



WAHTN

Western Australian Health Translation Network



**Consumer and Community
Involvement Program**

Your Voice in Health Research

Survey of Consumer and Community Involvement Program Community Members' Attitudes to COVID-19 Research and Consent

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Executive Summary

The purpose of this survey was to gain an understanding of community attitudes to involvement in medical research and forms of giving consent, on admission to hospital during the outbreak of the COVID-19 pandemic in Perth, Australia in April 2020. The survey was administered online to a selected group of consumers with an interest in health and medical research registered with the Health Consumers Council and the Consumer and Community Involvement (CCI) Program, previously known as the Consumer and Community Health Research Network (CCHRN).

A link to the online survey was emailed to the two groups on 17 and 20 April with 210 responses received between April 17 and May 1, 2020.

The findings of this survey have shown us that informed Consumer representatives, such as those members of the CCI Program and HCC, are eager to contribute to questions about the research process.

- Respondents to this survey feel strongly that research is important during a pandemic and there is a strong sense that COVID-19 positive patients who are admitted to hospital should be included in research.
- However it is also clear that there is a common feeling that consent should be acquired from the patient themselves, or next of kin.
- A waiver of consent was considered unacceptable by the majority of respondents but the rest of the consent options were acceptable to at least half.

More information needs to be collected from potential research participants, including the general public outside of the CCI Program and HCC networks, to validate the responses from this informed cohort. It would also be interesting to use the same survey to gather data on people's feelings outside of a Pandemic to measure any significant difference between 'normal life' and life in a pandemic.

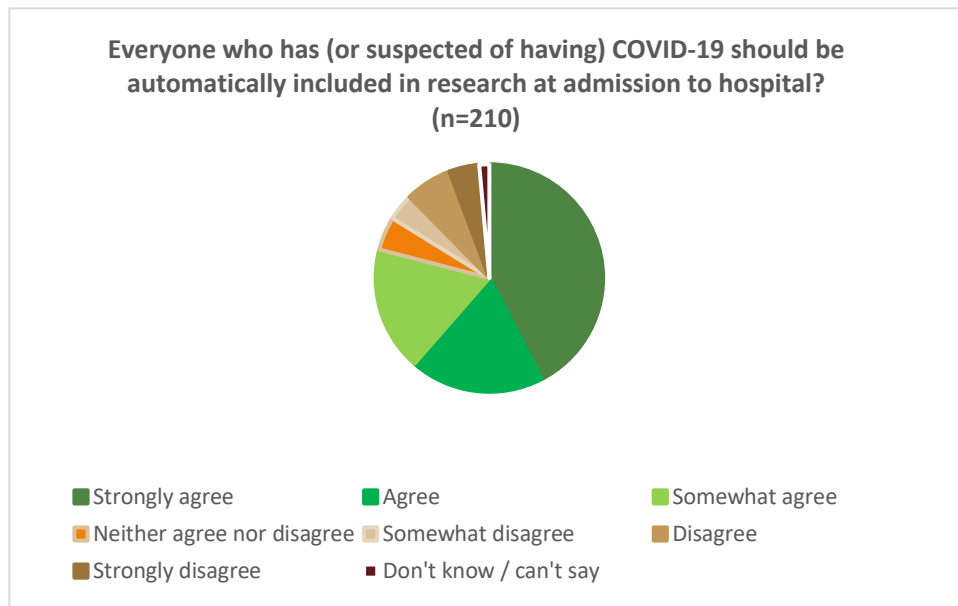
Summary of Findings

Most respondents were female (80%) with 90% residing in the Perth or Peel region. Almost 1 in 5 "Are a member of, or identify with" People with Disability. In terms of diversity, 2.4% identified as/with the Aboriginal or Torres Strait Islander community and a further 9% with "People from culturally and linguistically diverse communities" (CALD).

A range of ages were represented, however the sample was skewed towards older age groups, with just under a half (46%) aged 45-54, almost a quarter (24%) aged 35-44, and only 13% under 35. Most of those who participated either suffered from, or cared for someone with a health condition, with the most frequently mentioned being Respiratory conditions, including asthma (34%), high blood pressure (27%) and cancer (25%).

COVID-19 research was viewed as extremely important, with 88% of the sample expressing "Strong agreement" and only 3 of the 210 respondents disagreeing.

The vast majority (79%) expressed some level of agreement with the statement that “everyone who has (or suspected of having) COVID-19 should be automatically included in research at admission to hospital” with around 15% disagreeing.



There were some differences in views on automatic enrolment depending on whether they were asked about “research” in general, “clinical trials” or just “having samples included”.

Whilst levels of agreement with automatic enrolment into research dropped when it specified “Clinical Trial, which will allow them access to the treatment options currently available”, two thirds of participants still agreed everyone should be automatically enrolled.

Only 16% of the sample disagreed with the automatic enrolment of everyone’s “Samples (e.g. blood, urine etc.) at admission.

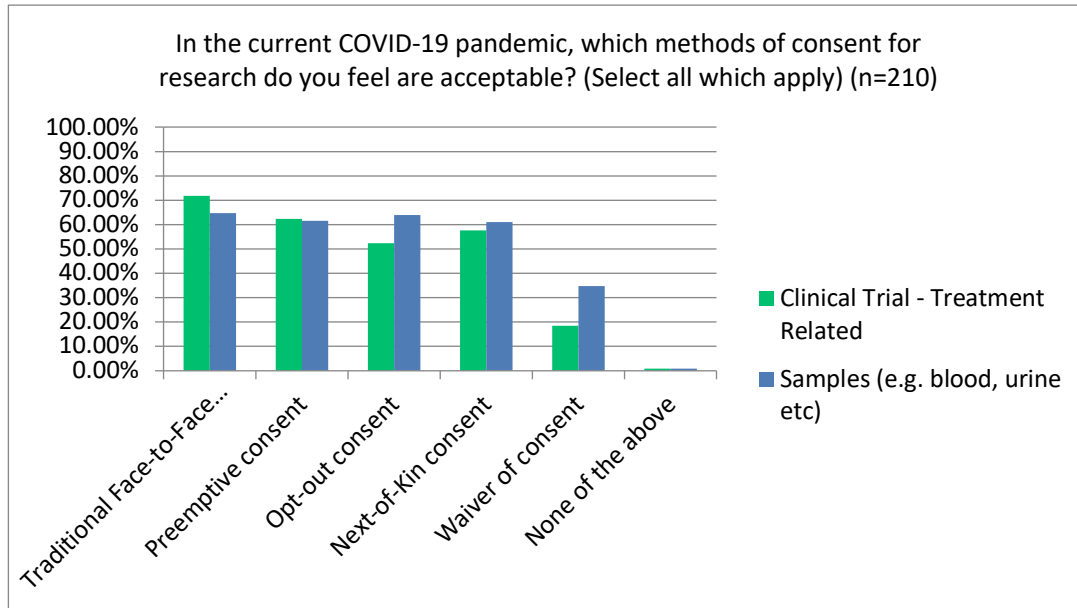
Attitudes toward methods of receiving consent for research were separated into two areas of research:

- Clinical Trial – Treatment Related
- Samples (e.g. blood, urine etc.)

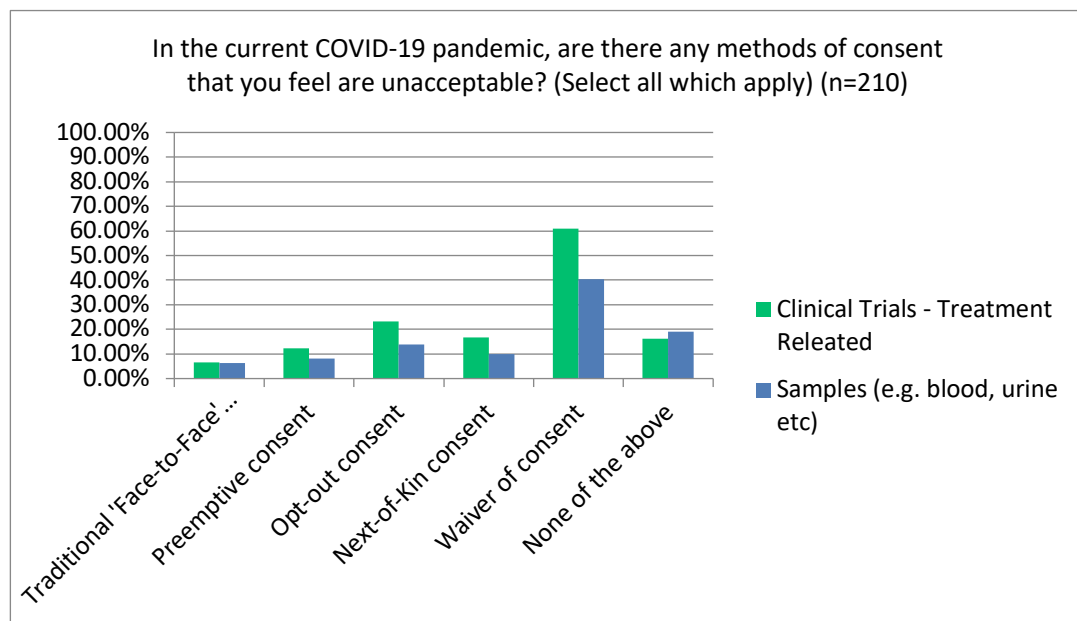
“Traditional Face-to face consent” was rated as acceptable by almost three quarters (72%) respondents followed by “Preemptive consent” at 62%. With more than half considering “Next-of-kin consent” and “Opt-out consent” acceptable.

Less than 1 in 5 participants (18.6%) felt “Waiver of Consent” was “acceptable” in the case of Clinical Trial – Treatment Related research and just over a third (35%) felt it was “acceptable” in research on Samples. Notably, only 10 respondents (5%) chose to skip this question.

Both “acceptable” and “unacceptable” viewpoints were collected and are shown below.



Interestingly, 61% of participants stated “Waiver of Consent” was “unacceptable”, indicating another 20% of the sample, who didn’t say it was acceptable, may have some uncertainty around this and consequently didn’t rate “Waiver of consent” in this situation as unacceptable.



Examples of comments given in the open ended section help illuminate respondents thought processes:

“I think everyone should be given the opportunity to be involved in research, but that it should always be a choice.”

“Some form of consent, and the ability to withdraw consent at any time, should always be in place. The last thing wanted is for a movement of anti-research activists to reduce the ability to do groundbreaking research.”

Introduction

Consent to participate in Health Research across Australia has been an issue of great importance to all stakeholders in research. Consumer and Community Involvement Program has been particularly aware of the issue relating to health consumers in regard to their opinions on access to research and the importance of transparency around risk.

During the COVID-19 pandemic it was felt that there may be a community perception that consent processes could be adapted to suit the dire need to find solutions to both improved care of people with, or suspected of having, COVID-19, or to find a vaccine.

In order to gain an understanding of the community reaction to the issue of Informed Consent in relation to Medical Research into the COVID-19 pandemic in Perth, Western Australia an online questionnaire was developed and administered through the CCI Program.

The CCI Program network consists of a group of individuals who have high health literacy or interest in regards to the mechanisms and process of research. The Health Consumers Council of WA was also used to disseminate the survey as their network is considered to have a similar profile. As health research can be a very complex issue and consent in particular, these networks were identified as the best groups to invite to complete the survey at this initial stage. An approach to the general population was considered but as this would be a much more costly exercise and potentially take much longer to organize funding and planning, in this instance to capture attitudes at this particular time in the COVID-19 pandemic timeline, a convenience sampling method was deemed appropriate.

The CCI Program is grateful to all community members who gave their time and consideration to complete this survey.

Methodology – Questionnaire and Data Collection

The questionnaire was set up and analysed in Survey Monkey and a copy is attached as Appendix A. Participation was sought from individuals linked to the CCI Program and the HCC.

A link to the online survey was emailed to CCI Program and Health Consumers Council and 210 responses were received between April 17 and May 1, 2020. Appendix B shows a summary timeline of the Corona Virus related measures undertaken in Australia during this time.

12 questions were asked including information about demographics, diversity, specific health conditions (in- line with current thinking about comorbidities that place people at high risk of poor outcomes from COVID-19) and the importance of undertaking research during the pandemic.

Questions were asked about whether automatic inclusion in research should be granted upon admission to hospital, generally and then in 2 sub-groups, Clinical Trials and sample based research.

The survey then described 5 common forms of consent already used in health research.

These included:

- Traditional face to face consent
- Pre-emptive consent
- Opt out consent
- Next of Kin consent
- Waiver of consent

Each of these methods of consent were described in plain language and then participants were asked to indicate whether these options were acceptable or unacceptable during a Pandemic.

The last question offered participants an open opportunity to make comment on any other issues relating to COVID-19 research.

The survey was designed to be completed in around 10 minutes and the average time of completion for the 210 participants was 6 minutes.

The Sample

In total 210 respondents participated with a 95% completion rate and a description of the sample demographics is provided below.

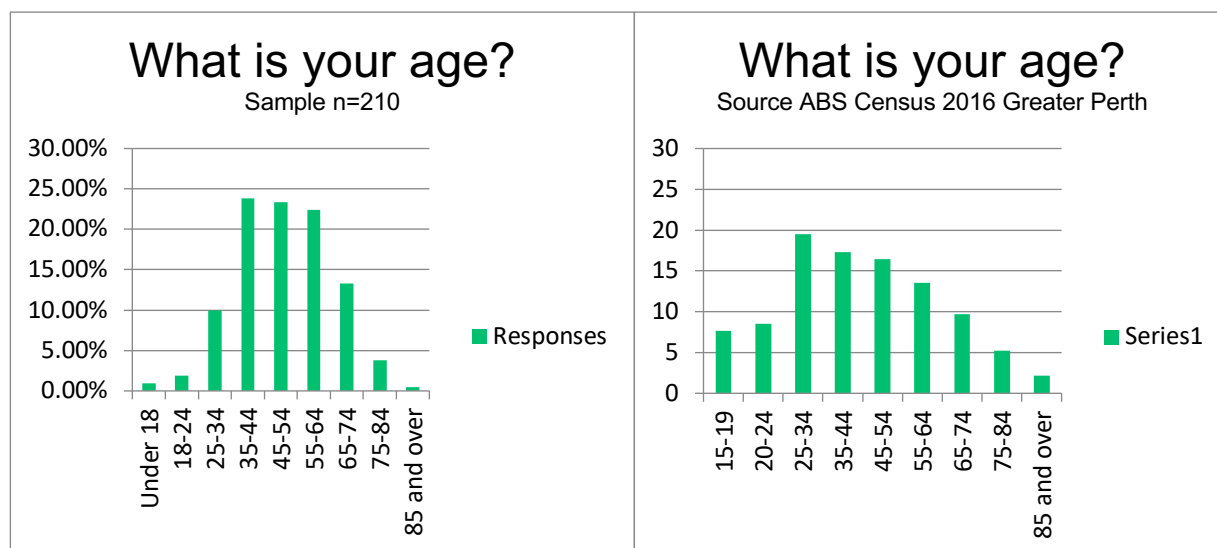
Age and Sex of Sample

The sample was heavily female weighted with the majority of respondents being female (168=80%), only 19.5% (41) male and 0.5% preferring not to say. According to the Australian Bureau of Statistics (ABS) 2016 Census there was an equal distribution of gender in Greater Perth. Female 50.4% and Male 49.6%.

Source:

https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/5GPER?opendocument

As the figures below show, the sample was more heavily weighted with people aged 35 to 74 years compared to the overall age distribution in the Greater Perth area reported by the ABS, with a corresponding lower representation of those under 35 and those 85 and over.



We also analysed the age breakdown by gender which showed a significantly lower representation of Males in the 35-44 year category and a higher proportion of Males compared to Females in the 3 categories representing those 65 and over (significant at the 95% confidence level ($p=.05$)).

Place of residence

The vast majority of respondents live in the Perth or Peel region as shown in the table below. 8 respondents (3.4%) report living in another state or territory of Australia and 1 was from overseas. There was no significant difference between males and females.

Where do you reside?

Region	Responses	
Perth or Peel region	89.52%	188
South West	1.43%	3
Great Southern	1.43%	3
Wheatbelt	1.43%	3
Goldfields-Esperance	1.43%	3
Kimberley	0.00%	0
Pilbara	0.00%	0
Gascoyne	0.00%	0
Mid West	0.48%	1
Australia State other than WA	3.81%	8
Other (please specify)	0.48%	1
	Answered	210

Diversity

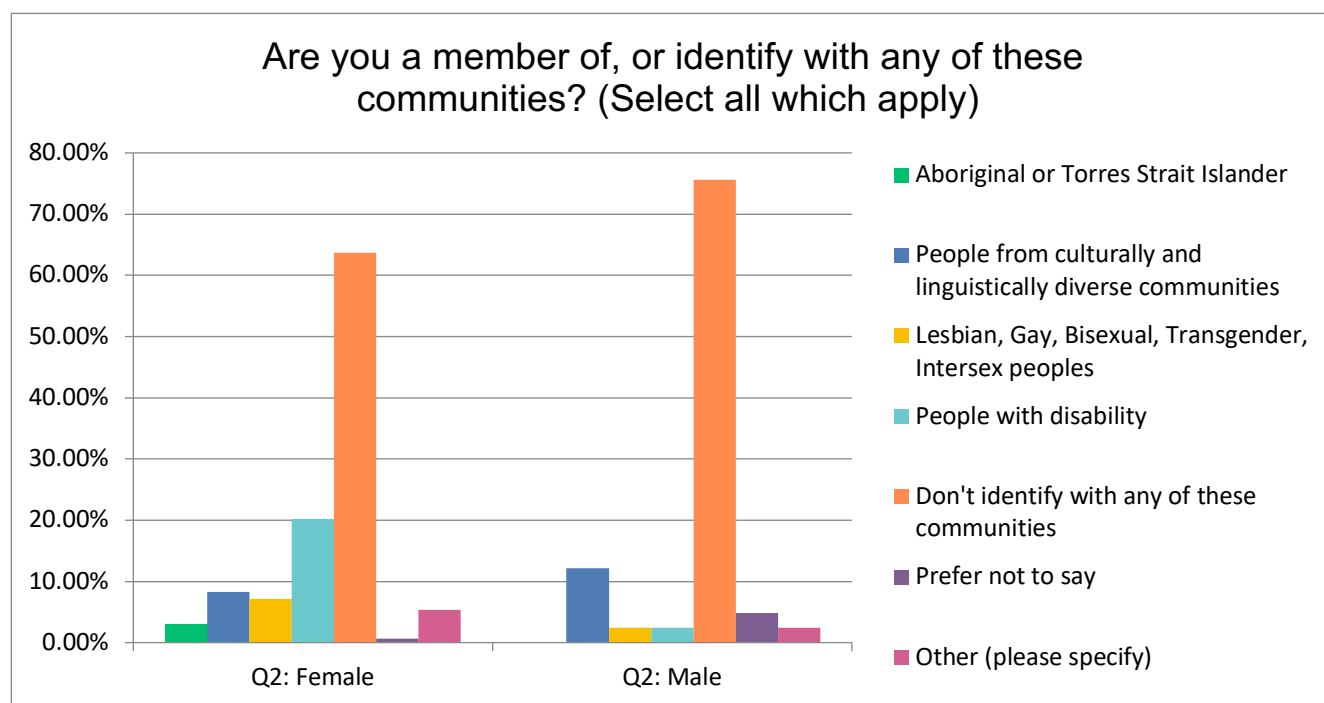
According to the ABS, Aboriginal and/or Torres Strait Islander people made up 1.6% of the Greater Perth population and 3.1% of WA in the 2016 Census. In this survey, 2.4% of respondents indicated they are Aboriginal or Torres Strait Islander people, or identify with, this community.

A further 9% indicated they came from a culturally and linguistically diverse community and 6.7% identified with the LGBTI community. Almost one fifth of the sample (17%) stated they had a disability, and notably 4 respondents indicated they are a Parent or Carer of a person with disability (for future research this category could be added to the survey).

Are you a member of, or identify with any of these communities? (Select all which apply)

Answer Choices	Responses	
Aboriginal or Torres Strait Islander	2.38%	5
People from culturally and linguistically diverse communities	9.05%	19
Lesbian, Gay, Bisexual, Transgender, Intersex peoples	6.67%	14
People with disability	17.14%	36
Don't identify with any of these communities	70.48%	148
Prefer not to say	1.43%	3

For future surveys, it would be valuable to add a “Carer” category.



When analysed by gender significantly more Female respondents (20% of 168) identified with “People with disability” than Males (2.4% of 41); significantly more Males (75.6% of 41) did not identify with any of these communities; compared to 63.7% of Females; and more Males (4.9%) “Prefer not to say”, compared to 0.6% of Females.

Health Conditions Profile

At least three quarter of respondents either “Have, or care for someone with, a health condition” which is not surprising given the self-selective nature of the sample and the original data base contacted.

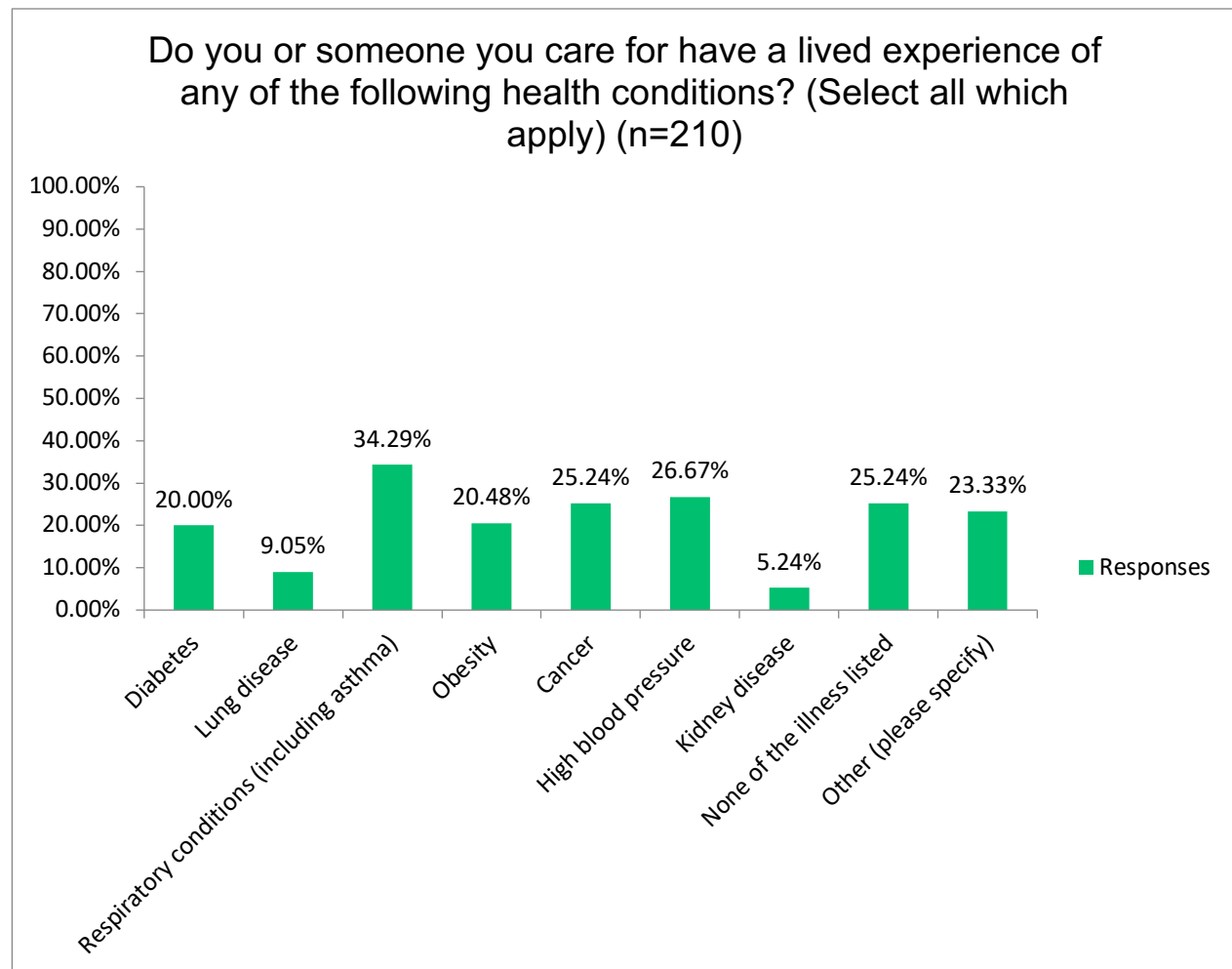
We see some significant differences by gender with only 12.2% of Males choosing “None of the illness listed” compared to 28.6% of Females.

Note: we can’t determine whether the respondent is the patient or carer with the health condition.

Of the health conditions listed (shown in chart below) the most frequently mentioned were:

- Respiratory conditions (including asthma) (Female and Male 34%)
- High blood pressure (Female 21% : Male 51%)
- Cancer (Female 24% : Male 29%)
- Diabetes (Female 18% : Male 27%)
- Obesity (Female 20% : Male 22%)

Almost a quarter of respondents mentioned some “Other health condition” and were asked to specify, so further coding was undertaken and these conditions are listed below the following chart.



On further analysis and coding of the “Other please specify” category we find the following distribution of health conditions.

OTHER HEALTH CONDITIONS MENTIONED

Do you or someone you care for have a lived experience of any of the following health conditions? (Select all which apply)

Other (please specify)	% of Sample of 210	Number (n)
Auto immune disorder	6.2%	13
Neurological disorder	3.8%	8
Neuromuscular or joint disease	3.8%	8
Cardiac/ Heart Disease	3.3%	7
Anxiety/ Depression	2.4%	5
Other Mental Ill Health	1.9%	4
Alzheimer/ Dementia	1.4%	3
Cystic fibrosis	1%	2
Liver problems/ disease	1%	2
Thyroid issues/ disease	1%	2
Bilateral cataracts	*	1
Back problems	*	1
Bleeding disorder	*	1
Child with mild intellectual disability	*	1
Cardiovascular disease	*	1
Endometriosis	*	1
Immune compromised	*	1
Intellectual and physical disability	*	1
Irritable bowel disease	*	1
Retinitis pigmentosa	*	1
Pain management	*	1
Rare genetic conditions	*	1
Ross River Virus	*	1

* Less than 1%

For future surveys, it could be valuable to include the top categories outlined above under “Other”.

Perceived Importance of COVID-19 Research

To better understand community attitudes toward COVID-19 research, respondents were initially asked to rate, on a 7 point scale, how important they consider COVID-19 research to be.

As the table below shows almost 9 out of 10 respondents “Strongly Agree” that this research is important and 96.2% either Agree or Strongly Agree.

Less than 2% of those surveyed did not agree that research is important, and this was only rated as “Somewhat disagree”.

Q6 COVID-19 research is important (select one)

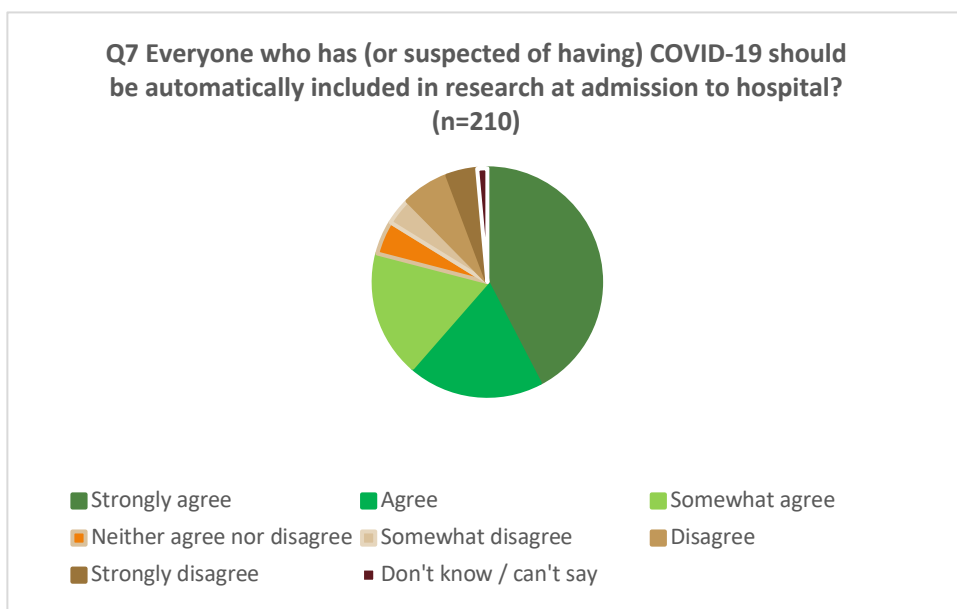
Answer Choices	Responses	
Strongly agree	88.10%	185
Agree	8.10%	17
Somewhat agree	2.38%	5
Neither agree nor disagree	0.00%	0
Somewhat disagree	1.43%	3
Disagree	0.00%	0
Strongly disagree	0.00%	0
Don't know / can't say	0.00%	0
Answered		210
Skipped		0

There was no significant difference between genders on this attitude.

Attitudes to Automatic Inclusion in Research on Hospital Admission for COVID-19

To gain a better understanding of community expectations and attitudes to automatic inclusion in research a number of questions were asked. These questions addressed both possible levels of inclusion in research and how consent could be obtained. The questions were framed as being related to patients with suspected or confirmed COVID-19 on admission to hospital.

The chart below shows responses to the general question on automatic inclusion in research at admission, showing almost 8 out of 10 participants agree.



As our hypothesis was that respondents may react differently to the idea of research “in general”, “Clinical Trials” and “having Samples taken”; as well as whether they were being asked to speak for the whole community versus only themselves, these 4 questions were addressed as follows:

Attitudes to “everyone” being admitted to hospital with suspected or confirmed COVID-19 receiving:

- Q7 Automatic inclusion in research at admission to hospital
- Q8 Automatic enrolment in a Clinical Trial, allowing access to the available treatment options
- Q9 Automatic inclusion of samples (e.g. blood, urine etc) in Clinical Trial Research

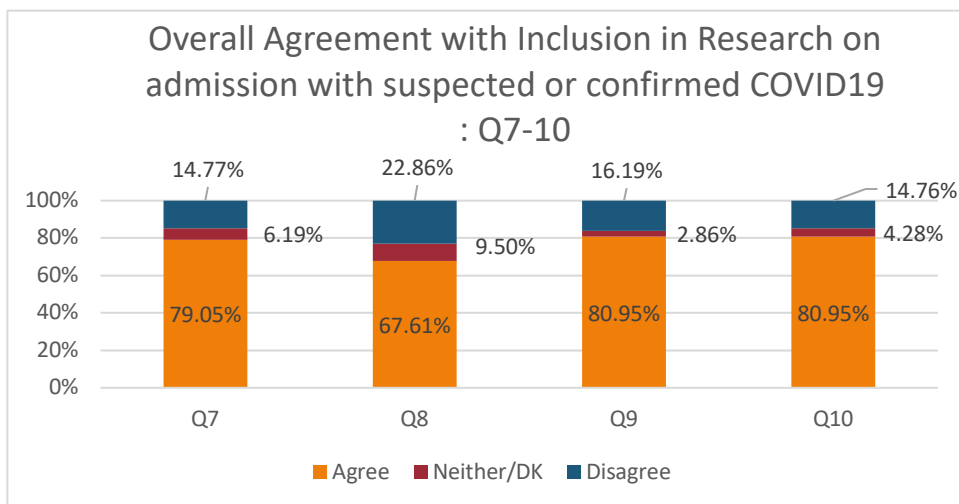
Attitudes if “you were the patient”, receiving;

- Q10 Automatic inclusion in all levels of research available.

Whilst there are some differences between the extent of agreement across the 4 questions, in all cases the majority, at least two thirds, express some level of agreement with “Everyone being treated for (or suspected of having) COVID-19 should automatically be included in Research for COVID-19 at admission to hospital”.

The chart below, shows the distribution of Agreement and Disagreement when all 3 categories from “Strongly Agree to Somewhat Agree” are combined in the lower segment of the columns, the middle segment being those who answered either “Neither agree nor disagree” or “Don’t know/Can’t say”, and the top segment of each column showing some level of disagreement.

At least approximately 15% of the sample express some level of Disagreement with any form of automatic inclusion in research on admission.



The following summary data shows the breakdown into the different levels of agreement and confirms the hypothesis that people’s attitudes differ somewhat depending on the types of research being asked about and whether it is about the whole community or them personally.

Q7 Everyone who has (or suspected of having) COVID-19 should be automatically included in research at admission to hospital? (select one)

Strongly agree	42.38%
Agree	19.05%
Somewhat agree	17.62%

Q8 Everyone who has (or suspected of having) COVID-19 should be automatically enrolled in a Clinical Trial, which will allow them access to the treatment options currently available at admission to hospital? (select one)

Strongly agree	28.57%
Agree	19.52%
Somewhat agree	19.52%

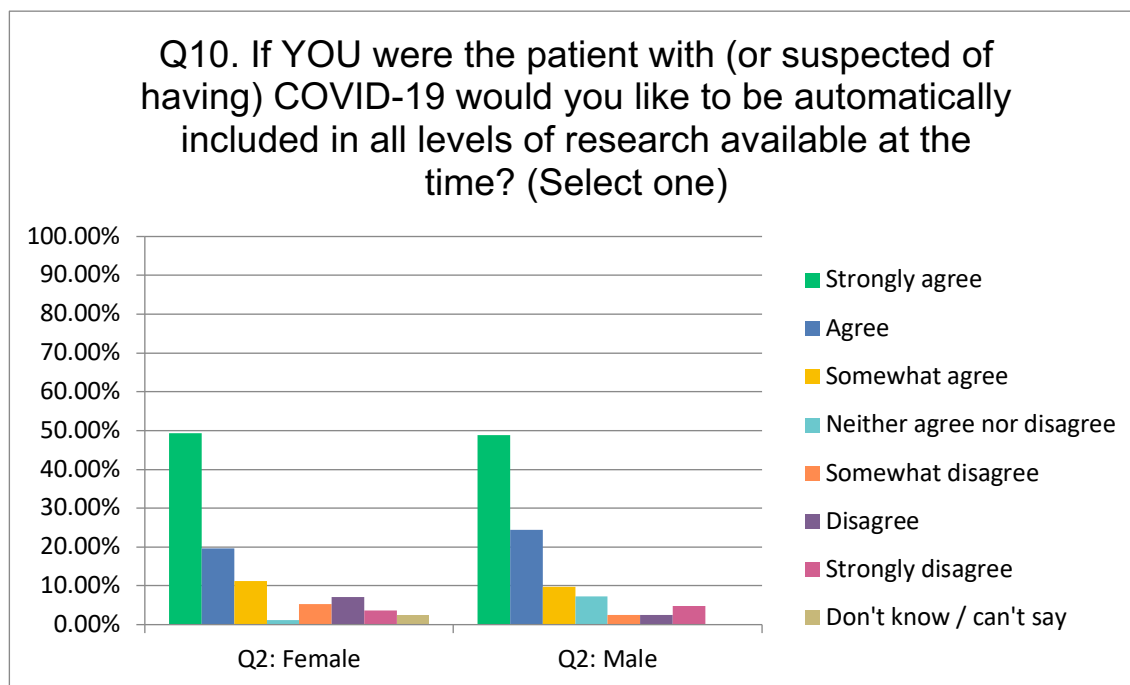
Q9 Everyone being treated for (or suspected of having) COVID-19 should automatically have their samples (e.g. blood, urine etc) included in Clinical Trial Research for COVID-19 at admission to hospital? (Select one)

Strongly agree	44.76%
Agree	20.95%
Somewhat agree	15.24%

Q10 If YOU were the patient with (or suspected of having) COVID-19 would you like to be automatically included in all levels of research available at the time? (Select one)

Strongly agree	49.52%
Agree	20.48%
Somewhat agree	10.95%

Notably there were no significant differences in attitudes between Males and Females across these 4 questions, except in Question 10 where a higher proportion of Males (7.32%) chose “Neither agree nor disagree” compared to Females (1.19%).



Attitudes to Methods of Receiving Consent for Inclusion in Research at Admission for COVID-19

The survey was designed so that questions regarding forms of consent came after gathering attitudes to being included in research on hospital admission. As a prelude to the following questions on consent respondents were given the following descriptions of different ways of receiving informed consent.

Questionnaire Script (See Appendix A for full script)

We would like to ask for your thoughts on how consent should be obtained from patients to take part in COVID-19 research. Below are descriptions of 5 different ways of receiving informed consent:

Traditional 'Face-to-Face' Consent

- This involves a member of the research team (often a doctor or nurse) giving you written information about a research study and going through the information with you **in-person**. This is usually when you are admitted to the hospital.
- You then have opportunities to ask questions or discuss the research further before deciding whether to take part.
- You are asked to complete a consent form if you agree (this may be a digital form/signature).

Pre-emptive Consent

- This involves considering whether to take part in research **before** you become unwell, or eligible for the study.
- With this type of consent, you read information about the study online or via written material, and are asked to decide about participating, if you were to become sick.
- There are opportunities to ask questions before deciding.
- As with all research, you do not have to take part, and you can change your mind at any time (including if you become sick).

Opt-out Consent

- This means that all eligible patients are **included in the study automatically**.
- Information is given to patients (e.g. as they arrive at the hospital) to tell them about the study, and anyone can choose not to take part (i.e. to 'opt-out').
- If you do not 'opt-out', you will be included in the study.
- You can 'opt-out' at any time.

Next-of-Kin Consent

- This means that if you are too sick to give consent to a study (e.g. you may be in the Intensive Care Unit, or arriving to the Emergency Department unconscious), **your next-of-kin will be asked to choose** whether you are included in a research study.
- There are strict guidelines on how this type of consent works.

Waiver of Consent

- This means that are **automatically included** in a research study. You may not be aware of your participation, particularly if the research is using samples or information that has already been collected.
- This type of consent is usually only used for 'low-risk' projects involving existing samples and/or information.

Acceptability of Different ways of Receiving Consent from Patients to participate in COVID-19 Research

Q11 In the current COVID-19 pandemic, which methods of consent for research do you feel are acceptable?

Respondents were asked this question, and could indicate multiple forms of consent for each of the two types of research involvement:

- Clinical Trial – Treatment related
- Samples (e.g. blood, urine etc.)

The majority of respondents answered this question, with only 10 choosing to skip it and 2 indicated “None of the above”.

“Traditional Face-to face consent” was rated as acceptable by more respondents than the other 4 forms. However, not all respondents stated this was acceptable and further analysis may be of interest to determine the profile of these 49 respondents who didn’t see this as acceptable.

Almost two thirds (62%) felt “Preemptive consent” was acceptable, with more than half of the sample seeing “Next-of-Kin” (57%) and “Opt-out consent” (52%) as acceptable.

ACCEPTABLE FORMS of CONSENT	Clinical Trial - Treatment Related (n=210)		Samples (e.g. blood, urine etc) (n=210)	
Traditional Face-to-Face consent	71.90%	151	64.76%	136
Preemptive consent	62.38%	131	61.43%	129
Opt-out consent	52.38%	110	63.81%	134
Next-of-Kin consent	57.62%	121	60.95%	128
Waiver of consent	18.57%	39	34.76%	73
None of the above	0.95%	2	0.95%	2

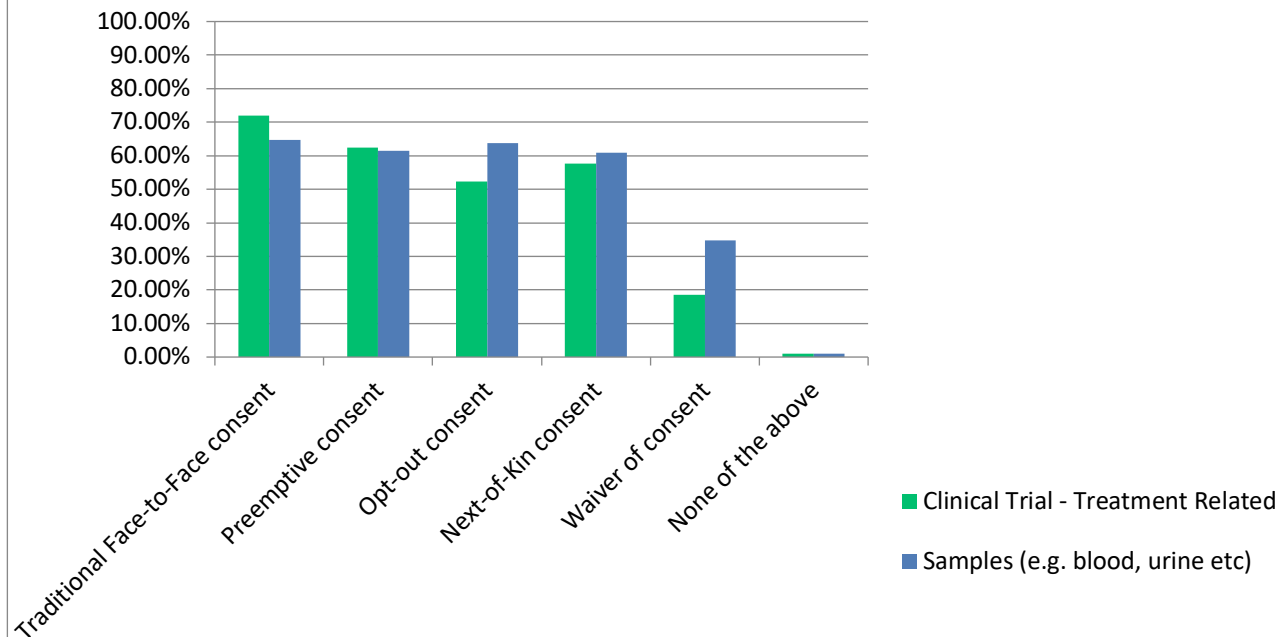
Answered 200: Skipped 10 - percentages based on 210

There were some distinct differences depending on the type of research:

- Less than 20% felt it would be acceptable to have a “Waiver of Consent” for Clinical Trial- Treatment Related research, whereas
- 35% stated it would be acceptable to have a “Waiver of Consent” for research on “Samples”.

However, there was no significant difference in terms of “Preemptive consent” or “Next-of-kin consent”.

Q11 In the current COVID-19 pandemic, which methods of consent for research do you feel are acceptable? (Select all which apply) (n=210)



Whilst respondents to this survey feel strongly that research is important during a pandemic and the majority stated patients who are admitted to hospital should be included in research, it is also clear that they feel consent should be acquired from the patient themselves, or next of kin.

A waiver of consent was not considered acceptable by the majority of respondents while the rest of the consent options were acceptable to at least half.

Unacceptability of Different ways of Receiving Consent from Patients to participate in COVID-19 Research

Q12 In the current COVID-19 pandemic, are there any methods of consent that you feel are unacceptable?

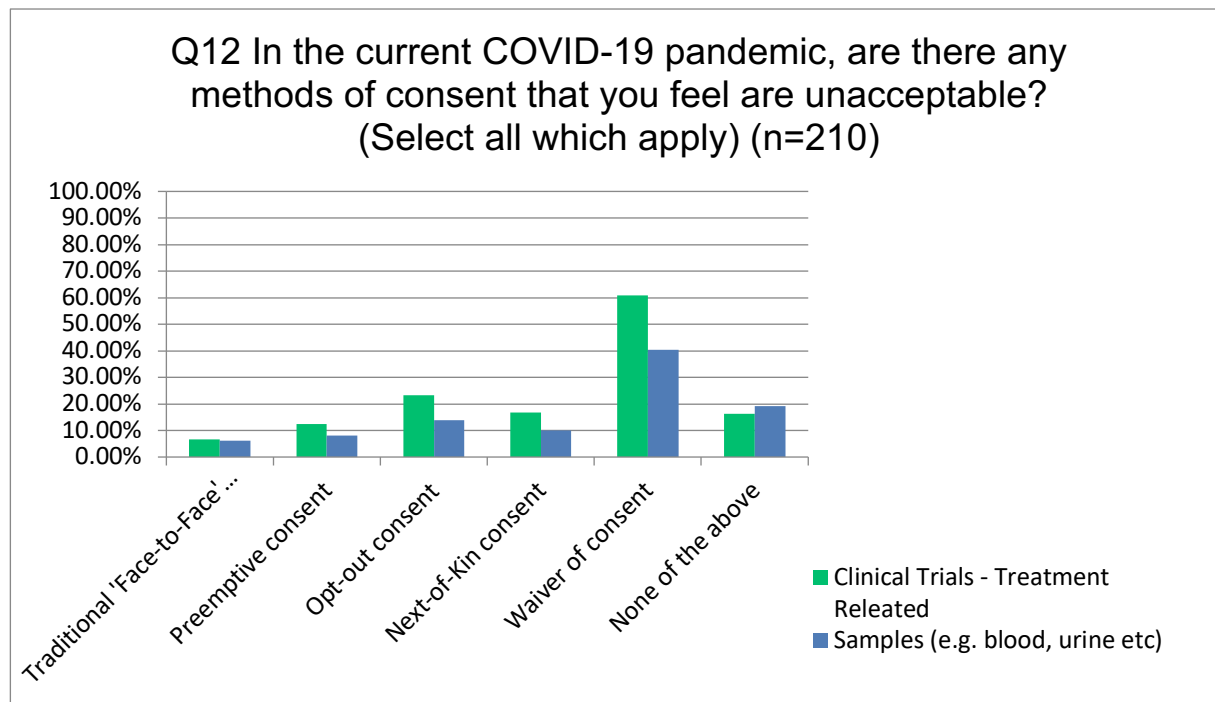
Further insight was gained by asking which of the forms of consent were unacceptable. Again, 200 people responded, with only 10 (5%) skipping. The high level of response throughout the survey indicates that informed Consumer representatives, such as those members of the CCI Program and HCC who participated, are eager to contribute to research.

The value placed on traditional “Face-to-face consent” is evident again, with less than 10% stating Traditional ‘Face-to-Face’ consent was unacceptable for either type of research.

Almost two thirds of the sample (60.95%) stated “Waiver of consent” was unacceptable for Clinical Trials – Treatment Related research whilst less than half (40%) stated “Waiver of consent” was unacceptable for research requiring Samples.

So whilst less than 20% stated “Waiver of Consent” was acceptable in Q11, almost double this proportion chose not to state it was “unacceptable”.

Notably, for 16% of respondents “None” of these forms of consent were viewed as unacceptable for Clinical Trials and 20% stated this for “Samples” during the current pandemic.



The table below shows the proportion of the total sample giving each response.

Q12 In the current COVID-19 pandemic, are there any methods of consent that you feel are unacceptable? (Select all which apply) (n=210)

UNACCEPTABLE FORMS of CONSENT	Clinical Trials - Treatment Related		Samples (e.g. blood, urine etc)	
Traditional 'Face-to-Face' consent	6.67%	14	6.19%	13
Preemptive consent	12.38%	26	8.10%	17
Opt-out consent	23.33%	49	13.81%	29
Next-of-Kin consent	16.67%	35	10.00%	21
Waiver of consent	60.95%	128	40.48%	85
None of the above	16.19%	34	19.05%	40

Answered 200 Skipped 10

In any future survey it may be valuable to ask those who rated a form of consent as “Unacceptable” to give their reasons for doing so. It would be particularly interesting to know why the 7% who rated “Traditional ‘Face-to-Face’ Consent” as unacceptable, did so.

More information could be collected from potential research participants, including the general public outside of the CCI Program and HCC networks, to validate the responses from this informed cohort. It would also be interesting to use the same survey to gather data on people’s feelings outside of a Pandemic to measure any significant difference between ‘normal life’ and life in a pandemic.

Other Comments

At the end of the survey participants were asked “Are there any other comments which you would like to make regarding COVID-19 research?”. Approximately two thirds (65.7%) chose not to make any further comment. The table below summarises the categories of responses given which again reflect the level of importance of research and the issue of forms of consent.

OTHER COMMENTS

Are there any other comments which you would like to make regarding COVID-19 research? (n=210)

Other (please specify)	% of Sample of 210	Number (n)
NO COMMENT	65.7%	138
ANSWERED	34.3%	72
Valuing research/ research essential	13.3%	28
Should automatically include in research for common good	3.8%	8
Value in automatic inclusion in research due to exceptional circumstances	3.3%	7
Speed and availability of research a priority	1.9%	4
Informed consent important/ essential (ethics, trust)	12.4%	26
Ethical challenges of consent (language barriers, cultural differences, disability etc) should be considered	2.9%	6
Unethical to automatically include in research/ trials	2.4%	5
Confusion or lack of clarity around consent terms or process	2.4%	5
Concern or query over anonymity in research	2.9%	6
Thank you for research/ work	1.9%	4
Other	3.3%	7

Examples of comments included:

“I think everyone should be given the opportunity to be involved in research, but that it should always be a choice.”

“COVID-19 research is essential. I cannot think of any reason why anyone would opt out of participating in this research.”

“Some form of consent, and the ability to withdraw consent at any time, should always be in place. The last thing wanted is for a movement of anti-research activists to reduce the ability to do groundbreaking research.”

“More testing will give a better indication of true figures.”

“IF possible, the patient/participant should ALWAYS be asked to provide consent. IF not possible (too ill) next-of-kin or waiver of consent is reasonable with an option for destruction of all samples and data at any time without penalty. For COVID-19, pre-emptive consent would require ALL peoples to be asked - seems unreasonable. Opt out is unnecessary if opt-in is ALWAYS preferred first option.”

“WA is ideally placed to conduct this research in view of the relatively effective strategies in place here and the high level research facilities located here as well as the interstate and international collaborations already established by our researchers.”

“Consent is super important. I understand that in the midst of a pandemic the ethical thing to do would be to balance the greater good with individual consent. However I feel everyone should have the right to consent and understand what they are consenting to.

“I believe that upon treatment or diagnosis is the right time to ask for consent - many people will think “I won't get it” and that will affect their decision to give preemptive consent.”

APPENDIX A – THE QUESTIONNAIRE

We are interested, in the context of the COVID-19 pandemic, how the community views the role of research in WA, and how we can deliver it appropriately, safely and respectfully during a time of pandemic.

By completing the below form, you are providing your consent to participate in this survey.

The survey consists of 13 questions, and should take no more than 15 minutes to complete.

All data will be stored by Survey Monkey in line with their [Data Retention Policy](#) and their [Data Processing Agreements](#). The results will be accessed exclusively by the Consumer and Community Health Research Network (CCHRN). All results of the de-identified data in a report format will be available via request.

This survey has been designed by the Consumer and Community Health Research (CCHRN). It is designed to allow the community to have a voice in the discussion about a possible temporary adjustment to governance and/or ethics models during a life threatening pandemic. If you have any questions about the survey, please contact [Ben Horgan](#) (CCHRN).

In submitting my response, I am giving consent to participate in the survey and I state that:

- I understand the purpose of the survey
- The Consumer and Community Health Research Network (CCHRN) has answered any questions that I had about the survey and I am happy with the answers
- I understand that answering this survey is completely voluntary and I do not have to take part
- I understand that my responses cannot be withdrawn once they are submitted, as they are anonymous and therefore it won't be possible to delete my answers
- I understand that no personal information about me will be stored and that the demographic questions will only be used for the purpose of analysing responses
- I understand that the results of this survey may be published, and that publications will not contain any identifiable information about me

Background

Medical research is about improving the health of the community and health outcomes for patients.

- In diseases like COVID-19 which are so new, we're still racing to understand how the virus causes disease, and why some people get quite sick while others don't
- If we can understand how the virus acts to cause disease, and what factors protect some people or make others more vulnerable, we can hope to prevent the disease, or reduce severity and complications
- We also don't know which treatments may be effective at stopping the virus, or the body's response to the virus. This means that outside of a clinical trial, doctors cannot offer patients any treatments or medicines for COVID-19
- Researchers around the world are trying different medicines to improve patient outcomes. However, we need to do this through research studies so that we share information about which treatments work and those which might be harmful. We need to do this in a safe and ethical way and within our current legal and ethical framework
- Our current best practice for research is a 'face-to-face' informed consent discussion with research staff. However, this approach is likely to be unfeasible and unsafe within the COVID-19 pandemic, in part due to the high volume of patients, as well as the number of staff needed to recruit patients and the infection risk to staff and patients. COVID-19 patients may also be too sick to consent to research studies
- We're interested in your views on the role of research during the COVID-19 pandemic, and your views on different methods of receiving informed consent during the pandemic. This will help us to understand consumer and community perceptions and expectations of research during the pandemic and will guide our ongoing conversations with consumers in designing COVID-19 research studies

1. What is your age?

- | | |
|--------------------------------|-----------------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 55-64 |
| <input type="radio"/> 18-24 | <input type="radio"/> 65-74 |
| <input type="radio"/> 25-34 | <input type="radio"/> 75-84 |
| <input type="radio"/> 35-44 | <input type="radio"/> 85 and over |
| <input type="radio"/> 45-54 | |

2. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Prefer not to say
- ☐ Other (please specify)
-

3. Where do you reside?

- | | |
|--|---|
| <input type="radio"/> Perth or Peel region | <input type="radio"/> Kimberly |
| <input type="radio"/> South West | <input type="radio"/> Pilbara |
| <input type="radio"/> Great Southern | <input type="radio"/> Gascoyne |
| <input type="radio"/> Wheatbelt | <input type="radio"/> Mid West |
| <input type="radio"/> Goldfields-Esperance | <input type="radio"/> Australia State other than WA |
| <input type="radio"/> Other (please specify) | |
-

4. Are you a member of, or identify with any of these communities? (Select all which apply)

- | | |
|--|---|
| <input type="checkbox"/> Aboriginal or Torres Strait Islander | <input type="checkbox"/> People with disability |
| <input type="checkbox"/> People from culturally and linguistically diverse communities | <input type="checkbox"/> Don't identify with any of these communities |
| <input type="checkbox"/> Lesbian, Gay, Bisexual, Transgender, Intersex peoples | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> Other (please specify) | |

5. Do you or someone you care for have a lived experience of any of the following health conditions? (Select all which apply)

- | | |
|--|---|
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Cancer |
| <input type="checkbox"/> Lung disease | <input type="checkbox"/> High blood pressure |
| <input type="checkbox"/> Respiratory conditions (including asthma) | <input type="checkbox"/> Kidney disease |
| <input type="checkbox"/> Obesity | <input type="checkbox"/> None of the illness listed |
| <input type="checkbox"/> Other (please specify) | |
-

6. COVID-19 research is important (select one)

- ☐ Strongly agree
- ☐ Agree
- ☐ Somewhat agree
- ☐ Neither agree nor disagree
- ☐ Somewhat disagree
- ☐ Disagree
- ☐ Strongly disagree
- ☐ Don't know / can't say

7. Everyone who has (or suspected of having) COVID-19 should be automatically included in research at admission to hospital? (select one)

- | | |
|--|--|
| <input type="radio"/> Strongly agree | <input type="radio"/> Somewhat disagree |
| <input type="radio"/> Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Somewhat agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neither agree nor disagree | <input type="radio"/> Don't know / can't say |

8. Everyone who has (or suspected of having) COVID-19 should be automatically enrolled in a Clinical Trial, which will allow them access to the treatment options currently available at admission to hospital? (select one)

- | | |
|--|--|
| <input type="radio"/> Strongly agree | <input type="radio"/> Somewhat disagree |
| <input type="radio"/> Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Somewhat agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neither agree nor disagree | <input type="radio"/> Don't know / can't say |

9. Everyone being treated for (or suspected of having) COVID-19 should automatically have their samples (e.g. blood, urine etc) included in *Clinical Trial Research* for COVID-19 at admission to hospital? (Select one)

- | | |
|--|--|
| <input type="radio"/> Strongly agree | <input type="radio"/> Somewhat disagree |
| <input type="radio"/> Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Somewhat agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neither agree nor disagree | <input type="radio"/> Don't know / can't say |

10. If **you** were the patient with (or suspected of having) COVID-19 would you like to be automatically included in all levels of research available at the time? (Select one)

- | | |
|--|--|
| <input type="radio"/> Strongly agree | <input type="radio"/> Somewhat disagree |
| <input type="radio"/> Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Somewhat agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neither agree nor disagree | <input type="radio"/> Don't know / can't say |

We would like to ask for your thoughts on how consent should be obtained from patients to take part in COVID-19 research. Below are descriptions of 5 different methods of consent:

Traditional 'Face-to-Face' Consent

- This involves a member of the research team (often a doctor or nurse) giving you written information about a research study and going through the information with you **in-person**. This is usually when you are admitted to hospital
- You then have opportunities to ask questions or discuss the research further before deciding whether to take part
- You are asked to complete a consent form if you agree (this may be a digital form or signature)

Preemptive Consent

- This involves considering whether to take part in research **before** you become unwell, or eligible for the study
- With this type of consent, you read information about the study online or via written material, and are asked to decide about participating, if you were to become sick
- There are opportunities to ask questions before deciding
- As with all research, you do not have to take part, and you can change your mind at any time (including if you become sick)

Opt-out Consent

- This means all eligible patients are **included in the study automatically**
- Information is given to patients (e.g. as they arrive at the hospital) to tell them about the study, and anyone can choose not to take part (i.e. to 'opt-out')
- If you do not 'opt-out', you will be included in the study
- You can 'opt-out' at any time

Next-of-Kin Consent

- This means that if you are too sick to give consent to a study (e.g. you may be in the Intensive Care Unit, or arriving to the Emergency Department unconscious), **your next-of-kin will be asked to choose** whether you are included in a research study
- There are strict guidelines on how this type of consent works

Waiver of Consent

- This means that you are **automatically included** in a research study. You may not be aware of your participation, particularly if the research is using samples or information that has already been collected
- This type of consent is usually only for 'low-risk' projects involving existing samples and/or information

* 11. In the current COVID-19 pandemic, which methods of consent for research do you feel are **acceptable**?
(Select all which apply)

	Clinical Trial - Treatment Related	Samples (e.g. blood, urine etc)
Traditional Face-to-Face consent	<input type="checkbox"/>	<input type="checkbox"/>
Preemptive consent	<input type="checkbox"/>	<input type="checkbox"/>
Opt-out consent	<input type="checkbox"/>	<input type="checkbox"/>
Next-of-Kin consent	<input type="checkbox"/>	<input type="checkbox"/>
Waiver of consent	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

12. In the current COVID-19 pandemic, are there any methods of consent that you feel are **unacceptable**?
(Select all which apply)

	Clinical Trials - Treatment Related	Samples (e.g. blood, urine etc)
Traditional 'Face-to-Face' consent	<input type="checkbox"/>	<input type="checkbox"/>
Preemptive consent	<input type="checkbox"/>	<input type="checkbox"/>
Opt-out consent	<input type="checkbox"/>	<input type="checkbox"/>
Next-of-Kin consent	<input type="checkbox"/>	<input type="checkbox"/>
Waiver of consent	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

13. Are there any other comments which you would like to make regarding COVID-19 research?

APPENDIX B – CORONA VIRUS MEASURES IN AUSTRALIA TIMELINE

Timeline of coronavirus measures v daily case count

This chart shows the total number of cases reported each day for Australia, with annotations showing national measures introduced to limit the spread of the coronavirus. Measures are shown starting from the date they're introduced through to ten days later, which is a rough estimate of the time we might expect to see any effect on cases, according to [researchers from the University of Melbourne](#). Last updated 2020-05-19

