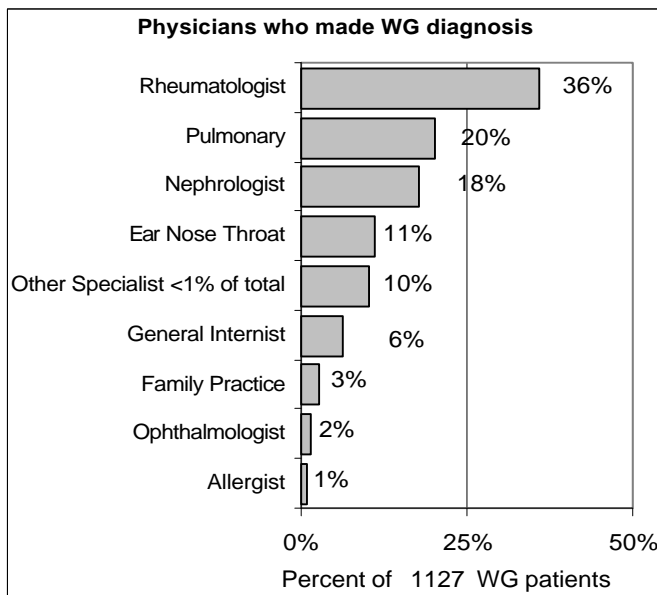
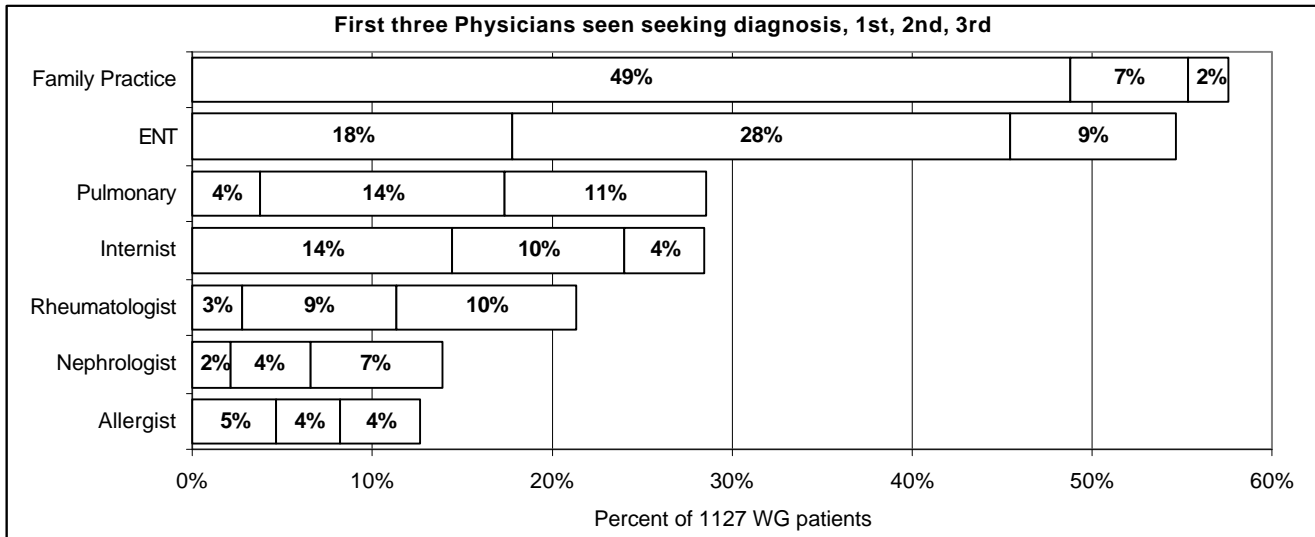
All individuals are USA citizens. note: some checked more than one race				
Race	USA % of Population	WG Pat.	Percent of total	% Adjusted by Census Data
White	(75.7%)	1033	97.7%	42.4%
Hispanic	(9.0%)	13	1.2%	4.5%
Native American	(.08%)	12	1.1%	46.2%
African American	(12.3%)	7	0.7%	1.8%
Asian	(3.0%)	5	0.5%	5.1%
Other		4	0.4%	-
Pacific Islander		1	0.1%	-

Question 4. Circle number for the highest level of school you ever achieved:

- 1.....Elementary 2.....High School 3.....College
 4.....Graduate School 5.....Trade or technical school



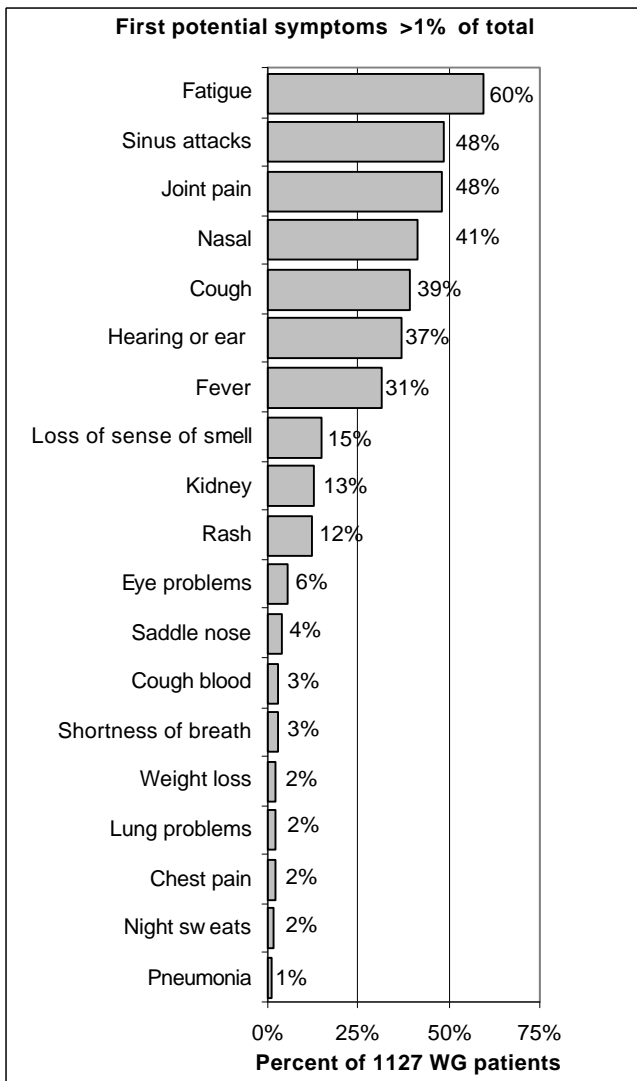
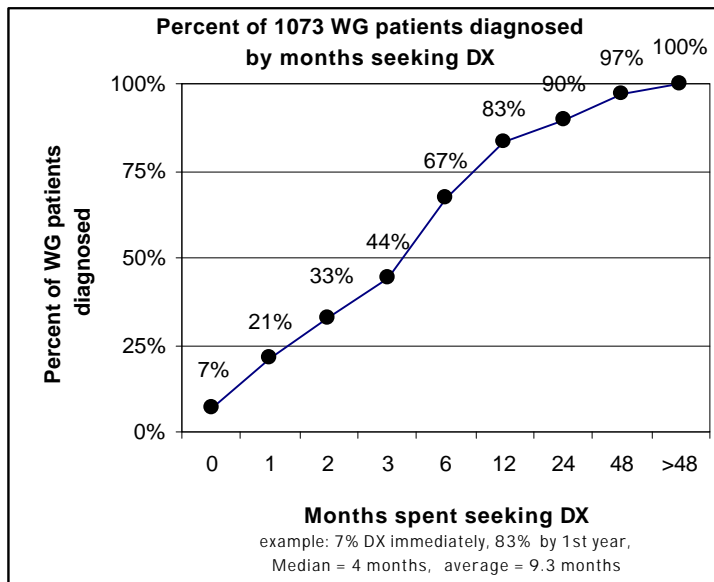
Question 5. The next questions ask about the physicians you first went to seeking diagnosis then who diagnosed you and who now care for your Wegener's Granulomatosis. Put a number in the boxes in the order you saw the physicians.



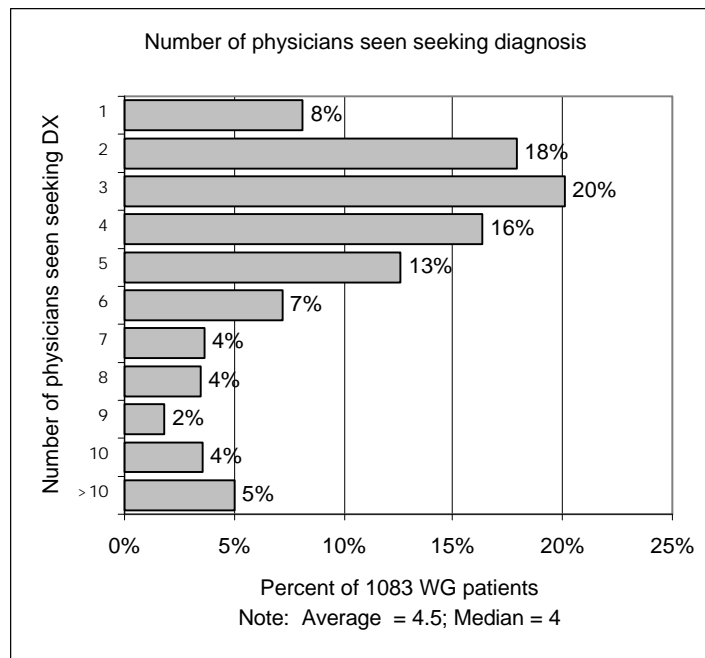
Question 6... First potential symptoms: ___

- (1)fatigue___ (2)fever___ (3)joint pain___
- (4)nasal obstruction or bleeding___ (5)sinus attacks___
- (6)rash___ (7)cough___ (8)deformed nose___
- (9)kidney problem___ (10)hearing or ear problem___
- (11)Loss of sense of smell___ (12)others specify___

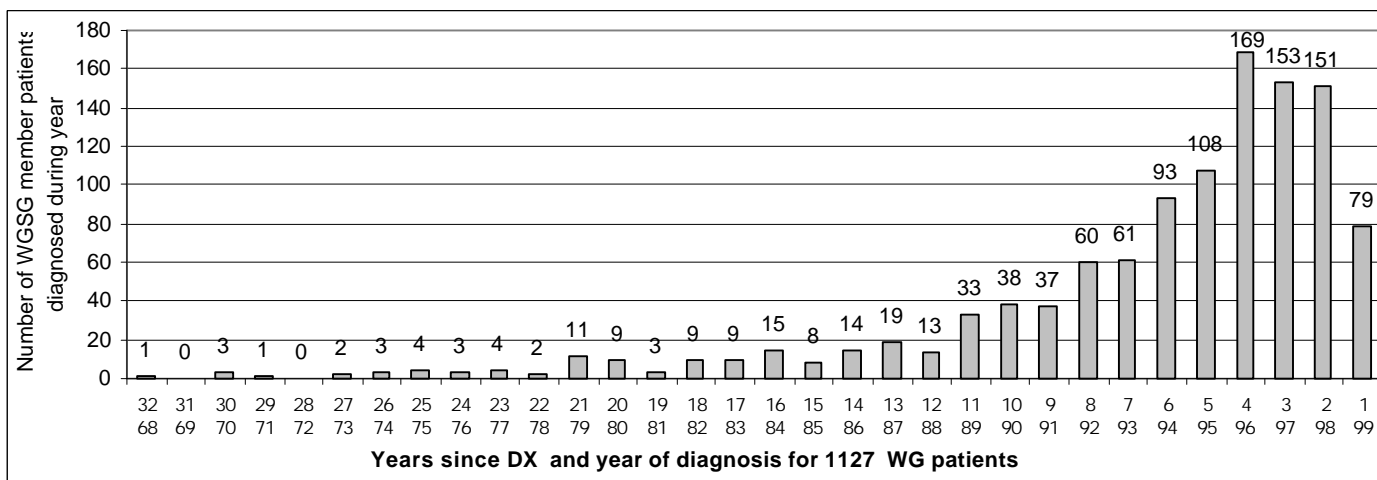
Question 7b..Months spent seeking diagnosis. ___



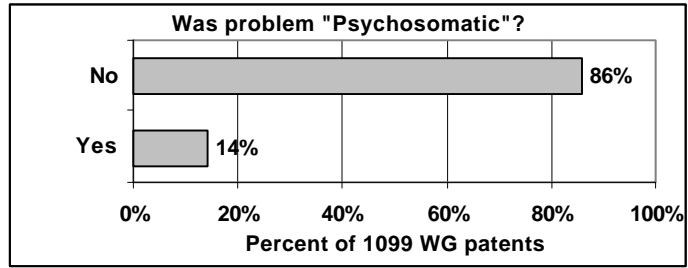
Question 8... How many physicians did you see before the WG diagnosis was made



Question 7a... When did a physician first tell you have WG?... ___



Question 9... During and before the diagnosis, was it suggested that the Problem was "psychosomatic"?

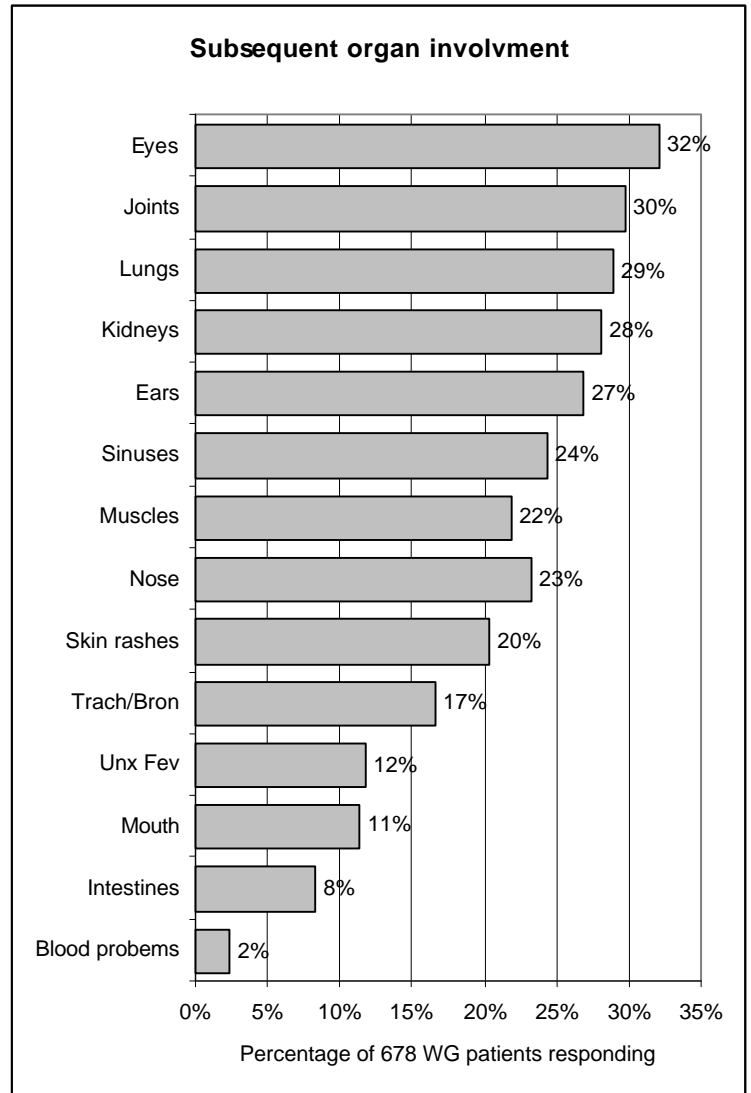
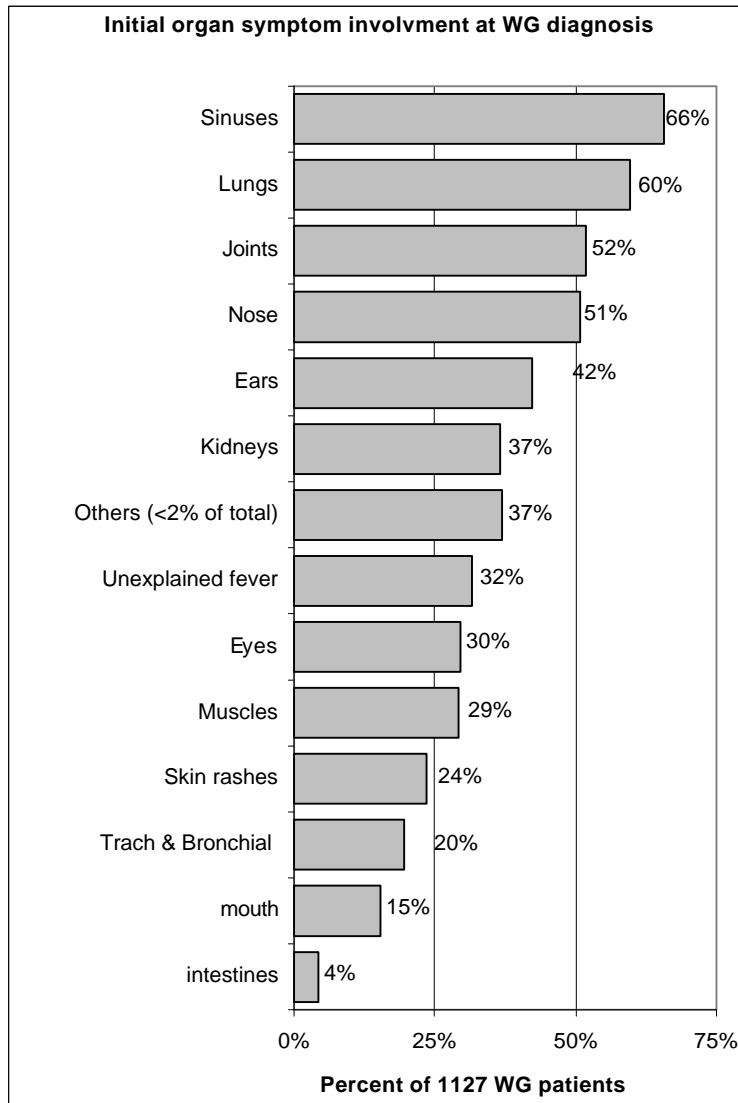


Question 10. As best you can recall, when you were **FIRST** diagnosed with WG, which parts of your body were originally involved? (check all parts involved)

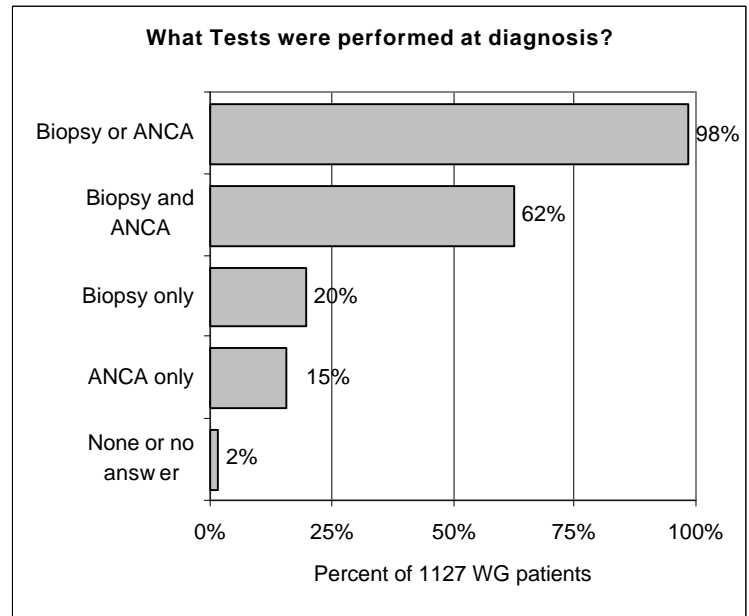
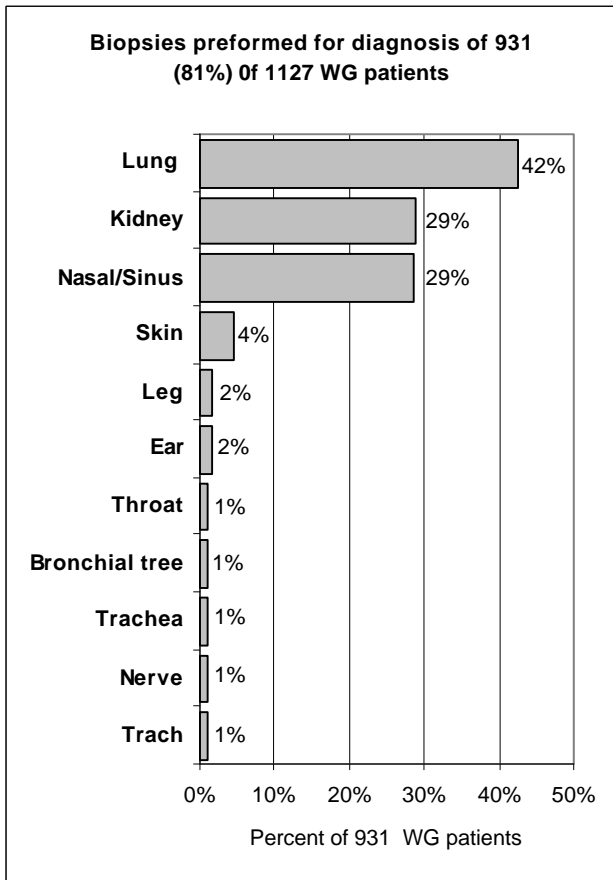
(1) Mouth___ (2)Nose___ (3)Sinuses___ (4)Ears___
 (5)Eyes___ (6)Trachea and bronchial tree___ (7)Skin rashes___ (8)Joints___ (9)Muscles___ (10)Lungs___
 (11)Kidneys___ (12)Intestines___ (13)Unexplained fever___ (14)Others___(please specify parts of your body)

Question 11... After DX have you had **additional parts** of your body involved? (check all parts involved)

(1)Mouth___ (2)Nose___ (3)Sinuses___ (4)Ears___
 (5)Eyes___ (6)Trachea and bronchial tree___ (7)Skin rashes___ (8)Joints___ (9)Muscles___ (10)Lungs___
 (11)Kidneys___ (12)Intestines___ (13)Unexplained fever___ (14)Others___(please specify)_

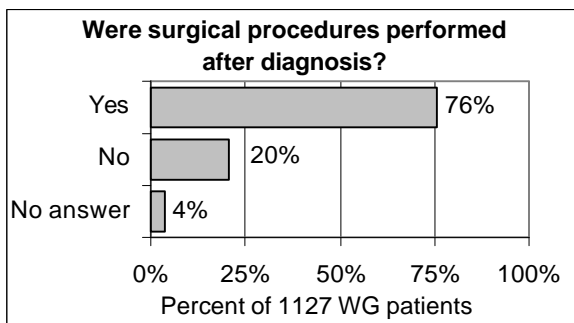
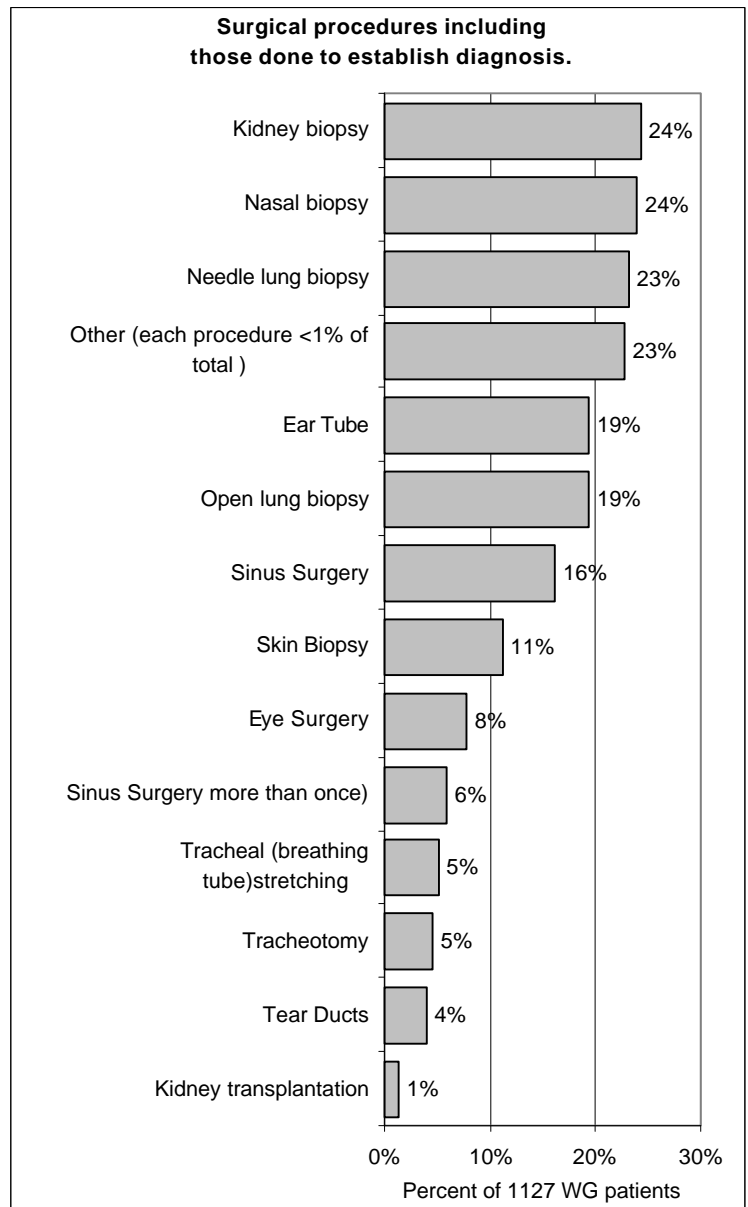


Question 12a... How diagnosed, biopsy (of what site), _____ or b. ANCA? _____ c. Or both? _____



Question 13a... Has your illness required surgical procedure(s) since it started? ___Yes ___No

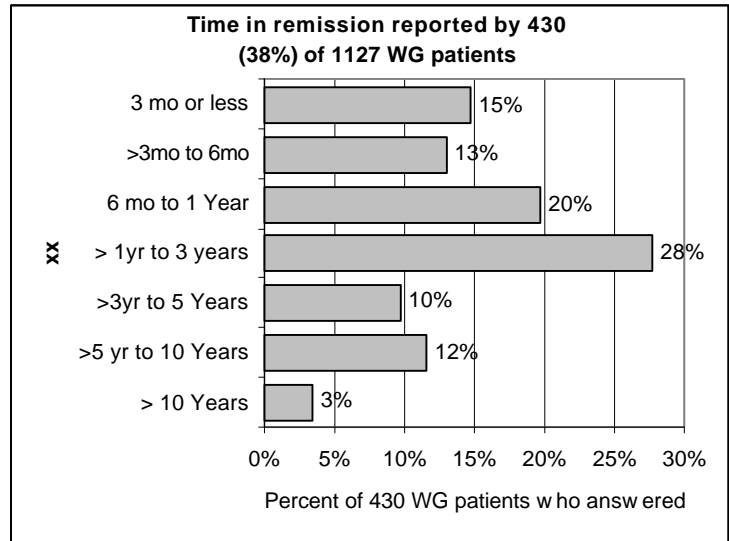
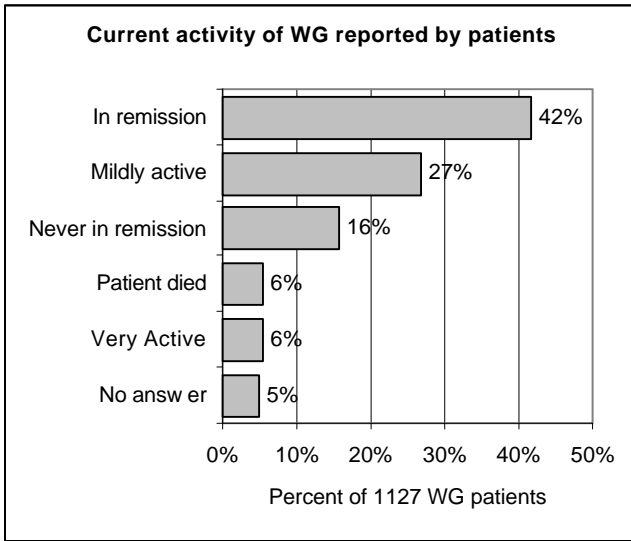
13b... If yes, please check all procedures that apply (including procedures done for establishing diagnosis)
 (1) None___ (2) Ear Tube___ (3) Tear Ducts___ (4) Sinus Surgery___ (5)(Sinus Surgery more than once)___ (6) Tracheal (breathing tube)stretching__(7) Tracheotomy (hole in your breathing tube)__(8) Nasal biopsy____ (9) Needle lung biopsy (through the skin or at bronchoscopy-tube to the lungs)_(10) Open lung biopsy (surgery to remove part of the lung)__(11) Kidney biopsy__(11b) Kidney transplantation__(12) Skin Biopsy__ (13) Nerve biopsy__ (14)Eye Surgery__(15) Other surgery...(please list)____



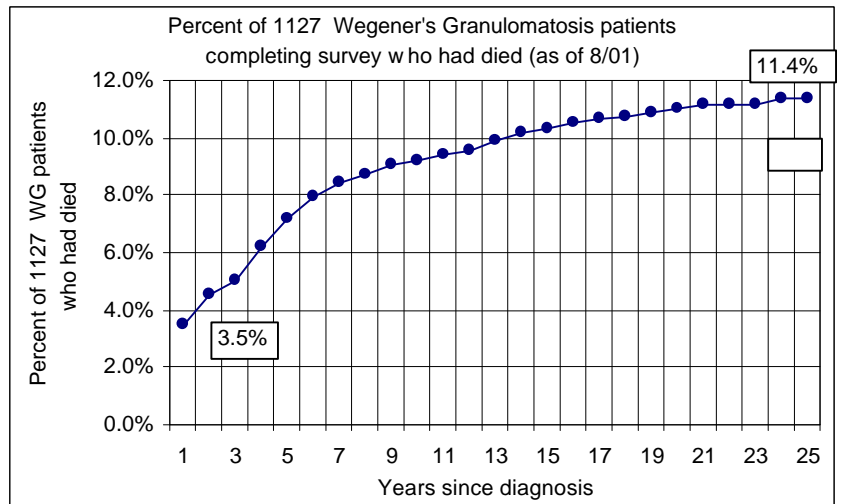
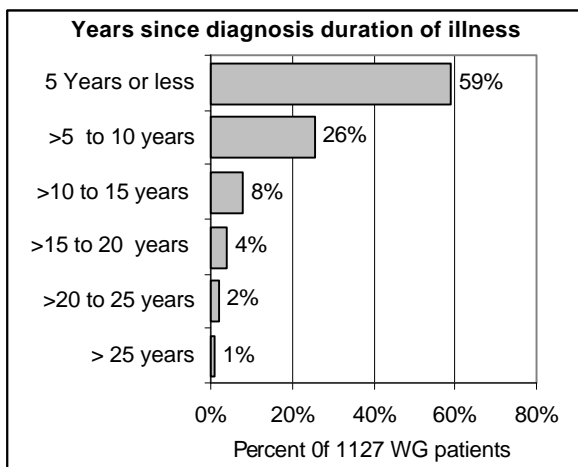
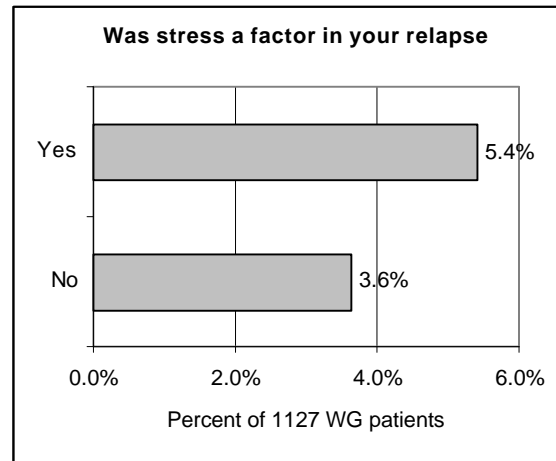
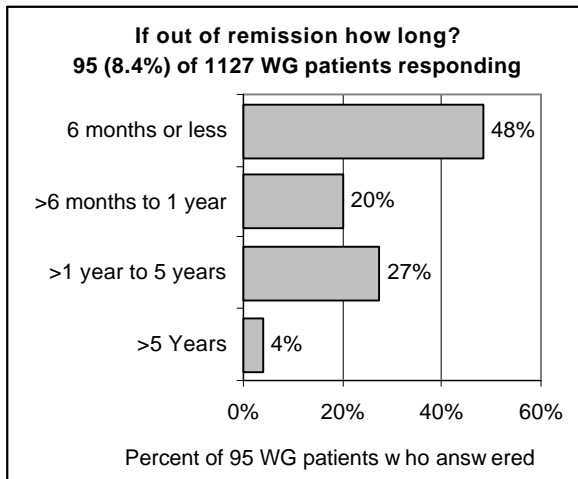
14 How would you estimate the CURRENT activity of your WG?

- a. (1)Never in remission after diagnosis _____
 (2)In remission _____ (3)Mildly active _____
 (4)Very Active _____

b. If in remission, how long? _____ months

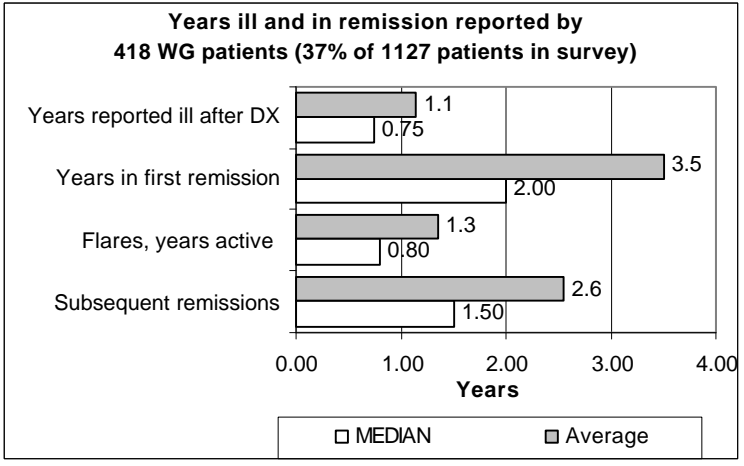


Question 14c. If out of remission, how long? _____ months, **14d** Was stress a factor in your relapse? ___Yes ___No



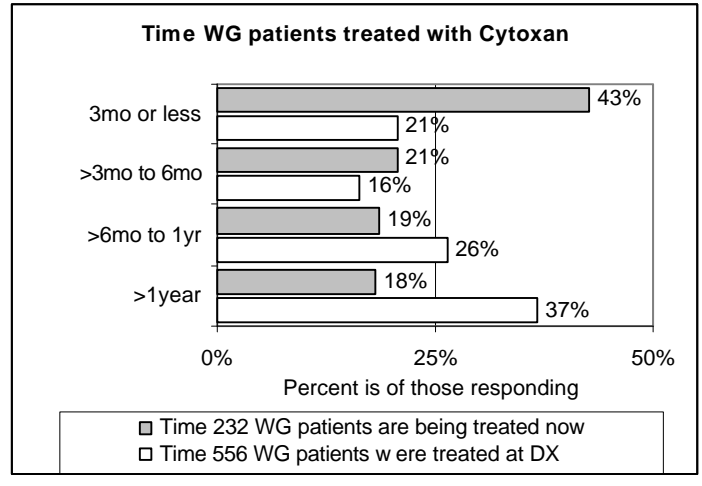
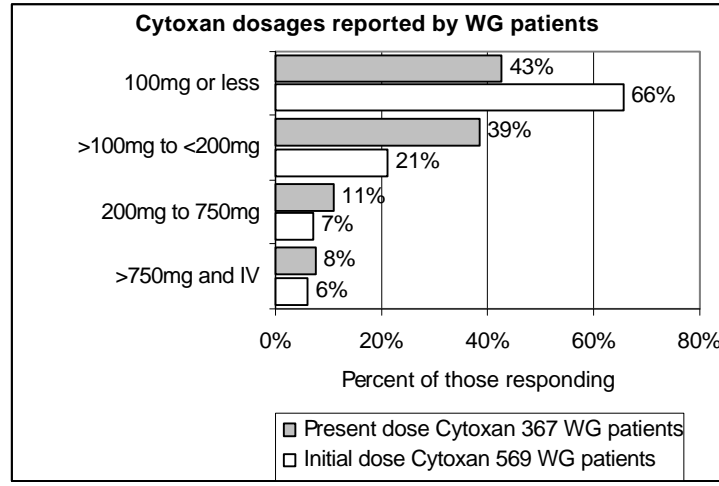
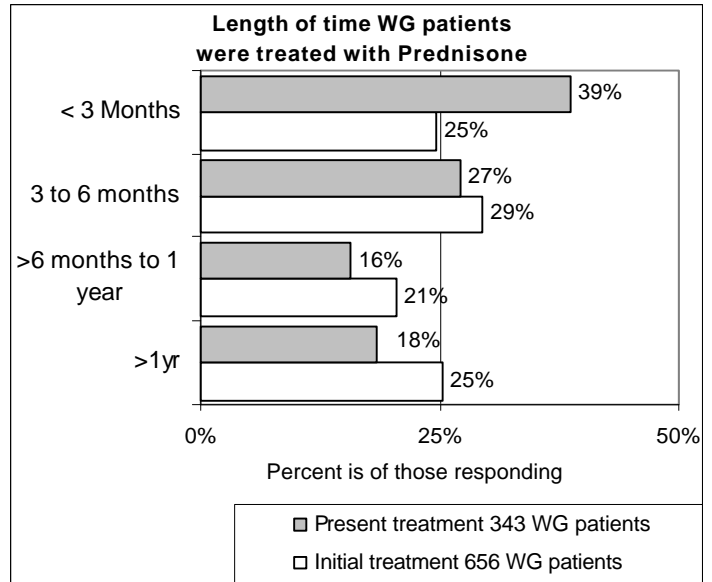
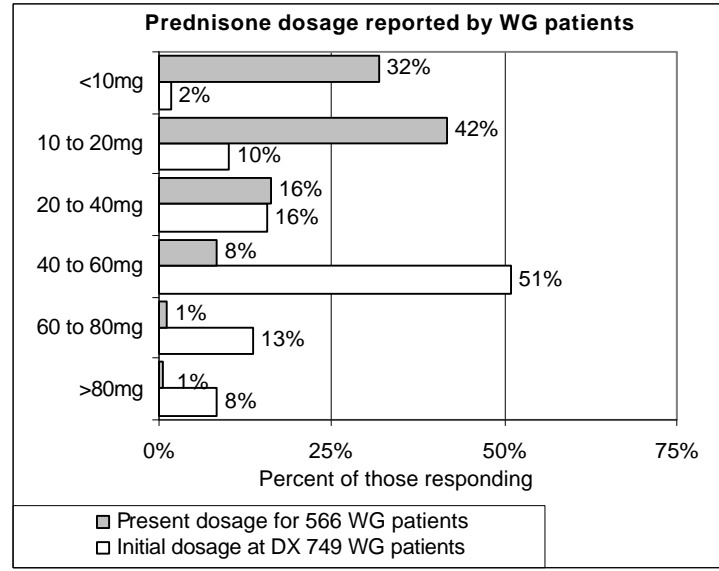
Question 15. What has been the pattern of your illness after diagnosis e.g. ill 6 months, remiss 1 year, flare 6 months, remission 1 year, etc:

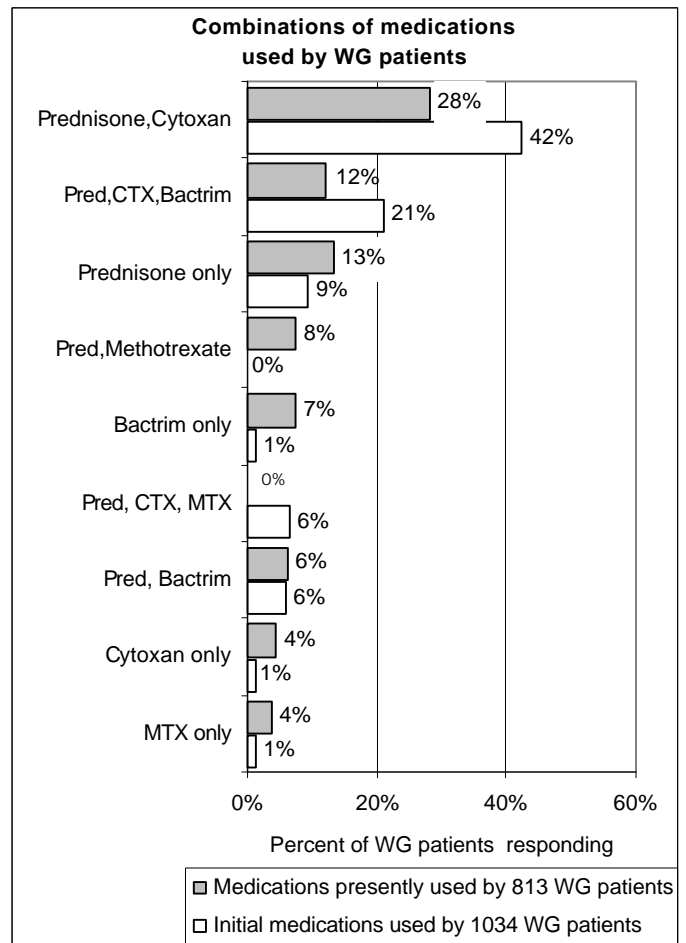
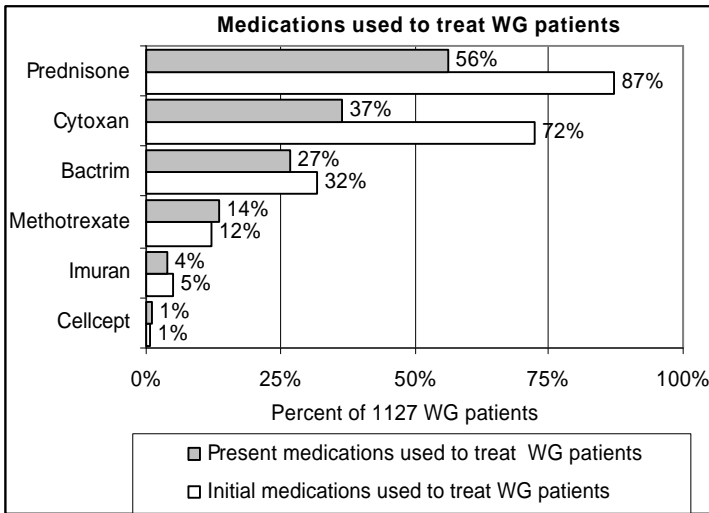
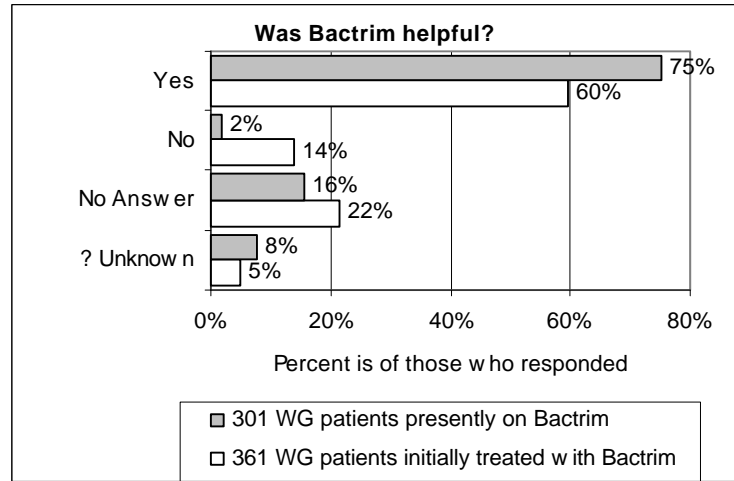
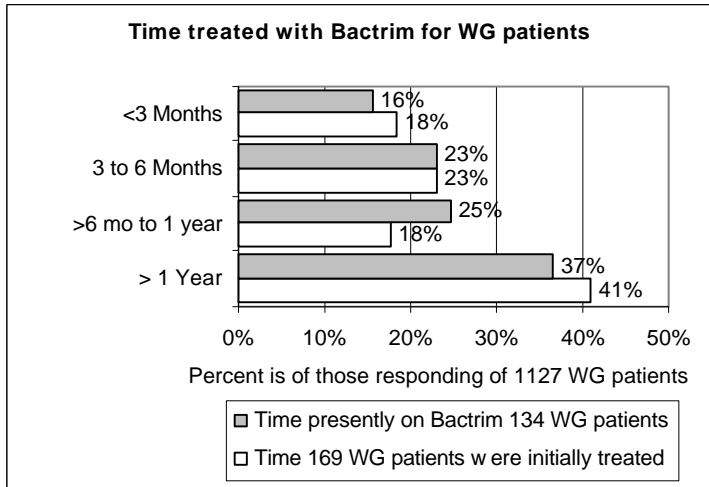
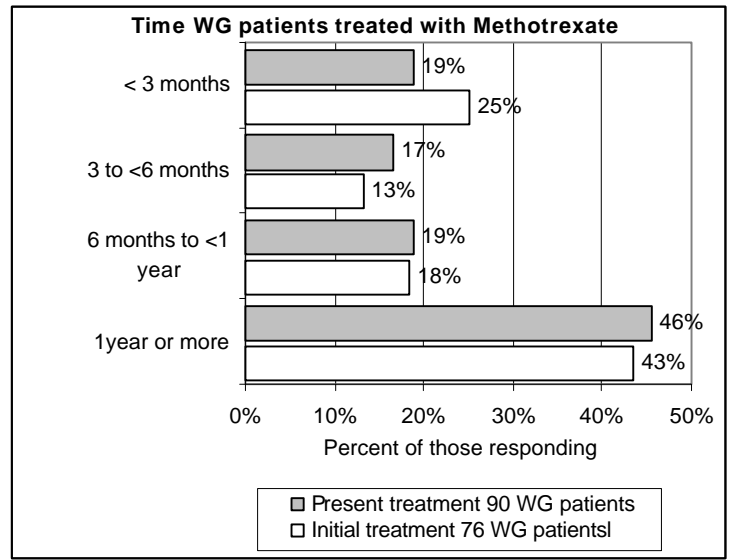
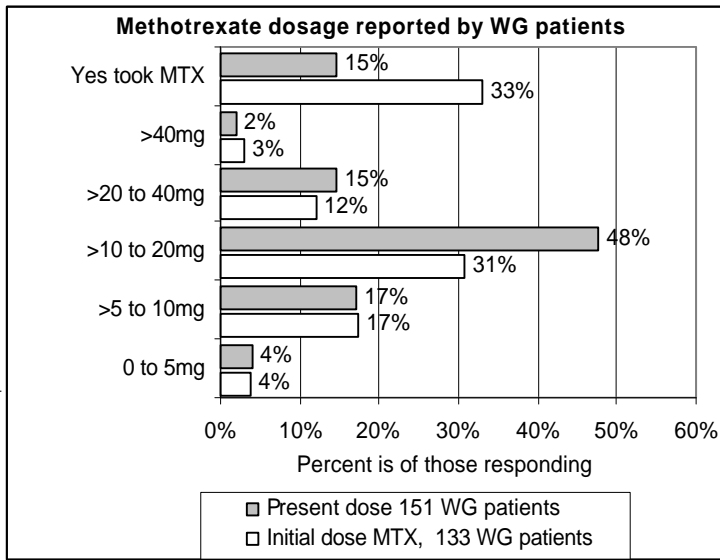
My pattern has been: _____

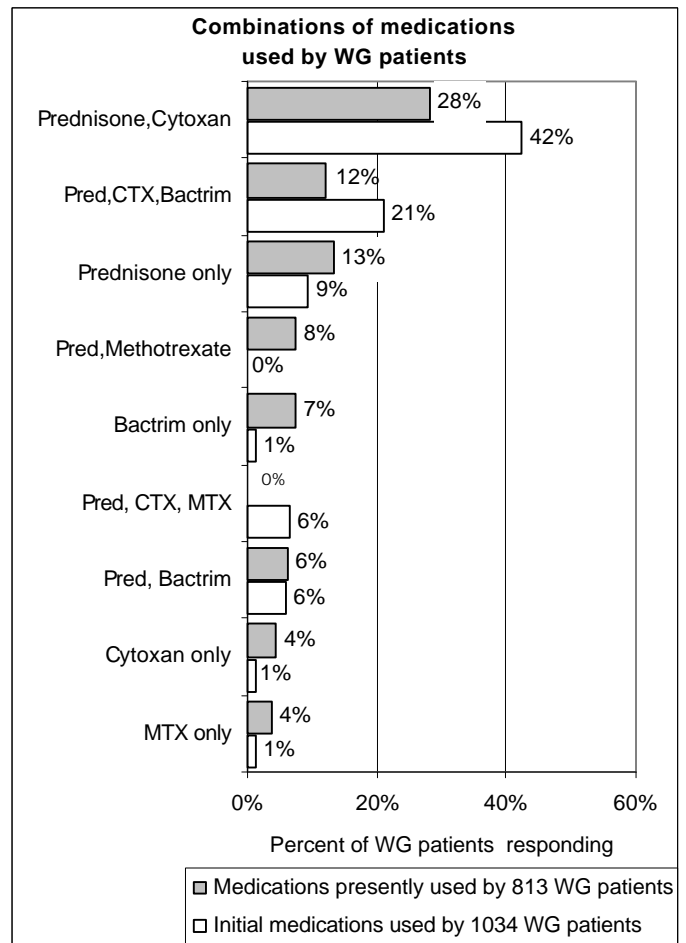
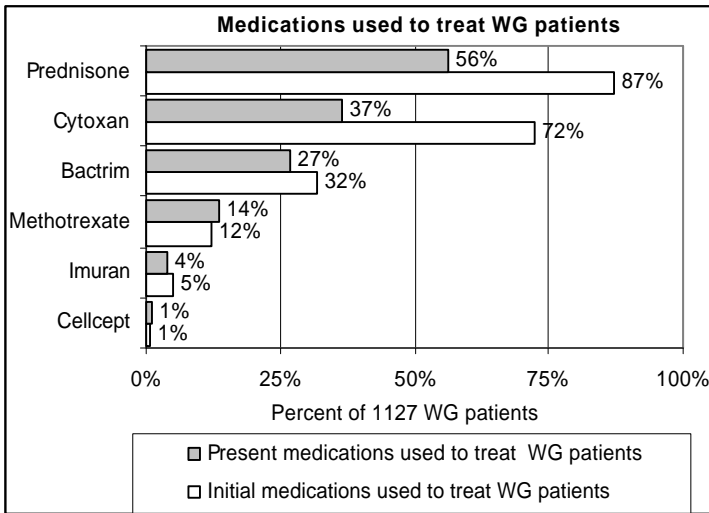
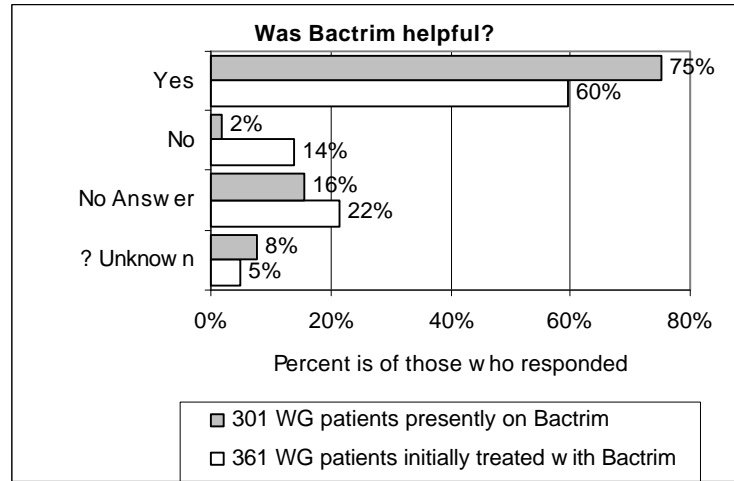
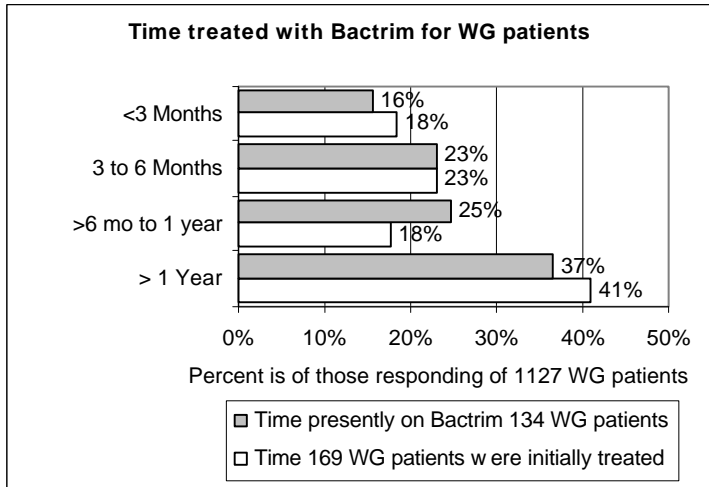
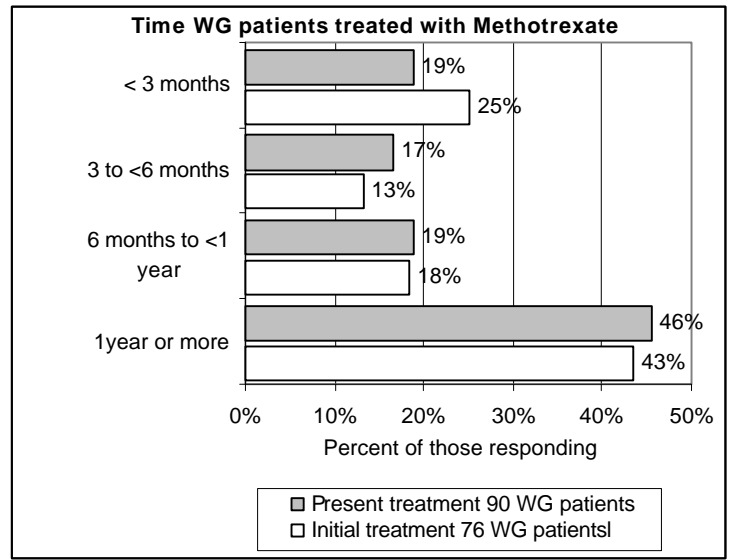
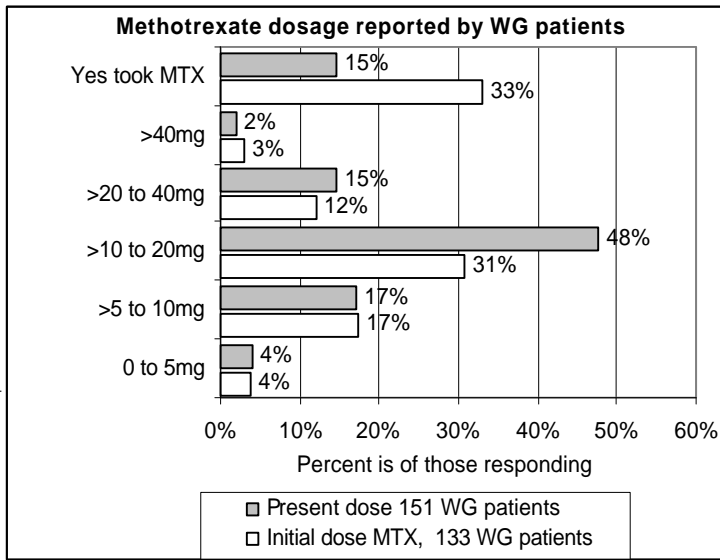


Q.16...Please list the medications you were initially treated with and those you are taking now. (Partial view of form used:)

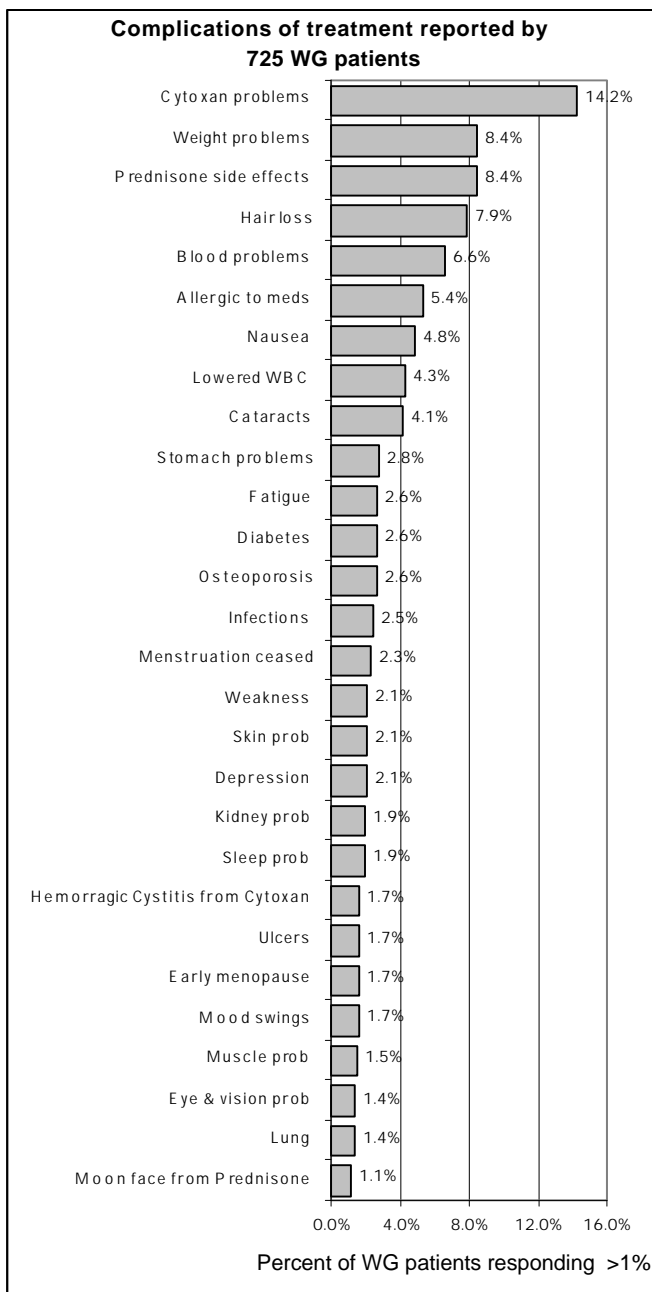
	Initially treated with				Treated with now?			
	Dosage	How Long?	Helpful?		Dosage	How Long?	Helpful?	
			Yes	NO			Yes	No
Prednisone (Corticosteroids)								
Cytosan (Cyclophosphamide)								
Other medications etc								



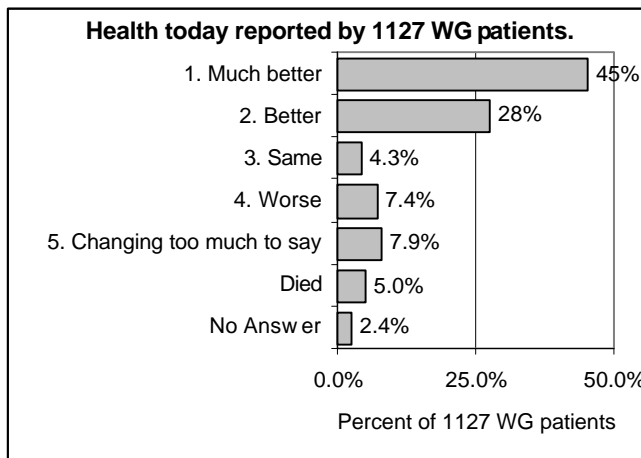




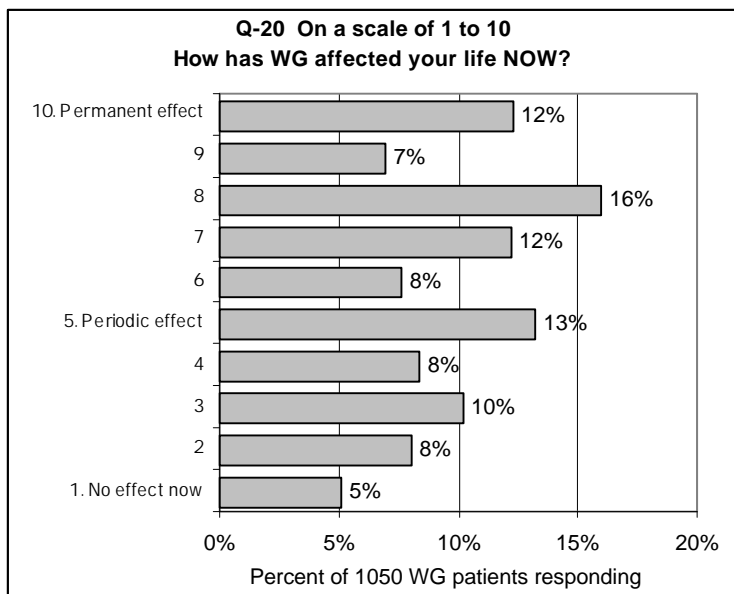
Question ...18. Any *complications of treatment*? _____



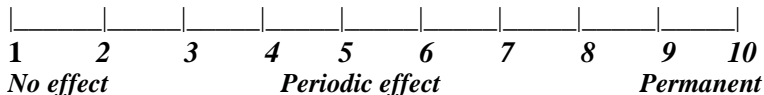
Question ..19. Compare your health *today* with when you were *first diagnosed*. . Please circle number:
 Health now is: *Much better.....1 Better.....2*
Same.....3 Worse.....4 Changing too much to say.....5



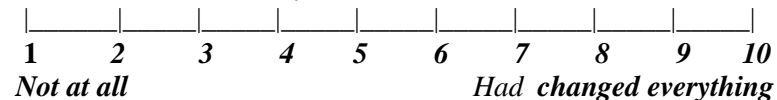
Question 20.



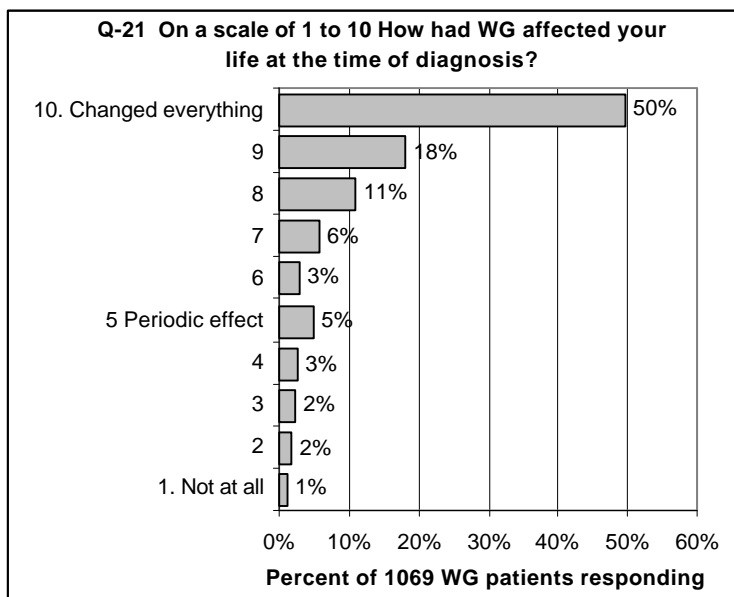
Question 20. How would you rate the *present* impact of the disease (including side effects of therapy) on your ability to perform you're daily activities at home and/or at work?



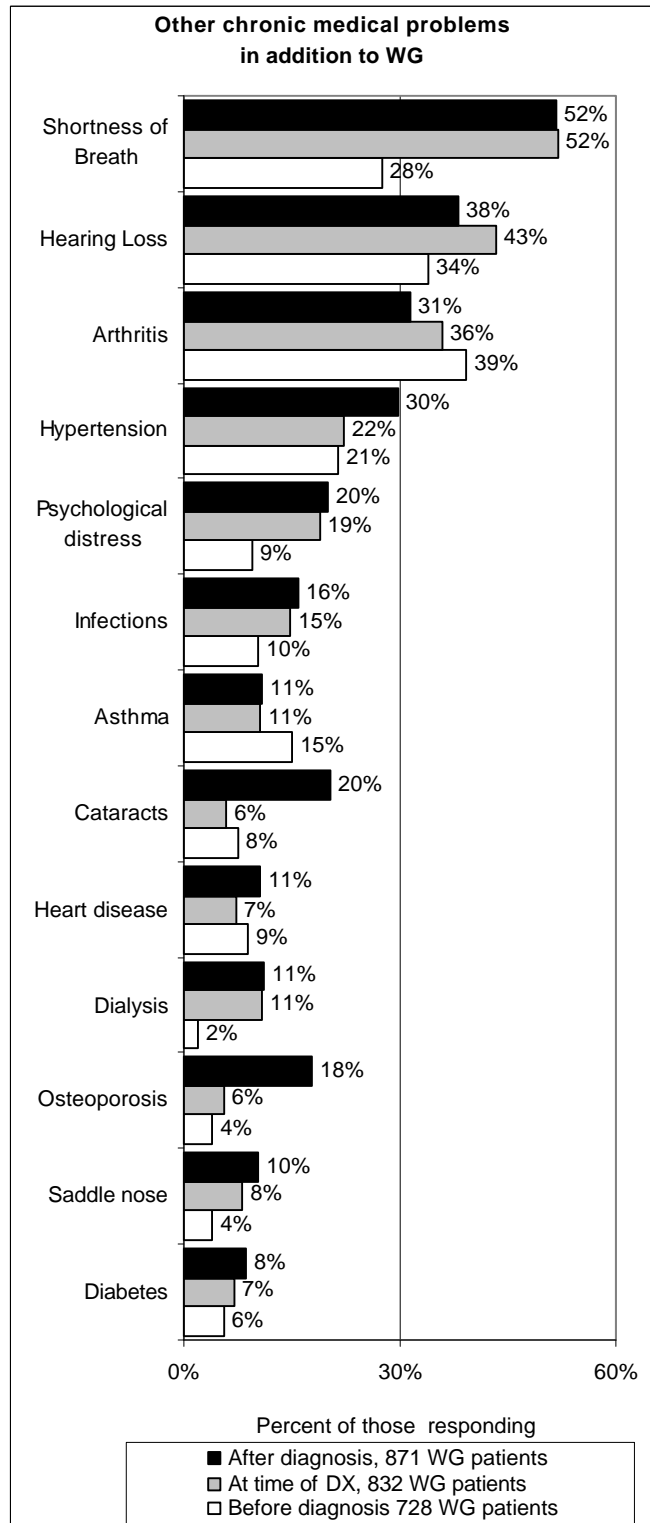
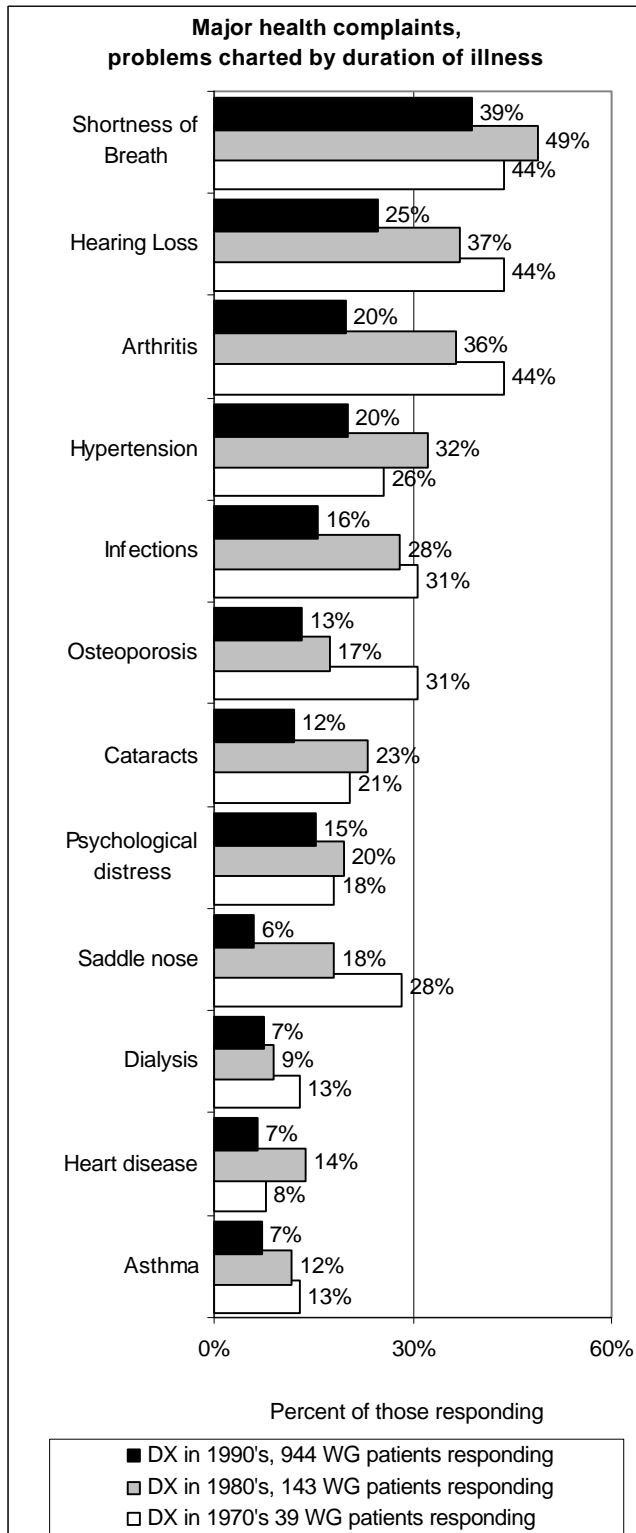
Question 21. On this chart how much had WG affected your life *at the time of diagnosis*?



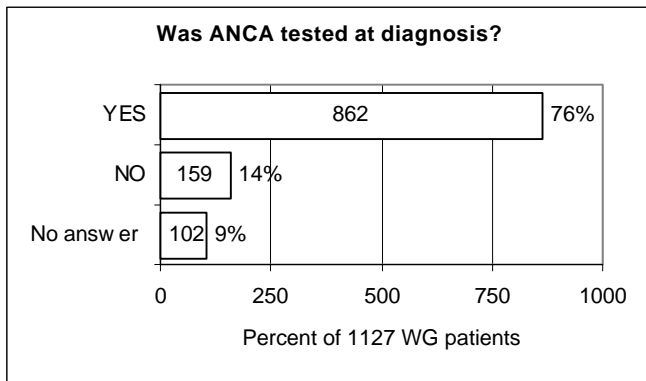
Question 21.



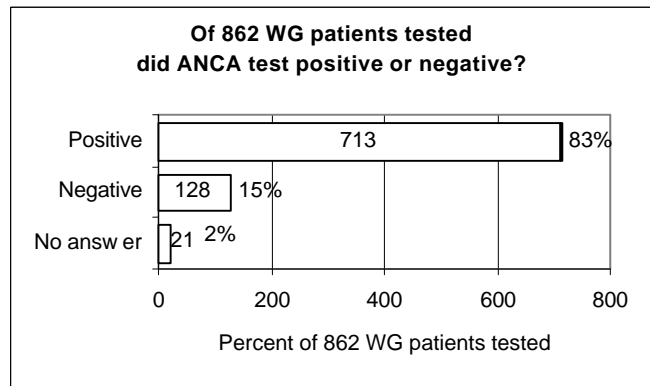
Q-22. The next section asks about *chronic medical problems* that you may have in addition to WG, or as a complication of its treatment.



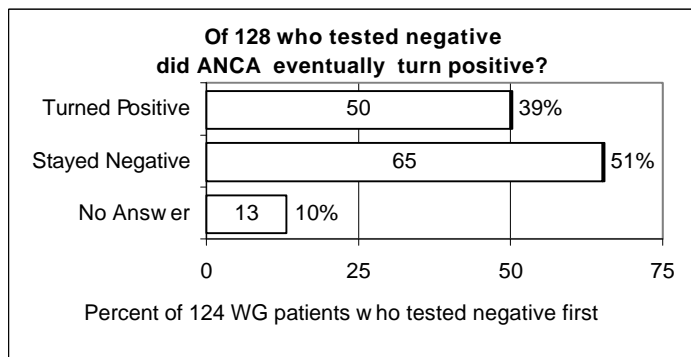
Question 23a. Was *ANCA testing* performed by your physician *at the time of your diagnosis*? Yes ___ No ___



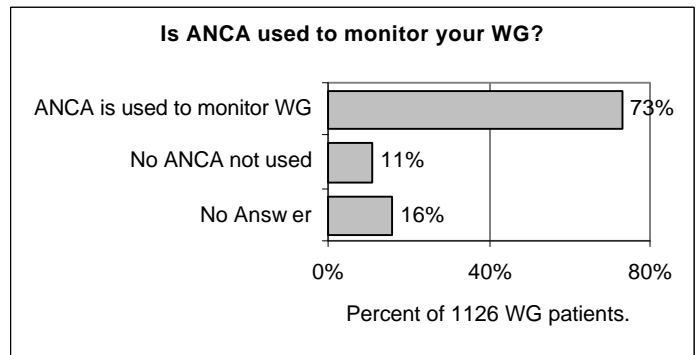
Q23b. If *Yes*, was the test *positive*? Yes ___ No ___



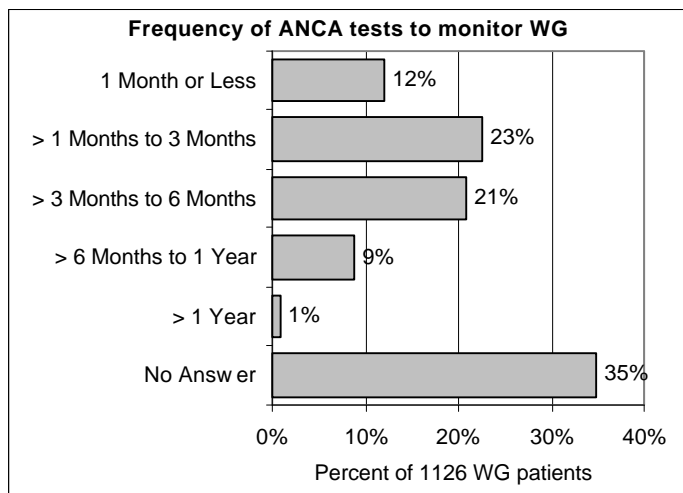
Q-23c. If originally *negative*, did it eventually turn *positive*? Yes ___ No ___



Q-23d. Does your physician now use *ANCA for monitoring* your disease activity? Yes ___ No ___

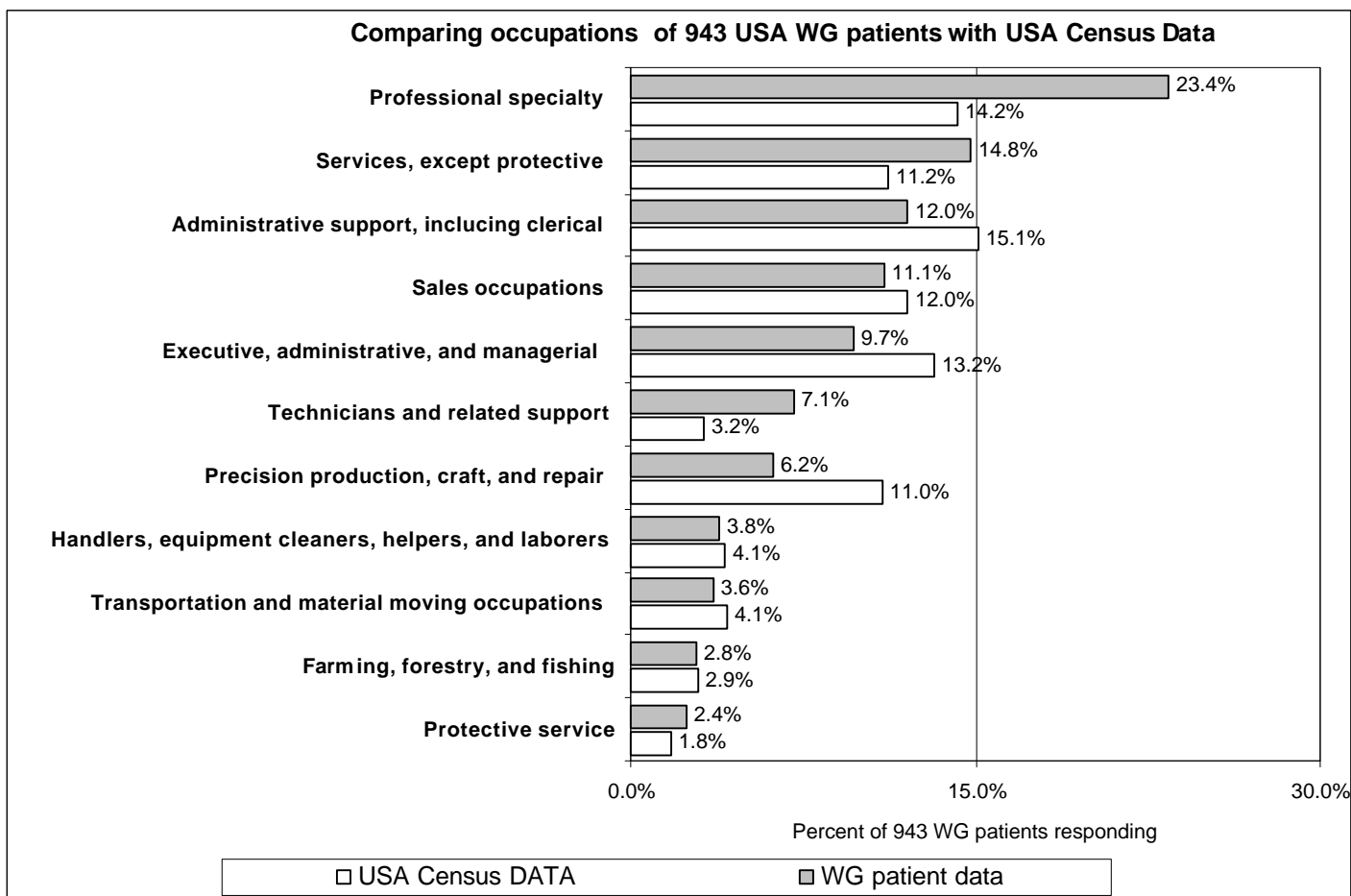


Q-23e. How *often* is the *ANCA test given*? _____



Question 24. List your main occupation(s) before WG diagnosis and area where you lived and worked .

Occupation _____ City _____ State _____ Zip (if known) _____



Some of the occupations Wegener's Granulomatosis patients have had before diagnosis were:

Professional specialty includes: Accountant, Architect, Art Teacher, Attorney, Chemical Eng., CPA, Engineer, Lawyer, Librarian, Minister, Pharmacist, Physician, R.N., Professor, Scientist, Teacher, Writer, etc

Services Include: Aerobic Inst., Apartment Maint., Aquatics Inst., Baker, Beautician, Chef, Childcare, Chiropractic Asst., Day Care, Dietary, Dog Care, Dry Cleaner, Florist, Health Provider, Hospital Employee, House Painter, Meat Cutter, Plumber, Postal Clerk, Printer, Seamstress, Service Rep, Social Worker, Telemarketing, Waitress,

Administrative support, including clerical : Admin asst., Admin., Clerk, Bank Teller, Billing Clerk, Bookkeeper, Cashier, Civil Service, Clerical, Data Entry, Exec Secretary, Legal Secretary, Paralegal, Receiving Clerk, Receptionist, Secretary, Telephone Operator,

Sales occupations include: Antique Sales, Auto Dealer, Carpet Sales, Drug Rep, Equip dealer, Grocer, Insurance, Purchasing Agent, Realtor, Retail sales, Sales Mngr., Salesman, Stock Broker, Store Clerk, Vendor

Executive, administrative, and managerial includes: Administrator, Advertising Mngr., Bank Officer, Business Mngr, CEO/Trade Assn, Chemical Plant Supv, Chief Accountant, Chief Engineer, College Admin., Company Director, Computer Mngr, Court Admin., Director, Labor Rel Mngr, Plant manager, Project Mngr, Software Mngr, Sr. Supervisor, Tech Director, VP, V.P.Gen'l Mngr, Zoo Director

Technicians and related support: Computer Analysis, Computer Operator, Database Specialist, Dental Assistant, Diamond Grader, Draftsman, Geologic Tech, Instrument Tech, Jet Mechanic, Lab Tech, Med Lab Tech, Munitions Inspector, Pharmacy Tech, Programmer, Service Tech, Surgical Tech, Telephone Tech, Video Production

Precision production, craft, and repair: Carpenter, Cement finisher, Contractor, Diesel Mech., Electrician, Foundry, Ironworker, make jewelry, Metal Fab, millwright, Plastic Mach oper, Quality Control, Sheetmetal, Ship building, Tool & Die, Welder.

Handlers, equipment cleaners, helpers, and laborers: Boxboy, Coal shipper, Crane Operator, Fork Lift op, Foundry, Hv Equipment Op, Laborer, Mover, Oil Rigger, Paper Cutter, Print Supply, Propane Filler, Resin Mixer, Septic Tank Pumper, Sewage system inspector, Storekeeper, warehouseman.

Transportation and material moving occupations: Airline Agent, Airline Flt. Dispatcher, Brake Align shop, Bus driver, Courier, Delivery Driver, Dispatcher, Truck Driver, Flight Attendant, Railroad, Semi Driver, Taxi Driver, Trucker

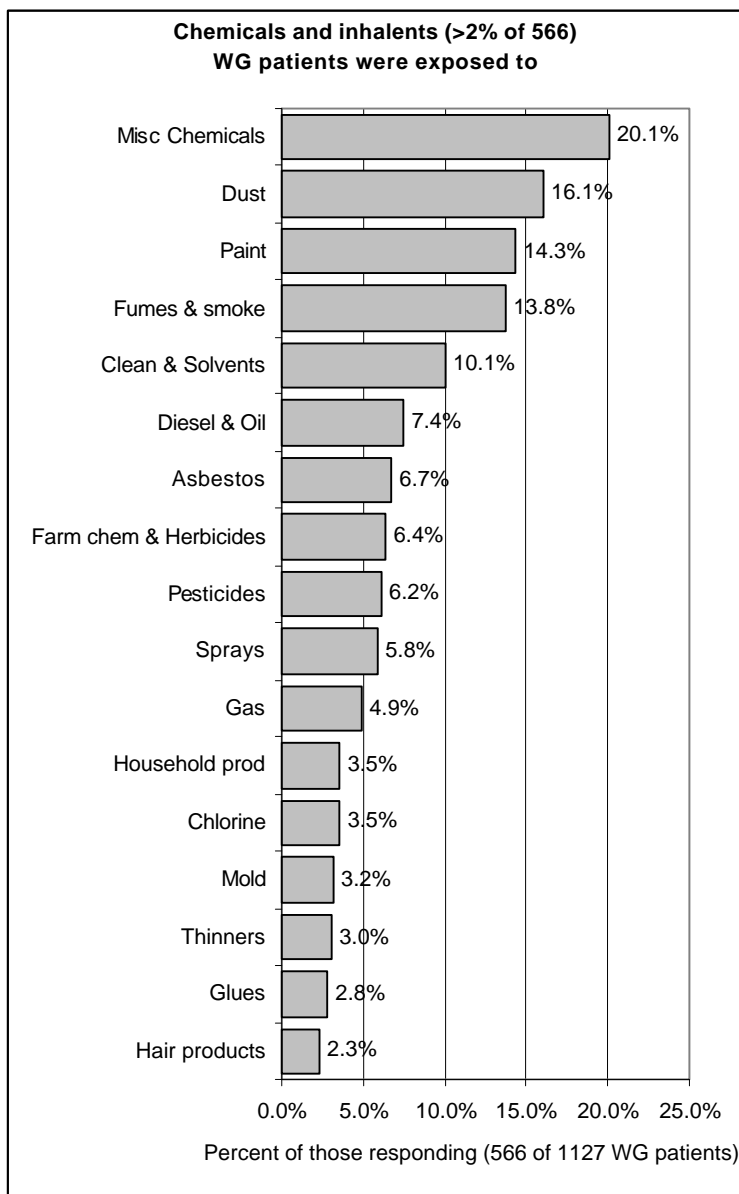
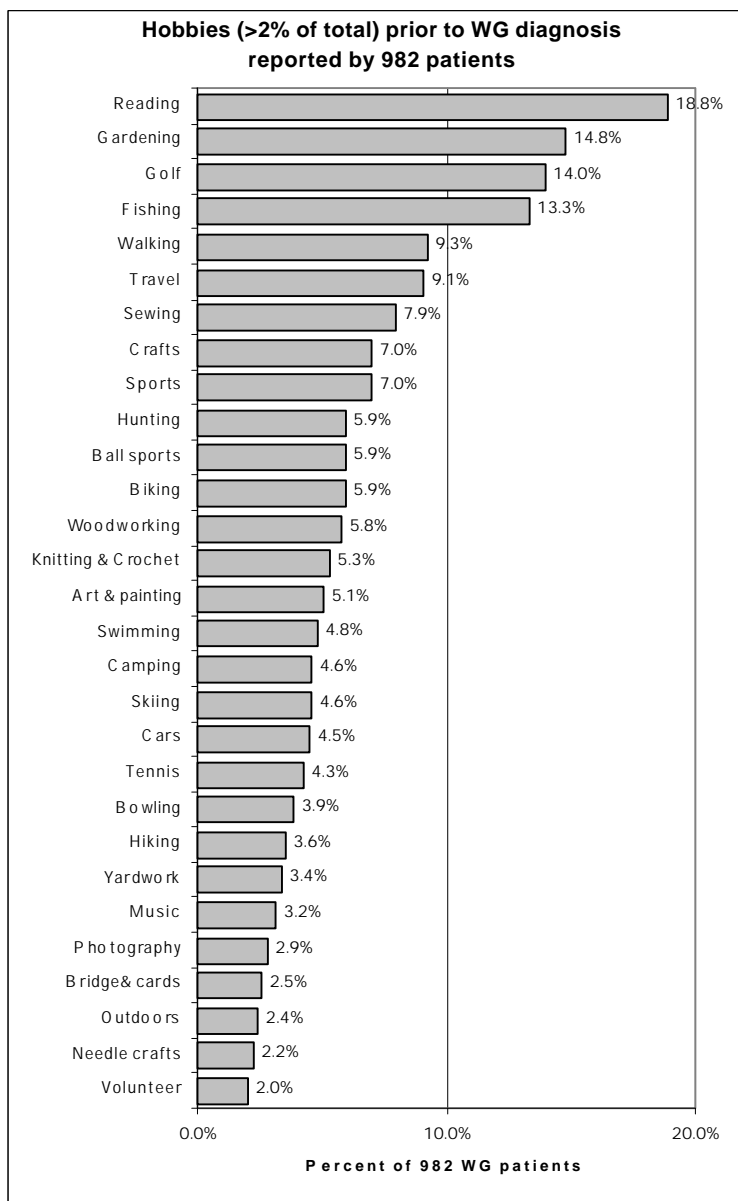
Machine operators, assemblers and inspectors: Assembler, Factory Worker, Hyd. Repair, Machine operator, Machine Repair, Machine Shop, Machinist, mechanic, Nuclear Bomb Assembly, Shipyard Machinist, Steelworker.

Farming, forestry, and fishing: Chem & Fertilizer, Bee Keeper, Crop Duster, Dairy Farmer, Garden Store, Grain Elevator, Greenhouse, Horse trainer, Landscaping, Lawn Service, Rancher

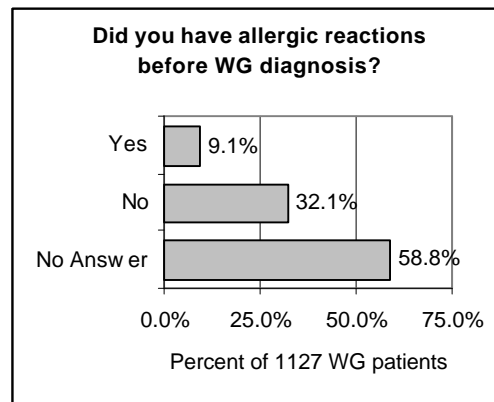
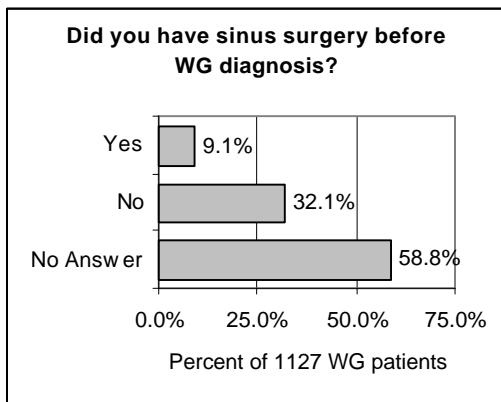
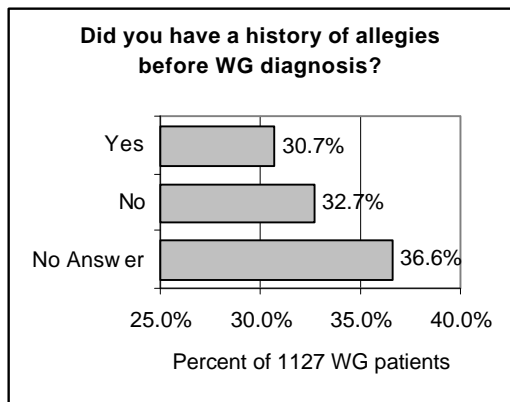
Protective service: Air Force, Crossing Guard, Customs Officer, Deputy Sheriff, Fireman, Forester, Military, Navy, Police (State), Special Deputy, U S Army, US Navy, Firefighter Vol., Forest Fire Lookout

Question 25. What were your *hobbies* before WG diagnosis?

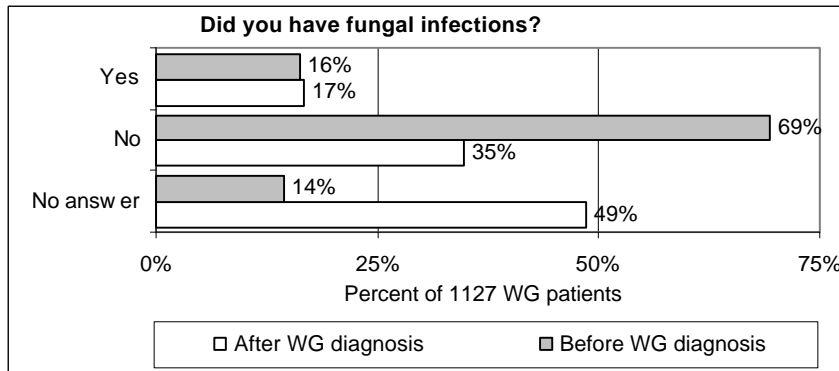
Question 26. What *chemicals or inhalants* did your *job, hobbies or environment* expose you to?



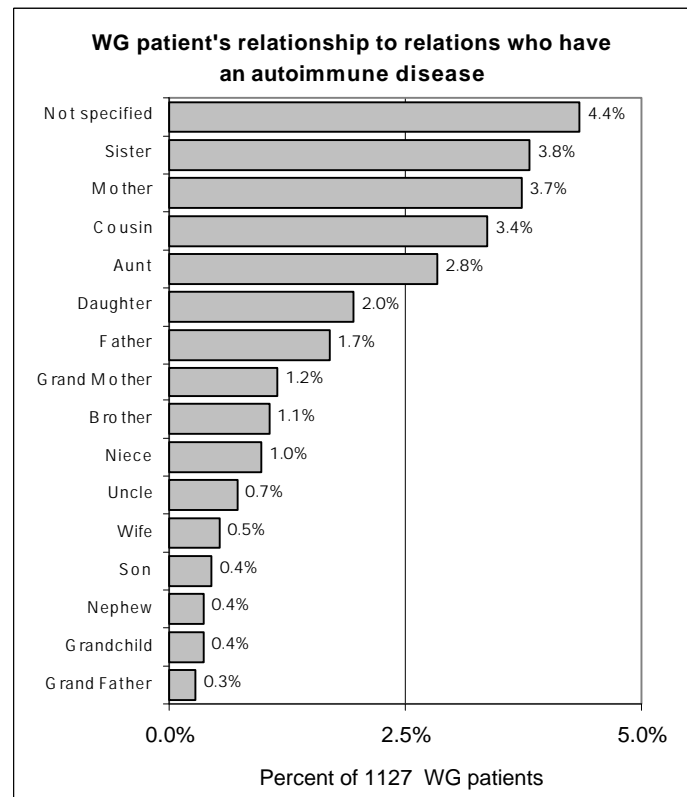
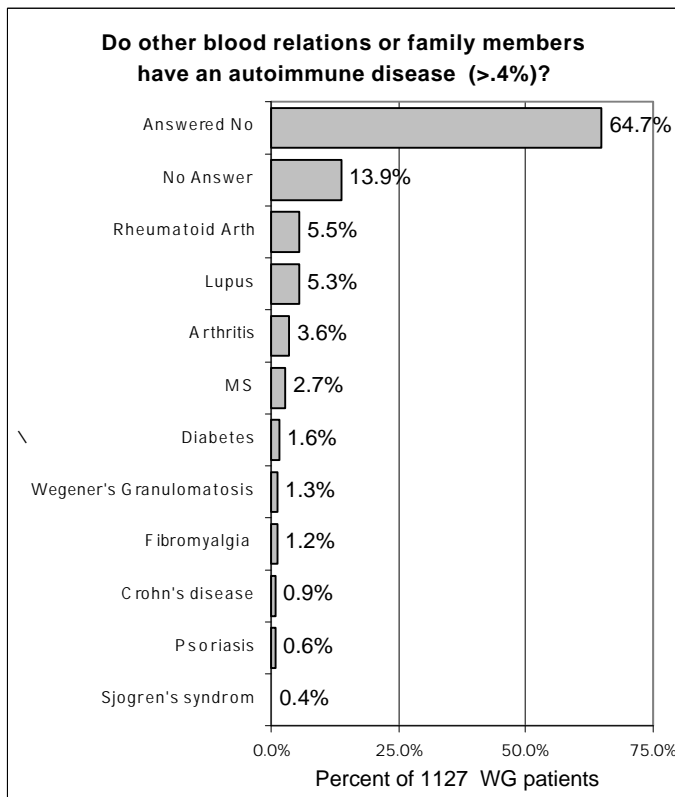
27. Before WG did you have a history of (1) *allergies* _____ (2) *sinus surgery* _____ (3) *allergic reactions* _____



Question 28. Did you have Fungal Infections, Before _____ Now? _____



Q-29. Do *other members* of your family or blood relations *have an auto immune disease?* If so, please specify _____



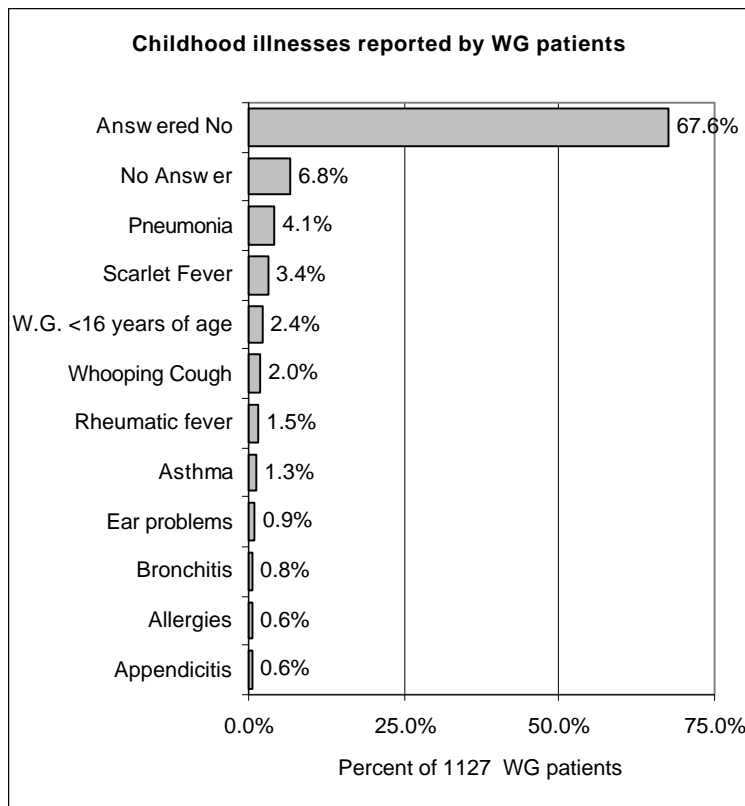
Note There were 15 patients who reported a relation who also had WG, relationship and number of cases were:

1 Father, 2 Brothers, 1 Grandfather, 1 Granddaughter, 3 Uncles, 1 Aunt, 3 Cousins, 1 Nephew, 1 Niece, 1 Daughter

Question 30. Are you a twin? _____

Patient 91 is a twin, 53 year old female DX age 43	Patient 116 is a twin, 34 year old male DX age 28
Patient 129 is a twin, 69 year old female DX age 63	Patient 146 is a twin, 47 year old male DX age 42
Patient 314 is a twin, 49 year old female DX age 41	Patient 269 is a twin, 58 year old male DX age 53
Patient 337 is a twin, 46 year old female DX age 39	Patient 662 is a twin, 55 year old male DX age 51
Patient 444 is a twin, 37 year old female DX age 29	Patient 756 is a twin, 72 year old male DX age 57
Patient 1053 is a twin, 78 year old female DX age 76	Patient 1156 is a twin, 68 year old male DX age 60
Patient 1178 is a twin, 64 year old female DX age 62	
Patient 1054 is a twin, 28 year old female DX age 26	

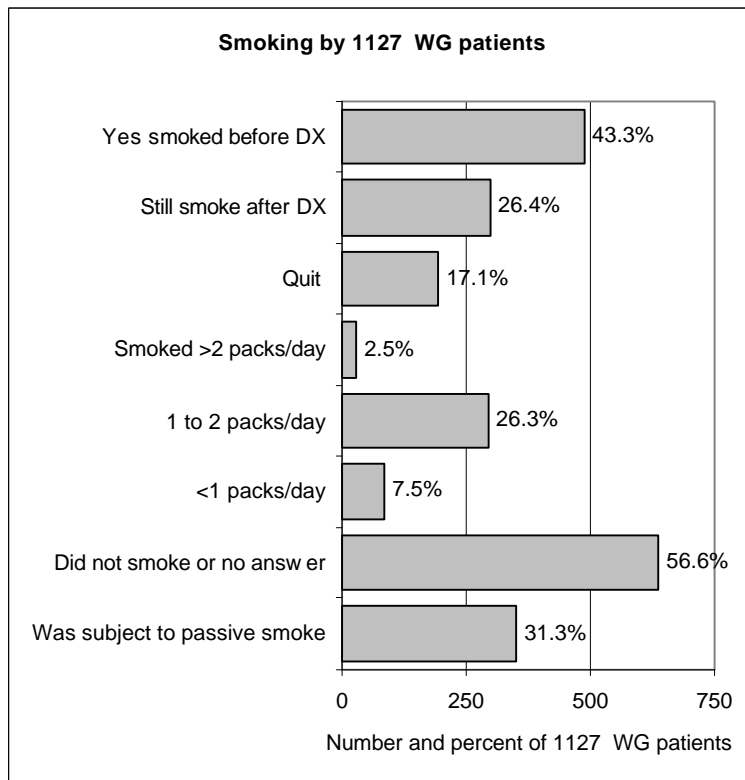
Question 31. Did you have a serious illness as a child _____



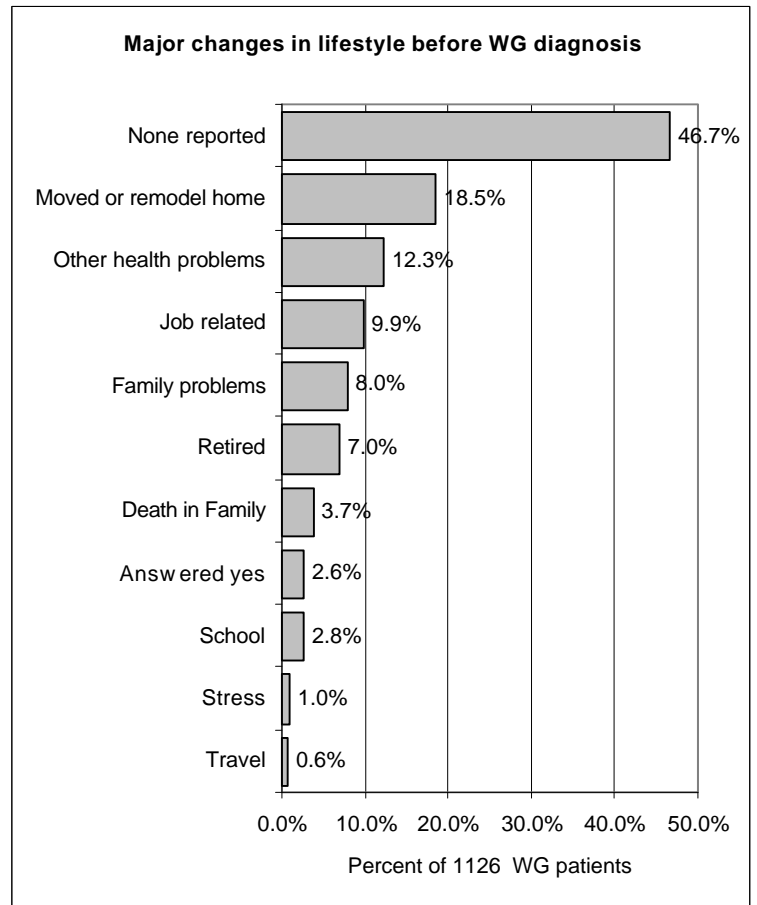
Q-32a. Did you *smoke* before WG? Yes ___ No ___

Q-32b If yes how many packs per day? _____

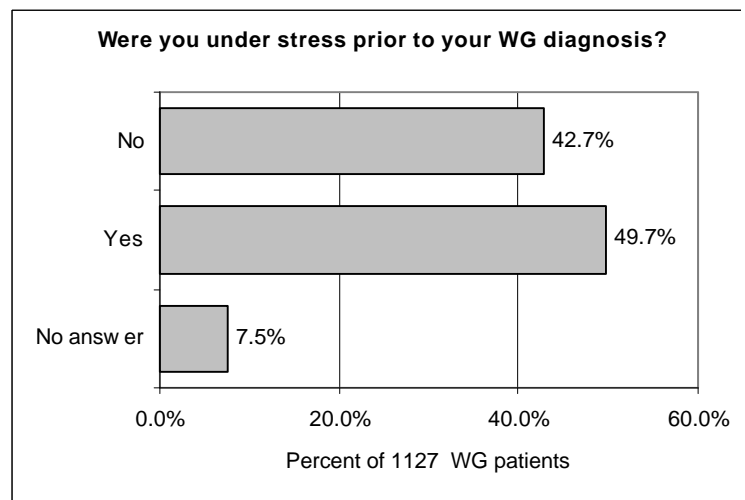
If No, were you subject to *passive* smoke? _____



Q-33. Did you undergo a major lifestyle change prior to the time first symptoms of WG started? (such as moving into a new house, retirement, serious operation etc.) _____

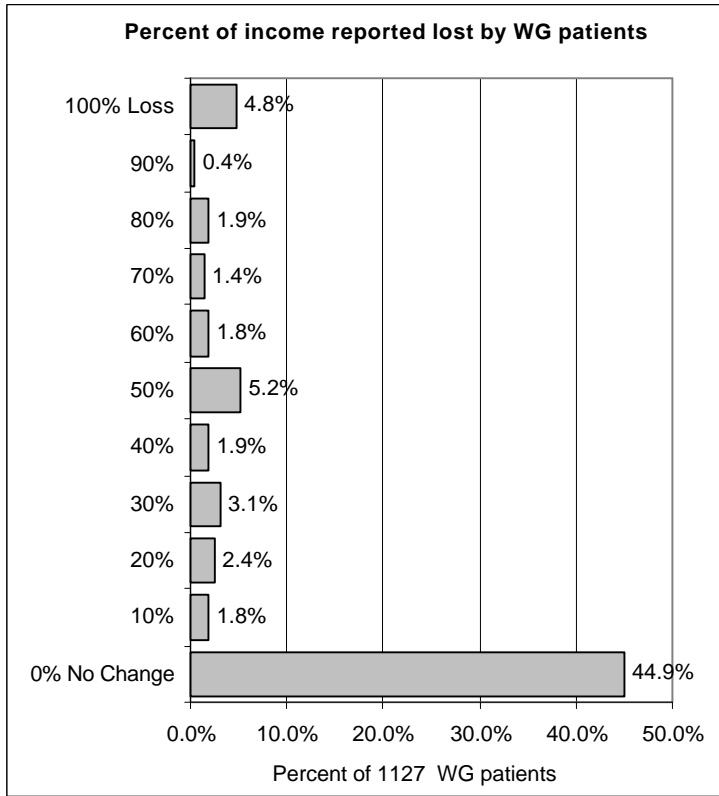


Question 34. Were you under *stress* prior to the time first symptoms of WG started? _____

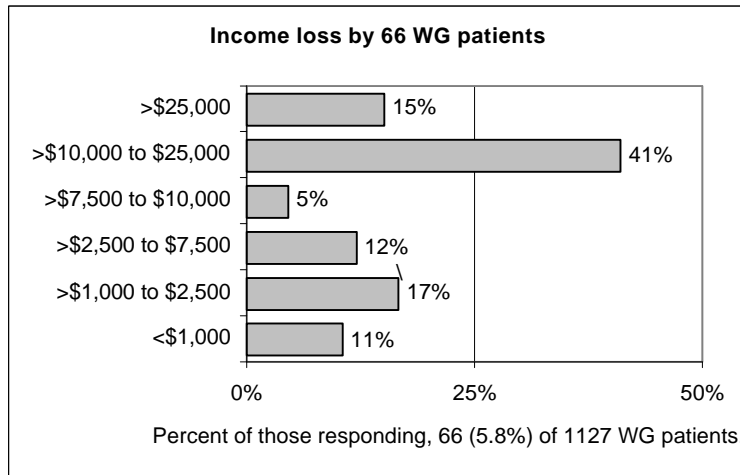


Question 35(a). What has been the economic impact of WG on your annual income?

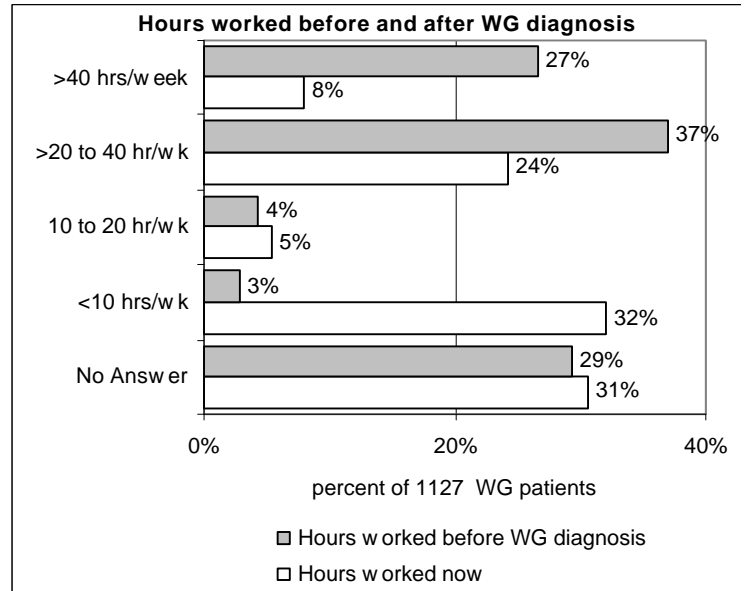
- (a) No change _____ **or** I now make
 (b) ___% (per cent) less income.



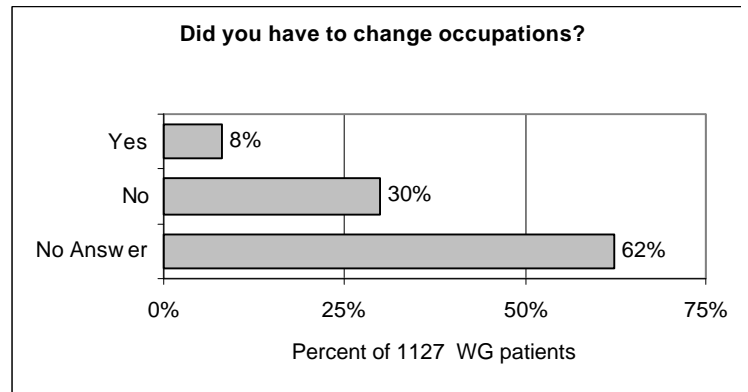
Q-35 (c) or I now make \$_____ less income



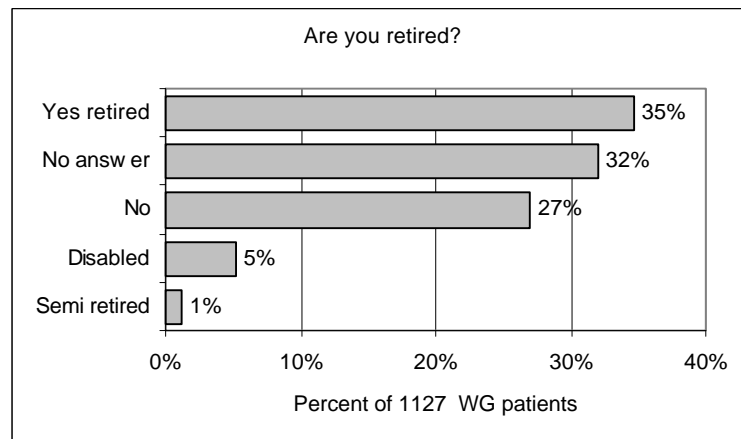
Q-36(a) How many hours a week did you work prior to Wegeners? _____ hrs
 (b) How many hours a week are you now able to work? _____ hrs



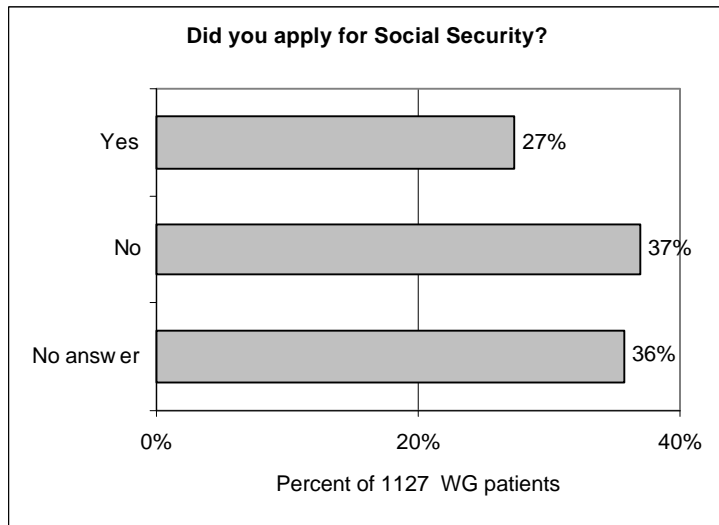
Q-36 (c) Did you have to change occupations? _____



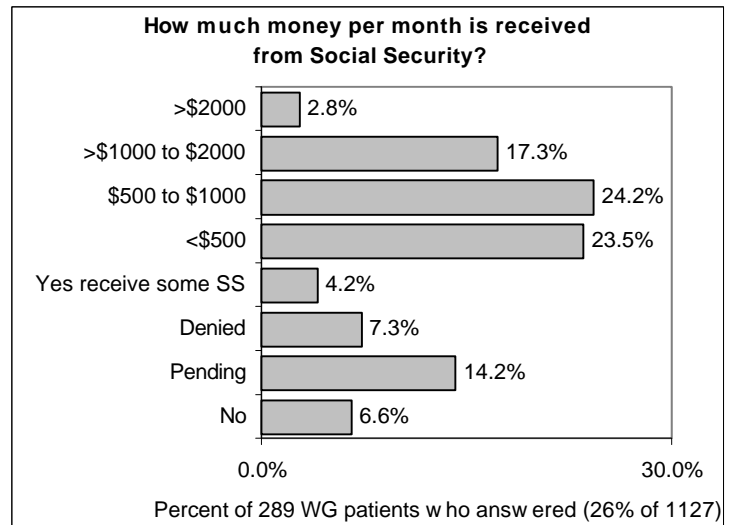
Q-36 (d) are you retired? _____



Q-37(a) Have you applied for disability payment through Insurance or Social Security? _____

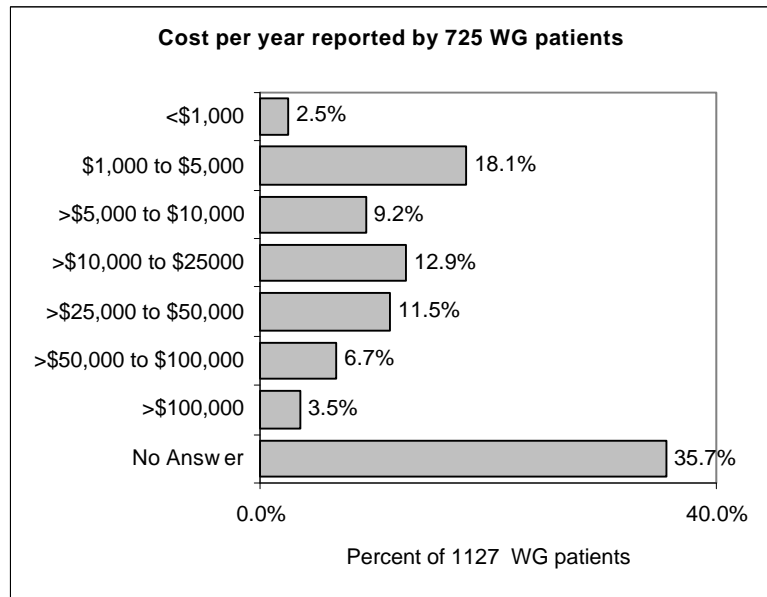


(b) How much money is being obtained per month from these sources? _____



Q-38. What would you estimate the cost per year for your illness. Include lost or lower wages, prescriptions, Doctor, Hospital, Lab etc. whether you or your insurance pays for it. \$ _____ per year

Note the total cost reported by 1127 WG patients was \$24,266,517, this was an average of \$33,517 per patient. The median per patient was \$15,000



Question 39. Is there an important Question that should have been asked on this survey that has not been addressed?

