

The Invisible Risk

The First Cancer Survey

May 2024

The First Invisible Risk Cancer Survey

This survey was conducted anonymously, with no personal details collected.

This report provides an in-depth analysis of survey data gathered from respondents regarding their experiences with cancer, specifically focusing on those with backgrounds in firefighting and other related services. The aim was to capture the experiences of both active and retired professionals, including those from aviation, military, and support roles, and understand the health implications, particularly cancer, associated with their service. Below is a summary of the key findings from the survey.

Findings and Purpose

The results discussed in this document are not derived from a medical or scientific viewpoint but instead reflect a range of responses gathered from real people. Some respondents have lived through cancer or other serious diseases. The aim of this survey is to capture an understanding of how well responders grasp the risks posed by contaminants and cancer in as clear and simple a way as possible.

These questions and answers represent personal opinions and experiences; they do not challenge any scientific or medical findings. The objective is to foster a shared understanding of responder cancer risks and contaminants, helping to assess whether the message is being effectively communicated and understood. Furthermore, this survey aims to highlight where efforts should be directed next. We encourage individuals to honestly reflect on their actions and consider whether they address the concerns raised in this survey.

I would like to express my gratitude to the scientists, suppliers, and officers worldwide who are tirelessly working to reduce these risks through innovation, education, and support. This is not just a United Kingdom issue but a global one.

We remember all those lost to cancer during or after their service, as well as their families. This cause is my personal motivation—ensuring the safety of future generations of responders and their families, while honouring the memory of those who have died. Their loss should not be in vain.

If you'd like to discuss or need support, feel free to contact me at john@simtrainer.uk.

Q1: Cancer Treatment Status

Respondents were asked if they are currently being treated for cancer or have been treated:

Yes: 118

No: 36

Treated and In Remission: 55

Defined as Terminal: 4

Awaiting Test Results: 7

Q2: Occupational Group Membership

Respondents identified their occupational group affiliations outside of firefighting (191 responses):

Aviation FF (serving): 22

Aviation (Retired): 14

Local Authority (Retired): 120

Industrial (Serving/Retired): 6

Military: 5

Air Ambulance: 5

Whole-time/On-call (not part of the UCLan survey): 18

Firefighter Wives: 5

Other: 14

Q3: Other Responses

Respondents provided further details on their associations, with several noting that they were family members of deceased firefighters, particularly emphasizing the need for acknowledgment of post-service exposures to health risks.

Q4: Military Affiliation

Of the respondents with a military background, 18 responses were received:

Army: 3

Navy: 1

RAF: 10

Fire Service (within military): 4

Non-Fire Service Role: 1

Retired: 3

Active Service: 0

Support Staff: 1

Q5: Geographic Location

Respondents indicated where they were based:

United Kingdom: 158

Ireland: 16

Channel Islands: 1

Q6: Duration of Firefighter/Responder Service

Responses showed the length of service for firefighters:

< 5 years: 3

5-10 years: 3

10-20 years: 39

20-30 years: 72

Over 30 years: 68 (retired members with cancer/in remission)

Over 40 years: 4

Q7: Gender

Most respondents were male:

Male: 181

Female: 10

Q8: Age Groups

Respondents' current age groups:

18-25: 12

25-35: 5

35-50: 24

50-60: 52

60-70: 61

70 and over: 48

Q9: Cancer Types

Prostate cancer was the most prevalent, significantly higher than other types:

Prostate: 59

Bowel: 18

Stomach: 0

Testicular: 7

Throat/Oesophageal: 5

Lung: 8

Pancreatic: 2

Breast: 6

Other: 80 (details in appendix)

Benign Tumour: 12

Non-Malignant Growth: 12

Q10: Other Cancer Types

Respondents who felt comfortable shared details of other cancers they had experienced, which are outlined in Appendix 1.

Q11: Cancer Treatment

The type of treatment received:

Surgery: 95

Radiotherapy: 52

Chemotherapy: 55

Monitored by GP: 13

Other (unspecified): 65

Q12: Treatment Details

Further treatment details are shared by respondents in Appendix 2.

Q13: Workplace Cancer Screening

Responses indicated a significant lack of workplace cancer screening:

Yes: 3

No: 177

Do Not Know: 6

Not Sure: 4

Q14: Symptoms and Family History

Respondents were asked about their symptoms and family history prior to diagnosis:

Yes, Some Symptoms: 69

No Symptoms: 69

Not Sure: 14

Family History of Cancer: 15

No Family History: 44

Q15: Cancer Staging

Respondents were asked to identify the stage at which their cancer was diagnosed:

Stage 1: 18

Stage 2: 32

Stage 3: 21

Stage 4: 16

Not Sure: 75

Q16: PSA Levels at Prostate Cancer Diagnosis

For respondents diagnosed with prostate cancer:

2.5-5: 7

5-10: 23

10-20: 14

Over 20: 10

Over 100: 2

Do Not Know: 14

Q17: Gleason Score

Respondents with prostate cancer were asked if they knew their Gleason score:

Yes: 42

No: 14

Maybe: 1

Not Sure: 9

Q18: Among those who shared their Gleason score, the distribution was:

Gleason 4-6: 9

Gleason 7: 27

Gleason 8: 4

Gleason 9: 2

Q19: Recurrence After Treatment

Out of 153 responses, respondents shared whether their cancer had returned after treatment:

Yes: 24

No: 93

Awaiting Results: 17

Yes, treated and now in remission: 12

Yes, untreatable: 6

Maybe: 5

Q20: Age at First Cancer Diagnosis

Participants provided details on the age at which they were first diagnosed with cancer:

20-30 years: 6

30-40 years: 8

40-45 years: 11

45-50 years: 19

50-60 years: 60

Over 60 years: 58

Q21: Family Members Diagnosed with Cancer Around the Same Time

Respondents were asked whether members of their close family were diagnosed with cancer at a similar time (163 responses):

Yes: 19

No: 144

Maybe: 3

Q22: Family Members Diagnosed with Cancer

Of the 19 respondents who answered "Yes" to Q21, they provided further details on who in their family had cancer:

Wife/Girlfriend: 10

Husband/Partner: 2

Mother: 4

Father: 7

Sibling: 2

Child: 3

This question highlights the potential transfer of contaminants from work to home, raising concerns about the health risks posed to firefighters' families.

Q23: Family Member Cancer Types

Details of the cancers diagnosed in family members are provided in Appendix 3.

Q24: Washing Contaminated Work Clothes

Participants were asked whether they washed dirty, smoke-stained clothes at home in the same washing machine as family clothes:

Wash work clothes and kit at home: 80

Wash work clothes and kit at work: 32

Mix of both: 72

This response indicates a significant number of individuals potentially exposed their families to contaminants.

Q25: Clean-to-Clean Work Practices

Of those still working, 49 respondents answered whether they practice "clean to clean" procedures (going to work clean and returning home clean to avoid contaminant transfer):

Yes: 41

No: 8

Q26: Support from Employer/Service for Disease

When asked if they feel fully supported by their service or employer (if still serving), respondents replied:

Yes: 13

No: 49

To some extent, not sure: 17

They could do more: 17

Other: 2

Q27: Further Thoughts on Support

Additional details on perceived support from the employer are in Appendix 4.

Q28: Breathing Apparatus Instructors

Respondents were asked if they were or are currently a breathing apparatus instructor:

Yes: 32

Yes, but only occasionally: 11

No: 124

Was but no longer active: 14

Q29: Compartment Fire Behaviour Instructor

Participants were also asked if they were or are currently a compartment fire behaviour instructor:

Yes: 16

Yes, but only occasionally: 7

No: 148

Was but no longer active: 5

Q30: Mental Health Support

The survey asked if respondents felt they would have benefitted from mental health support in addition to medical intervention:

Yes: 63

No: 40

Maybe: 75

This highlights the demand for mental health resources in addition to physical health treatment.

Q31: GP Understanding and Support

Respondents shared their perceptions of whether their GP fully understood and supported their concerns:

Yes: 78

No: 49

Maybe: 26

Not sure: 23

Q32: Awareness of SNOMED Codes for Firefighters

The survey asked if respondents were aware of the SNOMED codes for firefighters:

Yes: 48

No: 131

Maybe: 9

Q33: Impact of Early Screening

Participants were asked if they thought early screening or more information would have helped:

Yes: 133 (75% of respondents)

No: 9

Maybe: 35

Q34: Awareness of UCLAN Decon Program

Respondents were asked if they were aware of the UCLAN Decon Program:

Yes: 47

No: 131

Maybe: 12

Q35: Post-Incident Cleaning Procedures

Serving respondents were asked if they had clear post-incident cleaning procedures:

Yes: 26

No: 15

Maybe: 12

Q36: Access to Protective Equipment

Respondents were asked if they had access to protective equipment, cleaning wipes, and masks:

Yes: 42

No: 4

Maybe: 5

Q37: Organizational Action on Contaminant Risk

Participants were asked if they believe their organization is doing enough to address contaminant risk:

Yes, good progress to date: 6

No, more needs to be done: 53

Good start, but needs more work: 23

Not sure: 24

Need to know more: 13

Q38: Logging Contaminant Exposure

Of those still serving, respondents were asked if they log their contaminant exposures:

Yes: 15

No: 23

Not sure: 4

Ad hoc, not formally done: 7

Q39: Diagnosed Medical Conditions

Respondents were asked if they had been diagnosed with any of the following medical conditions:

Heart Disease/Cardiovascular events: 33

Heart Attack/Stroke: 15

Lung Disease (e.g., Occupational Asthma, COPD): 27

Diabetes: 31

Mental Health Issues (e.g., PTSD): 27

Other: 17

Q40: Other Medical Conditions

Further details on other diagnosed conditions are provided in Appendix 5.

Q41: Willingness to Participate in Future Surveys

Respondents were asked if they would participate in a follow-up survey focused on non-cancer-related health issues:

Yes: 145

No: 10

Maybe: 34

Appendix 1

Here is the breakdown of cancer types mentioned by participants:

1. Skin Cancer (Multiple Types) – 24 mentions
 - a. Basal Cell Carcinoma (BCC): 8 cases
 - b. Melanoma: 6 cases
 - c. Other/unspecified skin cancers: 10 cases
2. Bladder Cancer – 10 mentions
3. Non-Hodgkin Lymphoma – 9 mentions
4. Blood/Blood-related Cancers – 8 mentions
 - d. Leukaemia (various types): 6 cases
 - e. Other blood cancers: 2 cases
5. Bone Cancer – 3 mentions
6. Bowel/Colorectal Cancer – 3 mentions
7. Kidney Cancer – 3 mentions
8. Prostate Cancer – 2 mentions
9. Mesothelioma (Various Types) – 2 mentions
10. Liver Cancer – 2 mentions
11. Lung Cancer – 1 mention
12. Oral Cancer – 1 mention
13. Parathyroid Cancer – 1 mention
14. Penile Cancer – 1 mention
15. Cervical Cancer – 1 mention
16. Cholangiocarcinoma (Bile Duct Cancer) – 1 mention
17. CUP (Cancer of Unknown Primary) – 1 mention
18. Ear Cancer – 1 mention
19. Stoma (Colitis/Ostomy-Related) – 2 mentions
20. Other Cancers (Non-categorized, awaiting results) – 4 mentions
21. No Cancer Diagnosed – 8 mentions

Appendix 2

Further treatment details as shared by respondents:

1. Inoperable.
2. Hormone therapy.
3. Areas of Basal Cell Carcinoma (BCC) were excised; one area had a skin graft due to location on the nose.
4. Ongoing lymphoedema massage.
5. Radioactive iodine therapy following thyroid surgery.
6. Monthly assessments and medication for intra-abdominal and subcutaneous treatment.
7. Active surveillance by the urology department, including two biopsy procedures (one without anaesthetic and one under general anaesthetic).
8. Herceptin/Monoclonal antibodies for one year.
9. Intravenous immunotherapy.
10. Right kidney and both adrenal glands removed.
11. Brachytherapy in 2007, cleared but returned in 2023.
12. None.
13. Not currently having treatment.
14. N/A.
15. Refer to Q10 answer.
16. Monitored by hospital.
17. Immunotherapy.
18. BCG treatment.
19. Not diagnosed with cancer.
20. N/A.
21. Tamoxifen tablets for the next 5 years.
22. None.
23. N/A.
24. None.
25. Awaiting diagnosis.
26. Hormone therapy and brachytherapy.
27. No cancer diagnosis.
28. Terminal at point of diagnosis; became too unwell for first chemotherapy.
29. Prostatectomy.
30. BCG.
31. Active surveillance by urologist.
32. Not undergoing any treatment.
33. None.
34. Hormone replacement therapy (HRT) injections.
35. Two episodes of bladder cancer since retirement.
36. BCG.
37. Donor-sourced bone marrow transplant (unsuccessful) and Car T Cell therapy.
38. Immunotherapy.

39. Cream applied.
40. No cancer as per Q1.
41. Monitoring through blood and bone marrow samples by haematologist.
42. N/A.
43. Monitored by hospital.
44. N/A; had to select one of the options.
45. Clinical trial for Stage 3 prostate cancer; 5-year trial recently extended to 10 years.
46. Filling in questionnaire posthumously for a former colleague who is now deceased.
47. Prostate removed in October 2018; cancer was encapsulated in the prostate.
48. N/A.
49. Not currently receiving any treatment.
50. Removal of colon and replacement with stoma due to ulcerative colitis; could be smoke-related but consultant did not put in writing.
51. Removal at local clinic.
52. Colon cancer successfully removed.
53. Three-monthly injection and four tablets a day.
54. N/A.
55. Six-monthly reviews via cystoscopy.
56. First treatment involved eight weeks using cream; second treatment involved surgery.
57. Skin check and CT scans.
58. Emergency surgery to remove a tumour that perforated the bowel, followed by two sessions of 12 doses of Folfox and Oxaliplatin over two years.
59. Hormone injections.
60. Removal of squamous skin cancer behind left ear and skin graft from neck.
61. Awaiting tests.
62. Brachytherapy.
63. Permanent stoma after bowel cancer diagnosis; hormone treatment for prostate and monitoring every two months.
64. Referred to Addenbrookes; awaiting appointment.
65. Awaiting further tests with surgery in the next two weeks and possibly radiation therapy to follow.
66. No treatment as no cancer diagnosis.
67. Patient did not receive treatment; died seven weeks after diagnosis. Delays in operations eliminated any chance of treatment; cancer checks during service might have saved his life.

Appendix 3

Details of the cancers diagnosed in family members:

1. Lymphoma.
2. Not applicable.
3. Bowel cancer.
4. Answered "no" to Q21 but could not proceed without answering Q22.
5. Answer to previous question is "no," but had to provide an answer to complete and submit the questionnaire.
6. Incorrect answer due to inability to proceed without selecting an option, despite answering "no" to Q21.
7. Cancer of the womb, Stage 2/3.
8. Prostate cancer.
9. Non-Hodgkin's lymphoma.
10. Breast cancer.
11. Skin cancer (Basal cell carcinoma) on back successfully excised in February 2023.
12. Breast cancer.
13. Melanoma.
14. Skin cancer.
15. Prostate cancer.
16. Ovarian cancer.
17. Mother had skin cancer; father had bowel cancer.
18. Acute Lymphoblastic Leukaemia.
19. Breast and liver cancer.
20. Terminal bowel cancer; was a firefighter for 32 years.
21. Breast cancer.
22. Growth on liver detected after X-ray on hip; scans revealed numerous inoperable growths in various places, including bone cancer.
23. Lung cancer; sadly deceased after a long struggle.
24. Essential thrombocythemia.
25. Prostate cancer.
26. Prostate cancer.
27. Wife had breast tumour and has passed away; first brother had prostate cancer and is currently in treatment; second brother has passed away from an unknown type of cancer.
28. Breast cancer.
29. Lung cancer; former Sub Officer with 30 years of service.
30. Prostate, lymph, and bone cancers.
31. Breast cancer.
32. Throat cancer.
33. Colon cancer.

Appendix 4

Additional details on perceived support from the employer:

1. Just starting to take an interest despite the problem not being new. Lack of awareness, understanding, and concern in senior management in other aspects of the business.
2. Although they were unaware of my personal circumstances, I have never had any contact or enquiry about cancer during service or since retirement.
3. (No comment provided)
4. I am fully supported at all levels even though I am the managing director.
5. Used maternity leave, annual leave, and six weeks of sick leave to get through one year of treatment.
6. Require better training and knowledge, including guidance from subject experts, seminars, and Zoom meetings.
7. Maintained full pay during my time off work (4 years).
8. Believe that screening and private medical care should be offered but aren't. Individual and appropriate showering facilities and equipment cleaning facilities should be provided but aren't.
9. No one has ever been in contact.
10. Diagnosed only after retirement.
11. Retired.
12. Procedures and information are only being implemented as people have done research and educated others themselves. Not enough is being done by our employer to educate and inform.
13. Awaiting diagnosis.
14. Wellbeing checks are inconsistent.
15. Not known.
16. Very supportive.
17. Initially, they were ignorant of the risk, etc.
18. I don't think my brigade does or has done any cancer follow-ups.
19. Management needs to be more forthright with SOGs after a fire and decontamination procedures.
20. I was supported but occasionally feel that more could have been done or offered.
21. They kept me on full pay for 12 months, not 6, but had very little contact from them and nothing at all since retirement.
22. They fully looked after me post-diagnosis.
23. They could do more; no screening, no support. Availing of an employee-led benevolent leave program, but nothing from management.
24. Out on full pay from the benevolent fund, settled by firefighters, and allowed to go back on light duties until fully fit for work.
25. Fire service pays lip service.
26. More shower facilities and better PPE standards are needed.
27. Retired.

28. Zero help.
29. The local authority is way short of where we need them to be.
30. I don't think the understanding of the risk is captured within the MOD. There is a small cell aware and willing to drive the message, but there is so much red tape with rank, and it's all locally pushed and word of mouth.
31. Retired with a back injury; always had a weak bowel in service, blamed on smoke, water, and food.
32. We had to wear contaminated kit as we were issued only two jackets.
33. I haven't informed them of my cancer.
34. Pension frozen, only reinstated after cancer diagnosis, but written off due to service injury.
35. Retired over 30 years ago.
36. Not their problem.
37. Was medically retired eventually after they tried to sack me under capability; haven't heard from them since retiring.
38. On sick leave for 10 months for treatment but put on capability on my first day back at work.
39. Given paid time off for hospital consultations and recovery period.
40. Never informed of any help I could receive.
41. Service was unaware of the diagnosis.
42. Cancer only diagnosed after retirement, so had zero support from the employer.
43. No support at all; was more concerned about retraining and getting me back on the run, so I resigned.
44. No support whatsoever.
45. Retired in 2016.
46. Via organization health services and on-call doctor, also via union and line manager.
47. They don't know.

Appendix 5

Further details on other diagnosed conditions:

1. Experienced a TIA in November 2022 at work; possible reaction to COVID-19 vaccine.
2. Cerebral vascular disease.
3. Hypertension.
4. Became type 1 diabetic after pancreatic surgery.
5. Possibly had a TIA and signs of an aneurysm, leading to regular brain scans. Diagnosed with PTSD in 2002, related to an incident in 1979, and received helpful counselling.
6. Diagnosed with PTSD in 2014 and cancer in 2016; believe PTSD contributed to the cancer.
7. Atrial fibrillation (AF).
8. Heart attack at age 40.
9. Early menopause.
10. Hairy cell leukaemia, COPD, type 2 diabetes, skin cancer.
11. Sarcoidosis.
12. Kidney stones.
13. Ectopic cardiac rhythms.
14. Type 2 diabetes, taking insulin.
15. Heart attack in June 2021; PTSD and anxiety controlled by medication.
16. Chronic kidney disease, anxiety, and depression.
17. Anxiety.
18. Left bundle branch block, atrial fibrillation, and thickening of the heart muscle.
19. Heart attack and now experiencing angina.
20. Hemochromatosis.
21. Bacterial endocarditis with replacement of two valves (aortic and mitral).
22. Autoimmune condition affecting the lungs principally.
23. Crohn's disease.
24. Early stages of COPD, along with depression and PTSD.
25. Chemotherapy-induced peripheral neuropathy.
26. Heart attack followed by heart failure.
27. Colitis leading to colon removal and stoma installation; all occurred after retirement, not reported to the brigade as already on pension.
28. Type 2 diabetes.
29. Myocardial infarction in October 2017.
30. Benign prostate enlargement, multiple spinal disc prolapses, RSDS/CRPS, bilateral eyesight-threatening loss, type 2 diabetes, stomach and bowel bleeds, anaemia.
31. Adrenal gland growth.
32. Possible connection with assaults during service and incidents such as the Brixton riot.
33. Lifelong asthmatic.

34. Type 1 insulin-dependent diabetes since January 2013.
35. Medically discharged with PTSD due to service injury.
36. Not formally diagnosed with PTSD, but experiences weird and vivid dreams at night, such as searching for fire gear or driving to an incident and forgetting the route.
37. Sepsis.
38. Lung cancer.