

PCSIG Patient Acceptability Survey



Thank you for taking the time and volunteering to help.

[Company name] are creating a process that intends to make the collection of blood samples more convenient, by enabling them to be collected either at home, or somewhere more convenient for you, such as your local pharmacist. The purpose of this survey is to get your thoughts about your current experiences and your ideas in order to provide a good, or better, experience in the future.

The survey has [5-7] sections as follows:

- **About you (9-10 questions, about 5 minutes):** Helps researchers group responses better to understand different people's needs.
- **Current standard approaches (4 questions, about 3 minutes):** Understand what already works well and areas that can be improved
- **Current novel approaches (4 questions, about 3 minutes):** Understand what you think about novel (i.e. different) sampling approaches
- **What is needed (2 questions, about 3 minutes):** Understand what you need when giving blood for it to be a good experience
- **Anything else (1 question, about 3 minutes):** Opportunity to share anything you think we've missed
- **Reimbursement (1 question, about 3 minutes):** Repayment of your time for carefully completing this survey

Your responses will be seen by [insert as appropriate]. Following review, they will remove any information that can identify you and this de-identified information will be shared with [Insert company] and with the non-profit collaborative Patient Centric Sampling Interest Group [PCSIG](#) to support improvements in the collection of blood samples. We cannot guarantee to include everything you mention but will try to honour the main themes outlined by all respondents.

Once all survey responses have been anonymised, the unfiltered responses will be deleted within [30] days to protect your privacy. You may request copies of your responses at any time before this deletion, by emailing [insert email address].

Disclosure: Please avoid mentioning specific medicines or devices. If you do, and had a bad experience, then we will have to share that specific part of your response with [insert commissioning company's name]. Along with this we will share your initials and email address (if you wish to provide them) so that the company have the chance to contact you and try to understand what went wrong. To continue with the survey, please tick the relevant box below to let us know whether you agree to this sharing of information:

I agree with this sharing of information

I do not agree with this sharing of information and will not be proceeding with the survey (please hand this form back to whoever gave it to you). Thank you.

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Section 1: About you.

A diverse range of viewpoints is needed to ensure that the solutions work for as many people as possible (e.g. for all different education levels, incomes, race, ethnicity, gender identity, health state, etc). Collecting this information helps researchers understand whether they have achieved an appropriate level of diversity, or whether they need to ask more people. In addition, these questions help researchers to group responses better and understand if extra is needed to increase the accessibility of their approach in specific situations.

Please tick the relevant box to let us know if you are primarily:

- A patient (answering from my own viewpoint)
- Answering on behalf of someone you care for (and answering from their viewpoint)
- A healthcare provider answering questions on behalf of their patients
- Other (please specify)

Please tick the most relevant age category for the patient (yourself if you are the patient)

- | | |
|--|---|
| <input type="checkbox"/> Aged under 5 years | <input type="checkbox"/> Aged 19 - 30 years |
| <input type="checkbox"/> Aged 6-12 years | <input type="checkbox"/> Aged 31 - 50 years |
| <input type="checkbox"/> Aged under 13 years | <input type="checkbox"/> Aged 51 - 70 years |
| <input type="checkbox"/> Aged 13 - 18 years | <input type="checkbox"/> Aged over 70 years |

What was the patient's sex that was assigned at birth? (please tick the most relevant option)

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Female | <input type="checkbox"/> Male |
| <input type="checkbox"/> Other | <input type="checkbox"/> Prefer not to say |

What is the patient's gender? (please tick the most relevant option)

- | | |
|---|---|
| <input type="checkbox"/> Cisgender female (assigned female at birth and consider gender to be female too) | <input type="checkbox"/> Cisgender male (assigned male at birth and consider gender to be male too) |
| <input type="checkbox"/> Non-binary/third gender | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Prefer to self-specify (please specify using space to the right) | |
-

For Healthcare workers only: Do you specialise in a particular therapeutic area or patient population? (please specify)

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Where are you currently living? Please tick the continent option that best represents your location. For example, if you live in a country that spans multiple continents (e.g., Russia, Turkey, Egypt), please select the continent where your specific location is situated (e.g. if you live in Moscow, select Europe; if you live in Vladivostock, select Asia)

| | | | |
|--------------------------|---------------|--------------------------|-------------------|
| <input type="checkbox"/> | North America | <input type="checkbox"/> | Asia |
| <input type="checkbox"/> | South America | <input type="checkbox"/> | Australia/Oceania |
| <input type="checkbox"/> | Europe | <input type="checkbox"/> | Prefer not to say |
| <input type="checkbox"/> | Africa | | |

What is your race or ethnicity? (Please tick as many categories and subcategories as needed and where possible enter additional details (so that the researchers can improve the survey in future))

| | | | | | | | |
|--------------------------|--------------------------|--|---|---|--|---|---|
| <input type="checkbox"/> | Asian | <input type="checkbox"/> Chinese | <input type="checkbox"/> Filipino | <input type="checkbox"/> Indian | <input type="checkbox"/> Pakistani | <input type="checkbox"/> Japanese | <input type="checkbox"/> Pacific Islander |
| <input type="checkbox"/> | Black | <input type="checkbox"/> African | <input type="checkbox"/> Caribbean | <input type="checkbox"/> African/American | <input type="checkbox"/> African British | <input type="checkbox"/> Caribbean American | <input type="checkbox"/> Caribbean British |
| <input type="checkbox"/> | Hispanic/Latino | <input type="checkbox"/> Mexican | <input type="checkbox"/> Puerto Rican | <input type="checkbox"/> Brazilian | <input type="checkbox"/> Columbian | <input type="checkbox"/> Dominican | <input type="checkbox"/> Cuban |
| <input type="checkbox"/> | Indigenous/Native | <input type="checkbox"/> American Indian | <input type="checkbox"/> Alaskan Native | | | | |
| <input type="checkbox"/> | Middle Eastern | <input type="checkbox"/> Lebanese | <input type="checkbox"/> Iranian | <input type="checkbox"/> Egyptian | <input type="checkbox"/> Syrian | <input type="checkbox"/> Moroccan | <input type="checkbox"/> Israeli |
| <input type="checkbox"/> | White | <input type="checkbox"/> American | <input type="checkbox"/> British | <input type="checkbox"/> German | <input type="checkbox"/> French | <input type="checkbox"/> Polish | <input type="checkbox"/> Gypsy, Traveller or Roma |
| <input type="checkbox"/> | Other | | | | | | |
| <input type="checkbox"/> | Prefer not to say | | | | | | |

If the options have not been provided to accurately describe you, please specify

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Was your highest qualification? (please tick the most relevant response)

- | | | | |
|--------------------------|-------------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | At degree level or above | <input type="checkbox"/> | Below degree level |
| <input type="checkbox"/> | Another kind of qualification | <input type="checkbox"/> | No formal qualifications |

Do you have any professional, vocational or other work-related qualifications for which you received a certificate (please tick the most relevant response)

- | | | | |
|--------------------------|-----|--------------------------|----|
| <input type="checkbox"/> | Yes | <input type="checkbox"/> | No |
|--------------------------|-----|--------------------------|----|

What is your current employment status?

- | | | | |
|--------------------------|------------------------|--------------------------|-----------------------|
| <input type="checkbox"/> | Full-time | <input type="checkbox"/> | Part-time |
| <input type="checkbox"/> | Self-employed | <input type="checkbox"/> | Seeking opportunities |
| <input type="checkbox"/> | Unable to work | <input type="checkbox"/> | Full time education |
| <input type="checkbox"/> | Retired | <input type="checkbox"/> | Prefer not to say |
| <input type="checkbox"/> | Other (please specify) | | |
-

Which of the following best describes your current physical state of health?

- | | | | |
|--------------------------|--|--------------------------|---|
| <input type="checkbox"/> | Poor (health status is heavily impacting on quality of life) | <input type="checkbox"/> | Fair (living with health conditions but okay) |
| <input type="checkbox"/> | Good (minimal impact from health conditions) | <input type="checkbox"/> | Prefer not to say |

Are you living with a chronic condition or other health issue that requires ongoing monitoring and routine interactions with your healthcare team?

- | | | | |
|--------------------------|-------------------|--------------------------|----|
| <input type="checkbox"/> | Yes | <input type="checkbox"/> | No |
| <input type="checkbox"/> | Prefer not to say | | |

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Section 2: Current standard approaches.

When trying to improve, we must first understand what is most **helpful** for you with the current approach of going to clinic and having a blood sample taken from your vein using a needle.

Please add a **priority number** next to each of the options below, with **'1' being most helpful** and **'7' being the least helpful**.

| | |
|--------------------------|--|
| <input type="checkbox"/> | Convenience (including arranging appointment and getting there etc) |
| <input type="checkbox"/> | Waiting time |
| <input type="checkbox"/> | Total cost (including travel, time off work, tests etc) |
| <input type="checkbox"/> | Social acceptability (including impact on others, opinions of others) |
| <input type="checkbox"/> | Influence of previous experiences (level of pain, level of fear, ease/difficulty giving blood etc) |
| <input type="checkbox"/> | Using blood sampling services that are separate from your healthcare team |
| <input type="checkbox"/> | Being able to be involved (and 'hands on') in the sampling process |
| <input type="checkbox"/> | Other (please specify) _____ |

Please describe your reasoning (optional)

We also need to understand what is most **frustrating** for you with the current approach.

Please add a **priority number** next to each of the options below, with **'1' being most frustrating** and **'8' being the least frustrating**.

| | |
|--------------------------|---|
| <input type="checkbox"/> | Convenience level (including arranging appointment and getting there etc) |
| <input type="checkbox"/> | Waiting time |
| <input type="checkbox"/> | Total cost (including travel, time off work, tests etc) |
| <input type="checkbox"/> | How socially acceptable it is (including impact on others, opinions of others) |
| <input type="checkbox"/> | Influence of previous experiences (including level of pain, level of fear, difficulty/ease giving blood, etc) |
| <input type="checkbox"/> | Using blood sampling services that are separate from your healthcare team |
| <input type="checkbox"/> | Being able to be involved (and 'hands on') in the sampling process |
| <input type="checkbox"/> | Other (please specify) _____ |

Please describe your reasoning (optional)

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What method of communication do you prefer between appointments and samples being taken?

- | | | | |
|--------------------------|-----------------|--------------------------|------------------------------|
| <input type="checkbox"/> | Phone | <input type="checkbox"/> | Email |
| <input type="checkbox"/> | Written letters | <input type="checkbox"/> | App or website |
| <input type="checkbox"/> | None | <input type="checkbox"/> | Other (please specify) _____ |

How much effort should patients/care givers put into having their blood sample taken?

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Patients/care givers should make effort to be very involved in the process of arranging and having sample taken |
| <input type="checkbox"/> | Patients/care givers should leave everything to their healthcare team |
| <input type="checkbox"/> | Somewhere in the middle |

Do you have any history of problems with having blood taken from your vein?

- | | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | Often have problems |
| <input type="checkbox"/> | Sometimes have problems |
| <input type="checkbox"/> | It is usually no problem |

If you have had problems, please describe the types of problem you've had (optional)

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Section 3: Novel approaches.

We would like to gather your feedback on any experiences you may already have where the blood was taken in a different way other than using a needle in the vein. Have you used an approach for collecting blood by pricking your finger, or using a special device to gather a drop of blood while at home (or somewhere non-medical) and then post it via mail or courier?

If you have, then please base your answers on your experience. If you have not, please let us know using this question and then answer the rest of the section based on what you think you'd like.

Yes

No

If you have ticked 'yes' - How often have you used this alternative approach? (If you have ticked 'No' skip to the next page)

Once or twice

Several times

Routine use (e.g. monthly, every 3 months etc)

How was the blood collected (answer all that are relevant)?

Droplet from the finger

Device added to the upper arm or elsewhere on the body

Home test kit where you get the results on the device itself

Other (please specify)

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Please let us know what was **essential for having a good experience**.

Please add a **priority number** next to each of the options below, with **'1' being the most essential factor for a good experience** and **'5' being the least essential**.

| | |
|--------------------------|---|
| <input type="checkbox"/> | Convenience level (including arranging appointment and getting there etc) |
| <input type="checkbox"/> | Waiting time |
| <input type="checkbox"/> | Total cost (including travel, time off work, tests etc) |
| <input type="checkbox"/> | How socially acceptable it is (including impact on others, opinions of others) |
| <input type="checkbox"/> | Influence of previous experiences (including level of pain, level of fear, difficulty/ease giving blood, etc) |
| <input type="checkbox"/> | Using blood sampling services that are separate from your healthcare team |
| <input type="checkbox"/> | Being able to be involved (and 'hands on') in the sampling process |
| <input type="checkbox"/> | Other (please specify) _____ |

Please describe your reasoning (optional)

Please compare this novel approach with the standard approach of going to clinic and having a blood sample taken from your vein and tick the box in each row that matches your opinion closest

| | Higher with novel approach | About the same | Higher with needle collection from vein |
|--|----------------------------|--------------------------|---|
| Level of pain experienced | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fear of needles | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Frequency you are willing to have your blood taken | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Quality of life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

If given the option to have your blood sample taken at home by yourself or a carer, or in clinic, which would you prefer? (If you are a healthcare worker, please answer for what you think the majority of your patients would like)

| | | | |
|--------------------------|------------|--------------------------|-----------|
| <input type="checkbox"/> | At home | <input type="checkbox"/> | In clinic |
| <input type="checkbox"/> | Don't know | | |

Please describe your reasoning (optional)

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Section 4: What is needed.

Please can you let us know what practical things you need (or recommend) for you to say that a sampling process was good

Please use numbers in the boxes to let us know how important each element is, **with 10 being most important and 1 being not important**

| | |
|--------------------------|---|
| <input type="checkbox"/> | Clear written and video instructions |
| <input type="checkbox"/> | Option of video/photo of collection being done by another patient |
| <input type="checkbox"/> | Physical demonstration |
| <input type="checkbox"/> | The sampling kit being delivered to your home |
| <input type="checkbox"/> | A message, noise or light to say that the sample collection was successfully completed |
| <input type="checkbox"/> | Notification when the sample has been received by the lab |
| <input type="checkbox"/> | Knowing when the result has been checked by your nurse or physician |
| <input type="checkbox"/> | Being able to inform the lab/your healthcare team when you have posted the sample |
| <input type="checkbox"/> | Reminders to order kits, easy ordering process and a way to keep track of the number you have |
| <input type="checkbox"/> | Reminders for when to take the sample |
| <input type="checkbox"/> | Having a stock of sample kits at home in case the first collection attempt is unsuccessful |
| <input type="checkbox"/> | Having a helpline or support desk |
| <input type="checkbox"/> | Other (please specify) _____ |



Section 5: Anything else?

Future at-home blood sampling could involve taking a droplet of blood from your finger or arm and then sending this off in the mail.

Please share what you think we should consider when designing this process to work for you - what are your immediate questions, and thoughts around what would make this easier or harder to undertake?

Is there anything else you would like to share? (optional)

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Section 6: Reimbursement details

Please kindly provide your personal and bank details below. This is so that we can repay you for completing the survey and to also comply any sharing of information (if you have mentioned medicines or medical devices and something going wrong).

The following are used only if you have mentioned details of specific medicines or devices and bad experiences:

Email address

Initials

The following are used for reimbursement:

Account name

Account number

Sort code

Thank you for your time spent taking this survey!