

# Impact of the COVID-19 pandemic on people living without a functioning spleen in Australia

Please complete the survey below.

Your answers will be kept strictly confidential and you will not be identified. This survey is voluntary, and you are under no obligation to complete it. Please remember to press the submit button at the end of the survey, even if you have not answered all the questions.

Thank you for your time and effort!

## Your Demographics To get to know you better

Please select your age range:

- < 20
- 20-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- >80

What is your gender?

- Male
- Female
- Other
- Prefer not to answer

Which country were you born in?

- Afghanistan
- Albania
- Algeria
- Andorra
- Angola
- Anguilla
- Antigua & Barbuda
- Argentina
- Armenia
- Australia
- Austria
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia
- Bosnia & Herzegovina
- Botswana
- Brazil
- Brunei Darussalam
- Bulgaria
- Burkina Faso
- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- China - Hong Kong / Macau
- Colombia
- Comoros
- Congo
- Democratic Republic of Congo (DRC)
- Costa Rica
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Fiji
- Finland
- France
- French Guiana
- Gabon
- Republic of The Gambia
- Georgia
- Germany

- Ghana
- Great Britain
- Greece
- Grenada
- Guadeloupe
- Guatemala
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Honduras
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Israel and the Occupied Territories
- Italy
- Ivory Coast (Cote d'Ivoire)
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Democratic Republic of Korea (North Korea)
- Republic of Korea (South Korea)
- Kosovo
- Kuwait
- Kyrgyz Republic (Kyrgyzstan)
- Laos
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Liechtenstein
- Lithuania
- Luxembourg
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Republic of Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar/Burma
- Namibia
- Nepal
- New Zealand
- Nicaragua
- Niger
- Nigeria
- North Macedonia, Republic of
- Norway
- Oman
- Pacific Islands
- Pakistan
- Panama
- Papua New Guinea

- Paraguay
- Peru
- Philippines
- Poland
- Portugal
- Puerto Rico
- Qatar
- Reunion
- Romania
- Russian Federation
- Rwanda
- Saint Kitts and Nevis
- Saint Lucia
- Saint Vincent and the Grenadines
- Samoa
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovak Republic (Slovakia)
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Sweden
- Switzerland
- Syria
- Tajikistan
- Tanzania
- Thailand
- Netherlands
- Timor Leste
- Togo
- Trinidad & Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks & Caicos Islands
- Uganda
- Ukraine
- United Arab Emirates
- United States of America (USA)
- Uruguay
- Uzbekistan
- Venezuela
- Vietnam
- Virgin Islands (UK)
- Virgin Islands (US)
- Yemen
- Zambia
- Zimbabwe

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Which Australian state do you live in?

- Victoria
- Tasmania
- Queensland
- Other

Other Australian state that you live in:

- New South Wales    ACT  
 South Australia    Northern Territory  
 Western Australia

What is your current postcode of residence?

\_\_\_\_\_ (4 digit code, e.g. 3000)

**Questionnaire This section should take about 5 minutes to complete**

**If you do not feel comfortable answering a question you may leave it blank and move onto the next question. Please remember to press the submit button at the end of the survey, even if you have not answered all the questions.**

Reason for splenectomy or reason for non-functioning spleen:

- Trauma    Blood Disorder  
 Blood cancer    Cancer (e.g. bowel cancer)    Not planned (at the time of another operation)    Hyposplenism (been informed your spleen does not work)  
 Other

Other reason for non-functioning spleen:

\_\_\_\_\_

Have you had your spleen removed surgically?

- Yes  
 No

If yes, how long ago was it removed?

- 0-1 year ago  
 1-5 years ago  
 > 5 years ago

If no, when did you discover that your spleen was not working?

- 0-1 year ago  
 1-5 years ago  
 > 5 years ago

Has the COVID-19 pandemic, AT ANY TIME, had any impact on your ability to:

- Visit your GP (either in person or telehealth appointment), or visit a hospital  
 Exercise  
 Access food  
 Access medication  
 Maintain stable accommodation  
 Maintain personal relationships  
 Care for children at home  
 Obtain your 'spleen vaccines' (Prevenar 13, Pneumovax 23, Meningococcal etc)  
 (You may tick more than one answer)

Have you experienced, since March 2020, any government placed restrictions in your primary area of residence?

- Yes  
 No

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If yes, what restrictions have you experienced?

- Lockdown
  - Travel distance restrictions
  - Reasons for leaving the house
  - Public/private gathering numbers
  - Curfew
  - Social distancing
  - Other
- (You may tick more than one answer)

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Other restrictions experienced:

\_\_\_\_\_

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Has your employment status changed since the start of the declared pandemic (i.e. since 11/03/2020)?

- Yes
- No

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If yes, how?

- Less hours/cancelled shifts
  - Lost job
  - Business suffered financial problems
  - More hours
  - Changed job
  - Other
- (You may tick more than one answer)

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Other employment changes:

\_\_\_\_\_

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During this pandemic, do you feel that more support should be offered to people who do not have a functioning spleen?

- Yes
- No

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If yes, what kind of support?

- Financial
  - Emotional
  - Mental
  - Other
- (You may tick more than one answer)

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Other kinds of support that should be offered:

\_\_\_\_\_

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Did you drink more alcohol during the lockdowns?

- Yes
- No

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If yes, has this increased drinking continued after the lockdowns has ended?

- Yes
- No

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Was there an increase in recreational drug (marijuana, ecstasy etc.) use during this pandemic (other than alcohol)?

- Yes
- No
- I do not use recreational drugs

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Have you emailed or called Spleen Australia during the pandemic to ask about the virus or the COVID vaccines?

- Yes
- No

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If yes, how often?

- Once
- 1-2 times
- 3+ times

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Did you find that the advice you received from Spleen Australia was:

- Helpful  
 Somewhat helpful  
 Not very helpful  
 Did not ask for advice
- 

If not very helpful, why?

\_\_\_\_\_

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Have you looked at the Spleen Australia website for information about the pandemic?

- Yes  
 No
- 

If yes, how often?

- Once  
 1-2 times  
 3+ times
- 

Have you received at least one dose of a COVID-19 vaccine?

- Yes  
 No
- 

If yes, which COVID-19 vaccination did you receive?

- Astra Zeneca  
 Pfizer  
 Moderna  
 Other
- 

Other COVID-19 vaccination received:

\_\_\_\_\_

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If no, why?

- Waiting to get the vaccination that I prefer  
 Unaware of eligibility  
 Unable to go to the GP, pharmacy, mass vaccination centre or hospital to have it  
 Do not want to get it  
 Did not know it was available  
 Other
- 

Other reason for not receiving a COVID-19 vaccination:

\_\_\_\_\_

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Do you feel that current options of COVID-19 vaccinations (Pfizer, Astra Zeneca, Moderna, other) are safe to have?

- Yes  
 No
- 

If no, why?

- Worried about reported blood clotting connected to the Astra Zeneca vaccination  
 Worried about potential side effects  
 Worried these vaccinations were developed too quickly  
 Worried about the overall safety of vaccinations  
 Other
- 

Other concerns about the COVID-19 vaccinations:

\_\_\_\_\_

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What impacts, if any, has COVID-19 generally had on your life?

- I feel more susceptible to the COVID-19 disease because I do not have a functioning spleen
  - I worry about the effect COVID-19 might have on my physical health
  - I worry about the effect COVID-19 might have on my mental health
  - I worry about the effect COVID-19 might have on my financial situation
  - I worry about the effect that COVID-19 might have on my friends and family
  - I feel optimistic about the future after COVID-19
  - No impact
  - Other
- (You may tick more than one answer)

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Other impacts on your life:

\_\_\_\_\_

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Was the pandemic a trigger for you to register with Spleen Australia?

- Yes
- No

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If no, why?

- I registered before the pandemic
- I would have registered regardless of the pandemic
- Other

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Other triggers for registering with Spleen Australia:

\_\_\_\_\_

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Have you ever tested positive for the COVID-19 disease?

- Yes
- No

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Use this section to write any further comments you wish to add:

\_\_\_\_\_

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**Questionnaire Concluded**

This is the end of the survey.

Thank you for completing the survey to its end. It will help us better understand the quality of life impacts that are linked to the COVID-19 pandemic amongst patients with non-functioning spleens living in Australia.

For further queries, Spleen Australia can be reached on 03 9076 3828 or spleenregistry@alfred.org.au

Please press Submit to submit your answers and finish the questionnaire.