# Joondalup Family Health Study

## Report on the results from the initial Community Survey and from the Community Workshop Deliberative Survey

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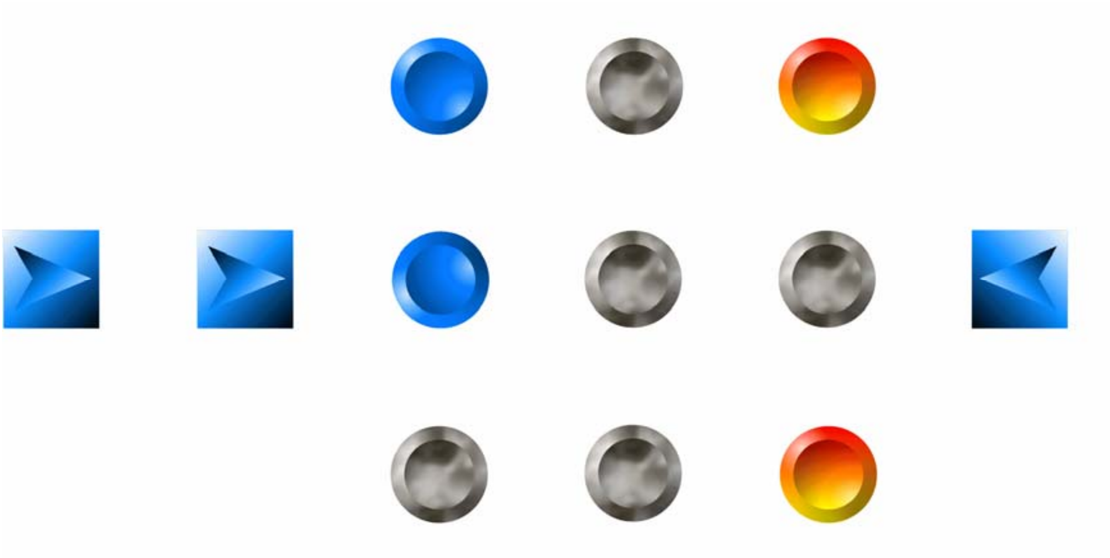

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# Contents

# Section 1: Executive Summary

## Background and Methodology

The Western Australian Institute for Medical Research (WAIMR) is proposing to conduct a long-term family health study in the City of Joondalup. Such a study requires extensive community participation in order to be successful, and thus understanding community reactions to the proposed study is an essential step in the development process.

Two complementary surveys were conducted as a feedback element of the initial community awareness program:

1. A community survey designed to reliably measure response to the proposed study within the context of existing knowledge and expectations of what such a study would involve and achieve.

2. A deliberative survey to measure the impact of more detailed information and the opportunity to discuss the project with the study team, other experts and other community members.

The community survey was intended to be the definitive indicator of community response to the survey. A questionnaire was sent to 7,500 residents of the City of Joondalup randomly selected from the WA Electoral Roll. 1,210 useable responses were received for analysis (a response rate of 16%). When weighted to correct the age and gender profile of the sample to the population, the effective sample size was $N_{eff}=819$, and had a sample reliability of $\pm 3\%$ at the 95% confidence level.

The deliberative survey was intended to identify the effects of more complete and detailed information on residents' attitudes towards the proposed study. It involved participants attending a self-nominated community workshop to discuss the study, with participants completing the survey at the beginning of the workshop to measure their initial opinions (directly comparable to the community survey), and then again at the end of the workshop (to measure any changes as a result of the workshop). A total of 109 residents attended the workshop and completed the deliberative survey. When weighted the effective sample size was just $N_{eff}=62$ (and a sample reliability of $\pm 12\%$ at the 95% confidence level).

Attendees at the workshop turned out to be primarily people who were keen to participate in the study, and were not therefore representative of the full range of views on the study that were seen in the community survey. However, the sample and the sample size were still able to give some insight into the likely response of residents to the study.

## Main Results

The results are basically very positive for the project. A summary of the key results would be:

- **Most people think that long-term family health studies are important** (53% consider them *very important*, with another 43% considering them to be *quite important*). The perceived importance of such studies, if anything, increased further as a result of the workshop. Older people felt that such studies are considerably more important than younger people.

- **The benefits of the study are expected to be realised more by later generations, but quite strongly by participants themselves**. 37% of people expect the benefits to be *very important* to their own generation, and another 51% expect the benefits to be *quite important* to their generation. These figures increase to around 70% and 95% respectively for both of the next two generations. The proportion of people who felt that the benefits of the study would be important to their own generation increased through the workshop.

- **Most people are *at least quite interested* in taking part in a study, and *at least quite likely* to do so.** 85% of respondents were very interested (39%) or quite interested (46%) in taking part in a family health study. Similar proportions indicated that they were likely to take part in a study conducted in Joondalup if it started within 12 months. Most people who were in a position to so do would also allow their children to participate. People who attended the workshop were already more likely than average to be interested and likely to participate, but this increased further through the workshop.

- The most **important considerations** in deciding to take part appear to be:
  - Possible benefits from genetic research, including for their own family's health;
  - The chance to do something good for the community; and
  - Security of personal data

  The importance of considering the broader benefits of genetic research and the chance to do something good both increased through the workshop – but so to did the need to consider the physical testing and need to provide personal lifestyle information.

- The **biggest advantages** seen in taking part were:
  - Free testing during the study
  - Regular testing during the study
  - Contributing to new cures or treatments
  - Contributing to new screening techniques

  Participants in the workshop placed more emphasis on the regular testing as opposed to free testing as an advantage. As a result of the workshop the attractiveness of an ethics oversight committee also increased.

- Most **people did <u>not</u> feel it would be too difficult to get time** to complete the physical tests. However, people who lived with younger children did indicate it might not be as easy as for other groups.

- There was a preference for **testing to be done**:
  - at a central location;
  - in one long session;
  - during the week; and
  - for children's testing to be done with parents rather than in schools.

  However, around 1-in-4 respondents preferred an alternative to each of these, and ensuring that a range of options is available will be important to facilitate participation by as many residents as possible.

- Most people saw **protection of genetic information** as being of the same or less importance as other medical data, but there was a substantial minority who felt it was more important (34%). 44% of respondents felt that genetic information was different to other medical information, and of these people 58% felt that protecting it was more important then protecting other health or medical information.

- Most people **preferred that the privacy and protection of personal data was the responsibility of the medical / research community** rather than the Government (77%).

Participation in the survey did not have any significant impact on respondents' likelihood to participate in the study, suggesting that a) it is difficult to change peoples' pre-existing interest in the concept; but b) that the details of the study are not likely to put off people who were otherwise interested in the concept.

## Conclusions

There is nothing in the community feedback that suggests the study would fail to obtain a favourable response from residents of the City of Joondalup. Latent interest in the concept of a study is high, and likelihood to participate is also high.

The biggest issue for the study may be encouraging participation from the key younger and younger family segments. Older people were more likely to be interested in participating – and attendance at the workshop showed that this is likely to be reflected in participation rates. Thus, ensuring sufficient participation from these younger groups is likely to be the main challenge for a study.

It is difficult to predict an overall likely participation rate, but some level of discounting of expected participation is necessary to allow for the inevitable effects of inertia on actual rates.

There is considerable information in the study that may be of use in developing effective communications strategies to encourage participation. A combination of appealing to the key attractors of contributing to the development of new technologies and cures; the personal benefits of regular and free testing; and the processes in place to protect personal information and data should be effective. This last issue of security is an important one – but it is likely to be a 'hygiene factor' rather than an attractor (ie: a necessary condition for participation, but not something that initially attracts interest).

Overall, this initial community feedback process would seem to suggest that the community within the City of Joondalup is open to and interested in the possibility of the Family Health Study being launched. There does not appear to be any obvious barriers to the study, and the main challenge will probably be to encourage suitable levels of participation from the important younger residents segment.

# Section 2: Background and Methodology

## 2.1 Information needs and methodology rationale

### Why a survey is needed

Longitudinal studies have long been a key part of medical and health research, allowing researchers to identify long-term correlates of health conditions, and in some cases revealing important cause and effect relationships which are not evident on a smaller time scale.

In Western Australia a family health study in Busselton has run for over 30 years, generating positive health outcomes for participants in the study area as well as data applicable to the wider community.

A team from the Western Australian Institute for Medical Research (WAIMR) proposed to establish a similar long-term Family Health Study in the Perth metropolitan area, incorporating additional data streams made relevant with advances in technology, such as genetic information. The City of Joondalup (COJ) was identified as a suitable location for the study (having a stable population with a wide age range including a sufficient volume of younger families).

A family health study requires strong participation from the community in order to be successful, and thus measuring the public response to the proposed study is an important pre-cursor to making the final decision to go ahead with the study.

### Chosen community feedback methodology

A community survey was seen as a critical component to the community feedback process. Many surveys use a single-wave model, collecting data to provide a snapshot of the existing attitudinal or behavioural landscape. Even longitudinal or tracking surveys generally just measure within the context of the existing environment.

While this works well with many subjects, there are occasions when measurement in the existing landscape does not give a complete picture. Typically, this occurs when the 'average' level of knowledge or understanding of a subject is (potentially) incomplete or inaccurate, or when attitudes could change given the opportunity to discuss the issues in more detail with a wider range of people.

In this case, a more 'deliberative' methodology can be useful. In a deliberative survey data is collected both before and after some form of 'intervention' – a pre-and-post-test methodology. In a deliberative survey the intervention is usually an experience designed to give survey participants a more complete and considered understanding of the issues at hand – and then to see whether this changes their views in any way.

The importance of this methodology is that it provides both information about the *existing* attitudes prevalent within the environment (the pre-test results), but also the attitudes that would *potentially* be prevalent if the wider community was exposed to the same additional experiences that survey participants are. Having access to both of these sets of information allows more informed decision making than either set in isolation.

It was felt that the level of understanding of a family health study within the community may well be insufficient for potential participants to meaningfully be able to provide feedback. More importantly, there was a concern that reactions to the genetic component of the study might be heavily influenced by pre-conceived attitudes based on less-than-complete information and discussion.

Therefore, a deliberative survey component was proposed for the community feedback process. The intervention used in the methodology was a community forum at which various experts (both from within the WAIMR team and other relevant disciplines) would present information and be available to answer questions from participants.

All residents of the COJ were invited to attend the workshop through a variety of advertising and communications. However, because the group of people who actually attend a workshop cannot be tightly controlled in terms of their representativeness to the wider population (in terms of their demographic profile and, even more crucially, their attitudinal profile), a deliberative survey of workshop participants only would not necessarily give a reliable picture of the community as a whole.

Thus, the final community feedback methodology used involved two parts:

1. A tightly controlled stratified random sample community survey; and
2. A deliberative survey with self-nominated workshop participants.

This methodology allows us to reliably measure currently existing prevalent attitudes within the community, and then observe any changes in the views of a calibrated sample that occur as a result of participation in the community workshop experience.

## 2.2 Detailed methodology

### **Community Survey**

The purpose of the community survey is to make a reliable measurement of the prevalent attitudes and opinions within the wider community. This will be the baseline measure of community attitudes, and also act as a point against which the workshop participants can be compared to determine how representative they are of the total community.

#### Sample Frame

The sample frame for the community survey was all residents aged 18+ within the City of Joondalup.

To obtain a reliable survey sample from this population requires two issues to be addressed:

- *Validity / Representativeness*
  The validity of a sample is primarily determined by its ability to accurately represent the total population. This is typically done by controlling its structural profile (eg: age, gender and spatial distribution) to match that of the population. The assumption is then made that the incidence rate of attitudes and behaviours of interest in the sample will reflect the incidence rate in the total population.

  A second element of validity is that each eligible individual within the target population has an equal chance of being included in the sample. If any sections of the population are systematically excluded, this can also introduce biases in the sample that invalidate it.

In this survey both these elements were addressed by using a random selection of survey recipients from the WA Electoral Roll. The Electoral Roll is the most comprehensive list of 18+ residents of the COJ, and random selection from this list gives each enrolled voter an equal chance of selection. Further, random selection picks up age and gender in incidence proportions from the population, and thus automatically matches the sample of survey recipients[1] to the population.

- *Reliability*
  The capacity for a sample to reliably represent a larger population is one of the more misunderstood elements of survey research in the wider community. Most people understand that the larger the sample the greater its reliability, and this is true - but *only* if the sample is representative and valid as described above. This is the reason that 'surveys' conducted by TV, radio and newspapers in which people are invited to phone in to respond are virtually *never* meaningful, regardless of the huge sample sizes they can sometimes generate.

  In fact, sample reliability is expressed as a maximum sample error of ±X% at a specified confidence level. The WA Office of the Auditor General recommends a sample reliability of no more than ±5% at the 95% confidence level. This literally means that 95% of the time, a result from a sample with this level of reliability will be no more than ±5% different to the result that would have been obtained from the entire population.

  The reliability of a particular sample can be determined used statistical tables based on the population size (and assuming validity / representativeness). For any population in excess of about 5000 people, an effective sample of N=384 people yields a maximum sample error of ±5% at the 95% confidence level, which is why surveys of N=400 people are common. The *effective* size of a sample is reduced when weighting is applied, meaning that larger raw sample sizes can be needed is weighting expected.

  In this survey, we targeted a maximum sample error of ±5% at the 95% confidence level, and thus our objective was to generate an effective sample size N>384.

Data collection methodology
A mail-out mail-back survey methodology was used for this survey. Randomly selected recipients received a package containing the questionnaire, an introductory letter from the WAIMR team, and a reply paid envelope to return the completed survey.

The mail methodology was chosen because a number of the questions required respondents to look at relatively long lists of options and to choose amongst them, and this type of question cannot be reliably completed in a telephone interview.

Recipients were given a three week window in which to return the completed survey for analysis.

Using the random selection methodology, the age / gender profile of the survey recipients should be proportional to the population. However, typically in a survey older

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[1] Note that this process matches the survey *recipients* to the population – but not the survey *participants*. Because participation in a survey is never perfectly in proportion to receipt of the survey, the final returned sample then needs to be weighted in a statistical process for analysis (see section 2.3).

people and females are more likely to respond, and therefore some weighting is usually required to correct the returned sample to the population profile.

### Questionnaire

The questionnaire was designed by an independent research consultant engaged by the WAIMR team to design, conduct and analyse the community feedback process.

The questionnaire was written using an iterative approach involving the research consultant and the WAIMR team. The final questionnaire was approved for used by the University of Western Australia's Research Ethics Committee. A copy of the questionnaire used can be seen in Appendix A of this report.

### Sample Size

The number of questionnaires mailed out was based on two figures: the required raw sample size for analysis and the expected response rate.

The target effective sample size is N>384, but because weighting will be required to match the sample to the population, the raw sample size needs to be 25% larger to allow for loss of effective sample size. Thus, the target minimum raw sample size is 500 completed surveys.

The response rate for a survey is always difficult to accurately predict. Typical response rates for a 'cold' mail survey will be 10-25%.

This suggests that sending out 5000 surveys should yield at least 500 responses. However, it is better to allow for a worst case scenario to ensure a sufficient sample for analysis, and thus we chose to send out 7500 surveys initially.

## Deliberative Survey

The purpose of the deliberative survey is to determine whether views towards the family health study change as a result of exposure to more (and more complete) information, and the chance to discuss it in a wider forum. If opinions do change, then these changes need to be considered in any communications or decisions made.

The deliberative survey was conducted at a self-nomination community workshop, and the sample for the workshop was calibrated against the wider community sample in order to see how closely participants represent the community.

### Sample frame and size

The sample frame for the deliberative survey was the same as the community survey – all 18+ residents of the COJ. However, because the workshop is a self-nomination process and the number of attendees is lower, the ability to control and allow for variation in the structural variables of age and gender is considerably lower.

Further, because of the self-nomination process, it cannot be known in advance how representative of the attitudes of the wider community that a workshop sample will be. The existence of the controlled community survey sample allows us to calibrate the workshop sample.

The sample size for the deliberative sample is determined by the number of people who actually attend the workshop on the day. Typical experience with other workshops shows that there is a considerable drop-out rate from nomination to attendance.

Questionnaire

The deliberative survey data was gathered using a modified version of the community survey questionnaire (see Appendix B).

Data collection methodology

Participants completed the survey twice during the workshop – once at the beginning of the day when they first arrived, and once at the completion of the workshop. Questionnaires were completed at the workshop tables, and returned to the table facilitators.

## 2.3 The Sample

### Community Survey Sample

A total of 1210[2] completed surveys were received from the 7500 mailed out in the community survey, a response rate of 16% - within the expected band of 10-25%.

As is typical with surveys, older people and women were more likely to respond to the survey, necessitating some weighting to the sample in order to balance the sample to the correct age / gender profile of the City of Joondalup. The table below shows the comparison of the population and sample profiles.

**Table 1: Age and gender profile of the City of Joondalup (based on 2001 Australian Bureau of Statistics Census data), and the comparative profile of the returned raw sample.**

| City of Joondalup Population Profile (2001 ABS Census data) | | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| **18-29** | 11% | 11% | **22%** |
| **30-39** | 9% | 11% | **20%** |
| **40-49** | 12% | 13% | **25%** |
| **50-64** | 11% | 11% | **22%** |
| **65+** | 5% | 6% | **11%** |
| **Total** | **48%** | **52%** | **100%** |

| Returned Raw Sample [N=1210] | | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| **18-29** | 3% | 6% | **9%** |
| **30-39** | 4% | 9% | **13%** |
| **40-49** | 8% | 14% | **22%** |
| **50-64** | 18% | 21% | **39%** |
| **65+** | 9% | 9% | **18%** |
| **Total** | **41%** | **59%** | **100%** |

The corrective weights are calculated as the ratio of the target (population) percentage to the observed (sample) percentage.

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[2] A total of 1224 surveys were received, but some lacked age or gender information required for weighting, and therefore could not be used for the analysis.

**Table 2: Calculated weights to correct the sample profile.**

| Returned Raw Sample [N=1210] | | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| **18-29** | 4.1238 | 1.7278 | *2.4629* |
| **30-39** | 2.1416 | 1.2336 | *1.5316* |
| **40-49** | 1.5397 | 0.9642 | *1.1667* |
| **50-64** | 0.6538 | 0.5087 | *0.5740* |
| **65+** | 0.5723 | 0.6842 | *0.6289* |
| **Total** | *1.1840* | *0.8747* | *1.0010* |

Note: weights for Totals are hypothetical and shown here for indicative purposes only. Only the actual cell weights are used in calculations.

The effect of weighting on effective sample size is due to the relative differences in how cells are up-weighted or down-weighted. In essence, when a cell is over-represented in the sample, when it is down-weighted (weight > 1.0) the 'extra' data is discarded. On the other hand though, when cells are up-weighted because of an under-representation in the sample, we still only have the same number of cases, they are just treated in analysis as though there are more of them. Thus, the effective number of cases counted for the analysis is reduced.

In this case, the effective sample size was calculated to be N=819, drop of 32% from the raw sample size. This is quite a large drop in effective sample size, and reflects the magnitude of the skew towards the older end of the age spectrum seen in the returned raw sample.

However, a sample with an effective sample size $N_{eff}=819$ from a population the size of the City of Joondalup gives a maximum estimated sample error of ±3% at the 95% confidence level. Thus, we have a very reliable sample with which to conduct the analysis.

## Deliberative Survey Sample

Wave 1 and Wave 2 deliberative surveys were completed by 109 participants at the community workshop. The target population profile for this sample is the same as shown in Table 1. The table below shows the observed profile of the workshop participants.

**Table 3: Age and gender profile of the workshop participants.**

| Workshop Sample [N=109] | | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| **18-29** | 3% | 0% | **3%** |
| **30-39** | 4% | 10% | **14%** |
| **40-49** | 4% | 15% | **19%** |
| **50-64** | 12% | 27% | **39%** |
| **65+** | 12% | 13% | **25%** |
| **Total** | **35%** | **65%** | **100%** |

Overall the age and gender profile of workshop participants was not radically different in nature to the community survey sample, with women and older people especially likely to participate. The weights required for the deliberative survey sample can be seen below.

**Table 4: Calculated weights to correct the workshop sample profile.**

| **Workshop Sample [N=109]** | | | |
|---|---|---|---|
| | **Male** | **Female** | **Total** |
| **18-29** | 3.7114 | - | *5.4184* |
| **30-39** | 2.2487 | 1.0609 | *1.4003* |
| **40-49** | 2.9254 | 0.9000 | *1.3264* |
| **50-64** | 0.9534 | 0.4187 | *0.5876* |
| **65+** | 0.4197 | 0.4737 | *0.4478* |
| **Total** | *1.3802* | *0.7953* | *1.0000* |

Note: weights for Totals are hypothetical and shown here for indicative purposes only. Only the actual cell weights are used in calculations.

The effective sample size of the workshop sample, after weighting, was just $N_{eff}=62$, which has a maximum sample error of ±12% at the 95% confidence level. However, the main importance of the deliberative sample is to determine whether there are any major changes in attitudes as a result of the workshop experience, and for this purpose the deliberative sample will be sufficient.

## 2.4 Conclusion on the Samples

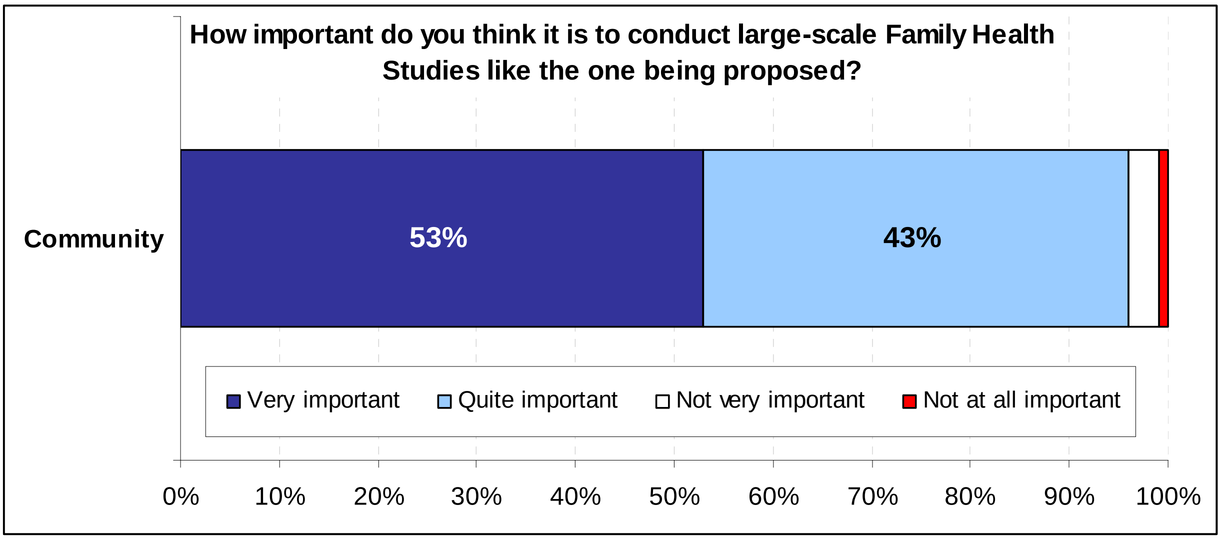
The community survey sample is reliable and robust. The effective sample size allows detailed analysis at both the overall community level, and also at the level of smaller sub-groups of interest. The researcher is very confident in the capacity of this sample to reliably reflect the views of the community.

The deliberative sample would be more problematic in isolation, being relatively small in absolute size and being in need of considerable weighting which further impacts its effective size. However, in conjunction with the community survey, the deliberative survey gives us a sufficient sample in order to identify whether there are any major changes in opinions that were generated by the experience of the workshop – which is its primary purpose in the overall feedback process. While care must be taken in interpreting the results from this sample, there is little doubt that it can substantially add to the overall information that will be generated by the community feedback process.

## 3.1 Importance of Long Term Family Health Studies

The large bulk of the community feel that long term family health studies are important. 96% of people indicated that they are at least quite important, and over half that they are *very* important.

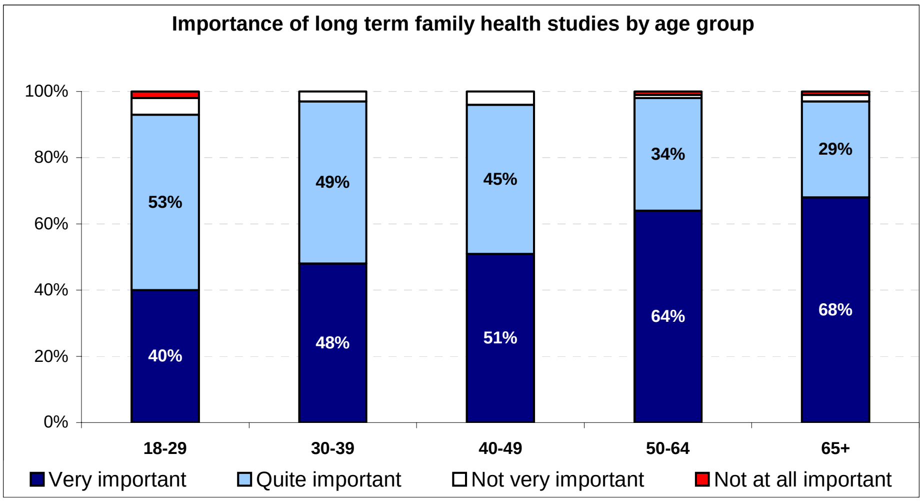
**Figure 5: Perceived importance of long term family health studies.**



Women were a little more likely than men to feel that such studies were very important (58% vs 48%), but this has little impact on the overall perception of importance.

Perceptions of importance increased considerably with age (see chart below). However, while this effect is statistically significant, even in the younger age groups such studies are still generally seen as important. The key implication of this result is that it suggests younger people may be somewhat less motivated to participate than older people.

**Figure 6: Perceived importance of family health studies by age.**



**Deliberative Survey**

The participants in the community workshop were essentially supporters of the study. 100% of the people who attended the workshop initially felt that such studies are *very important* (72%) or *quite important* (28%) – suggesting that as a group they were slightly more positively disposed towards the concept of a study than the community as a whole.

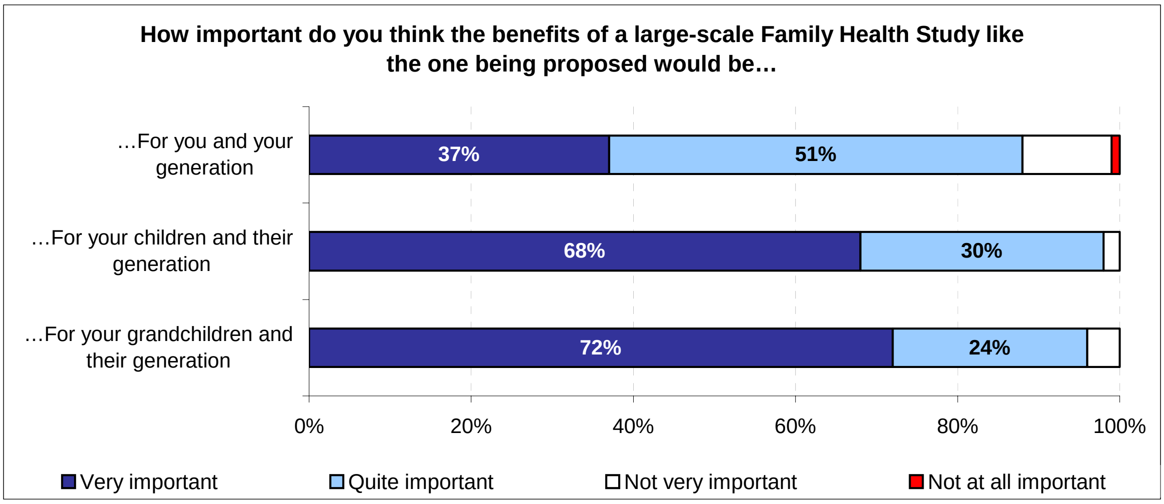
After participating in the workshop, the perceived importance of long-term family health studies increased still further, with the proportion of participants who felt they are *very important* increasing from 72% to 90% in the post-workshop survey.

## Who benefits from such a study

Nearly 90% of people expect that the benefits of a study such as the one being proposed would be available to them and their own generation, with one-in-three people expecting the benefits to be *very important* to their own generation.

Two thirds of people expect the benefits to be *very important* to the next two generations.

**Figure 7: When the benefits of a long-term family health study are expected to manifest themselves.**



Interestingly, it might be expected that older people would be less likely to expect benefits from a long-term study to be available to their generation, but this was not the case. If anything the 18-29 age group were least likely to expect benefits in their generation, while the 50-64 age group were *most* likely to expect benefits.

### Deliberative Survey

Participants in the community workshop initially expected that the benefits of the study would be slightly more important to all generations, suggesting their overall expectations of the study are higher than the community in general. 47% initially expected the benefits to be *very important* their generation, compared to 37% across the broader community; while 85% of participants initially expected that the benefits would be *very important* to both their children's and grandchildren's generations.

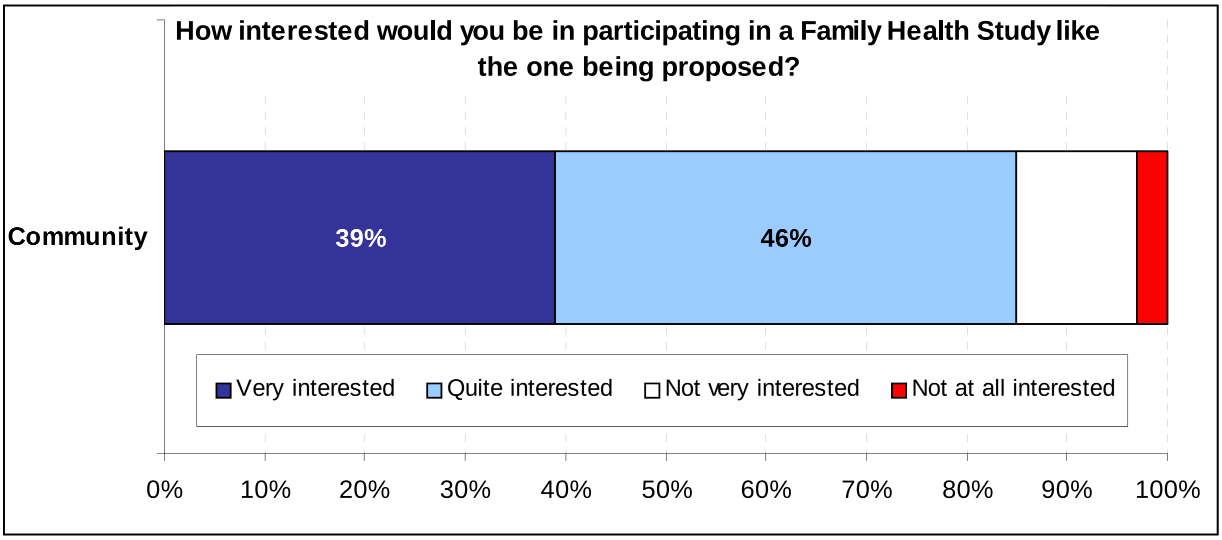
After the workshop, participants' expectations of the benefits from the study being important to each of the three generations increased further. In the post-workshop survey 62% of participants expected the benefits to be very important to their generation, and 93% for each of the next two generations.

## 3.2 Pre-existing Interest in Participation

Participants in the survey were asked twice how interested they were in participating in the study – once at the beginning of the survey and once at the end after they had had the chance to consider some of the issues covered. The first of these can be considered to be a 'pre-existing' level of interest, and is probably the best indicator of latent interest within the community.

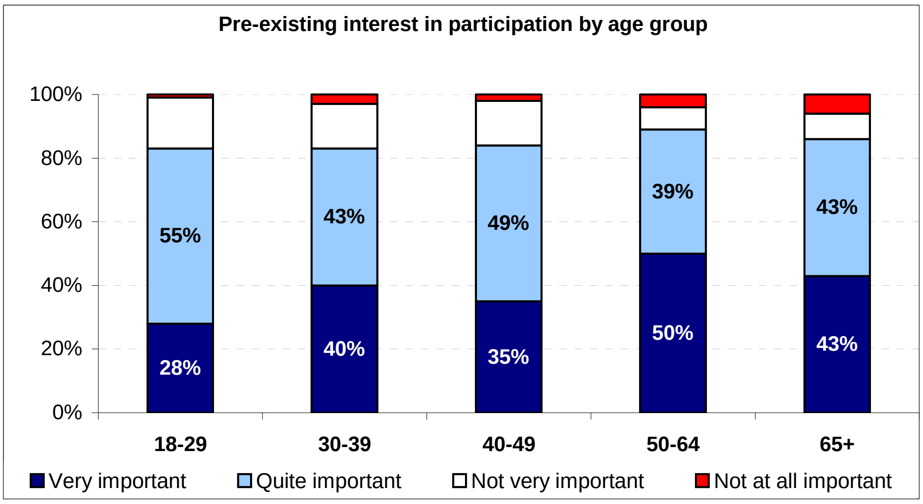
There does appear to be a high level of interest in participation in a family health study, with 85% of respondents to the survey being either *very interested* or *quite interested*.

**Figure 8: Pre-existing levels of interest in participation.**



There was no meaningful difference in the level of interest of males and females. Nor were there dramatic differences based on age groups with over 80% of all age groups at least quite interested.

**Figure 9: Pre-existing levels of interest in participation by age group.**



**Deliberative Survey**

As well as being a little more positive about the importance of long-term family health studies, participants at the workshop were also much more likely to be interested in taking part. 80% of the participants were initially *very interested* in participating, and this figure increased to 88% in the second wave of the deliberative survey.

Comparing these figures to the wider community (as seen in Figure 8), it is apparent that the sample of participants in the workshop (and therefore the deliberative survey) is quite different attitudinally. This skewing of the workshop participants away from the community is not unexpected, and is the primary reason why the community survey was conducted in addition to the deliberative survey. However, it does mean that the reader must be cautious in interpreting the deliberative survey results, always remembering that the sample is representative of "likely participants", rather than "the broader community as a whole".

## Likelihood to participate

In keeping with these levels of interest and the perceived importance of long-term studies, a large proportion of respondents indicated that they would be likely to participate in a family health study if it was conducted in the COJ starting within the next 12 months.

81% of respondents were very likely (37%) or quite likely (44%) to participate.

The 18-29 age group was the least likely group to participate (comparative figures were 21% and 52%). There were no differences in the likely participation of people who have children living with them by comparison to the wider population.

85% of people aged under 50 would allow any children aged 6-18 to participate in the study. A similar proportion of people who actually *do* have children aged six or over living with them indicated that they would allow the children to participate in the study (34% very likely to do so, 51% quite likely).

**Deliberative Survey**

Not surprisingly, given the previous result, participants in the deliberative survey were also more likely to have a higher likelihood of participation. 76% were initially *very likely* to participate, and this increased to 91% after the workshop.

More interestingly though, the proportion of participants who were *very likely* to allow their children aged 6-18 to participate actually dropped marginally from an initial 79% to 68% after the workshop. While these figures were still higher than in the general population, it would seem that for a small number of individuals the workshop experience made then feel *less* like involving their children. It is not clear from the survey data in isolation why this should have been the case, but even though it is based on a very small number of cases, it is of interest as to why this inconsistent result would be seen.

## 3.3 Drivers of Participation

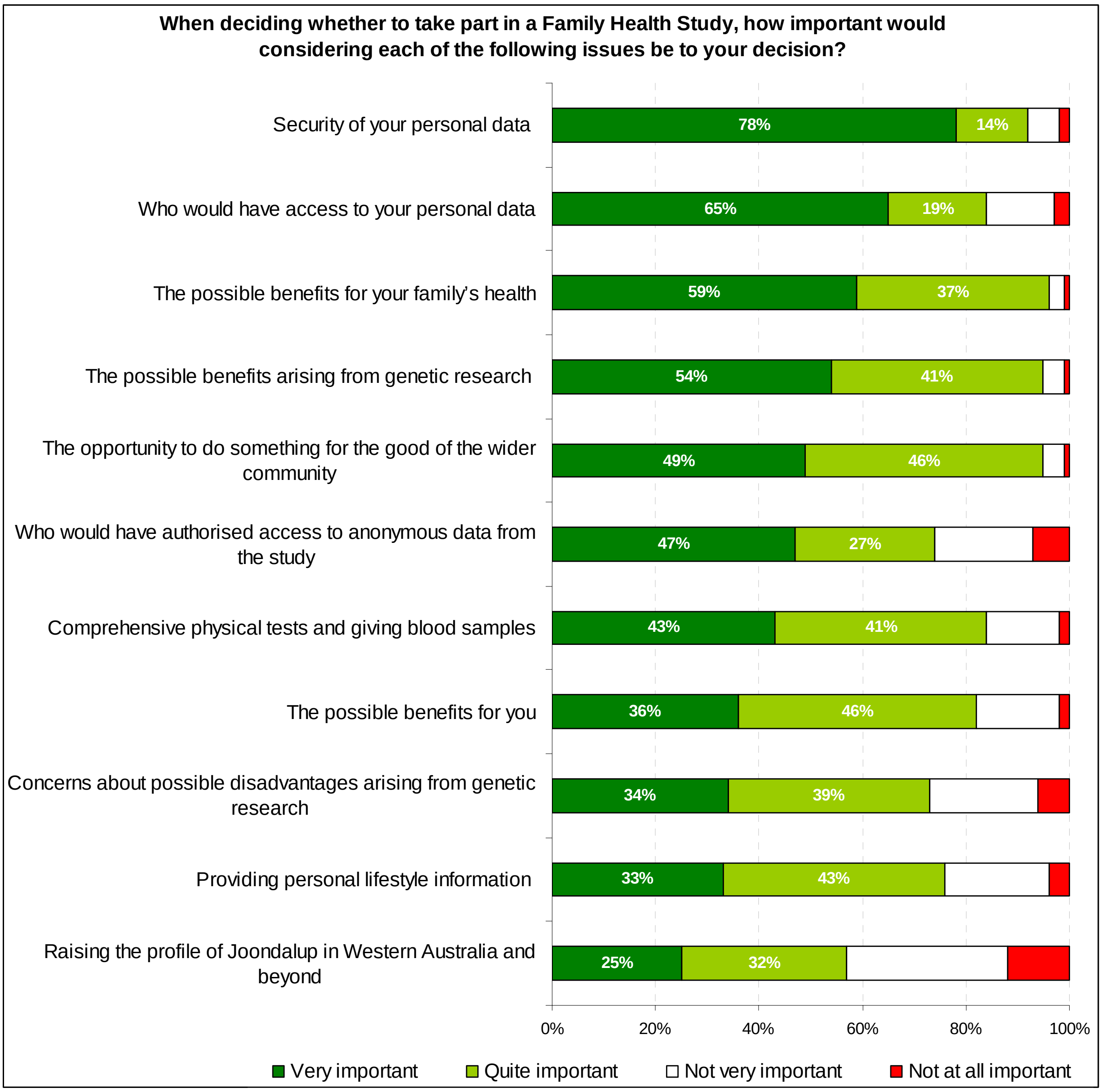
### Considerations

Security of personal data is a key consideration for potential participants, and considerably more important than issues of access to anonymous data.

The other most important considerations are generally very positive, predominantly relating to the potential benefits of the study. Concerns about the actual requirements of participation were relatively less important.

Of the two 'altruistic' considerations, it appears that 'doing something good for the wider community' is a more attractive proposition than 'raising the profile of Joondalup'.

**Figure 10: What is important to the decision to participate in the study.**



**Deliberative Survey**

There were two results of interest in the deliberative survey:

1. The workshop participants gave a very similar pattern of responses in terms of both the order of importance and the level of importance of each consideration; and
2. Most considerations became marginally more important after the workshop. In particular a greater proportion gave a ‘very important’ rating in the post-workshop survey for: the possible benefits arising from genetic research and the opportunity to do something good for the community; but also to having comprehensive physical tests and providing personal lifestyle information.

In addition to indicating the importance of each of these considerations, respondents were also ‘forced’ to rank the most important consideration and the top three considerations. This is a slightly different way of addressing the question, forcing respondents to have to choose from amongst a range of considerations that they might have rated as equally important.

This version of the question revealed a similar, but not identical, pattern of considerations. The possible benefits were clearly the most likely to be ranked ‘most important’, suggesting that these might be the most effective single message to potential participants.

Security of personal data remains important, and obviously addressing concerns in this area is important. However, in terms of motivating participation, this issue might be better treated as a hygiene factor rather than as a driver in itself.

One in three respondents indicated that the opportunity to do something for the good of the community was one of the three most important considerations for them.

**Table 11: Ranking of important considerations in the decision to participate.**

| | Most important | Top 3 |
|---|---|---|
| The possible benefits for your family’s health | 24% | 56% |
| The possible benefits arising from genetic research | 26% | 50% |
| Security of your personal data | 12% | 45% |
| Who would have access to your personal data | 16% | 37% |
| The opportunity to do something for the good of the wider community | 7% | 32% |
| The possible benefits for you | 6% | 22% |
| Concerns about possible disadvantages arising from genetic research | 3% | 16% |
| Comprehensive physical tests and giving blood samples | 4% | 15% |
| Who would have authorised access to anonymous data from the study | 1% | 13% |
| Providing personal lifestyle information | 1% | 7% |
| Raising the profile of Joondalup in Western Australia and beyond | 1% | 5% |

**Deliberative Survey**

The results from the deliberative survey were extremely similar to those from the community survey (with one minor exception), and further there were no significant changes to this pattern of results across the two waves of the survey.

The exception was that participants in the workshop were less likely to rank *security of your personal data* as an important consideration. 12% of the community sample ranked this as the most important consideration, and 45% as one of the top three considerations. The comparative figures for the workshop participants were 2% and 26% in the first wave of the deliberative survey and 1% and 30% in the second wave.

Overall though, it would seem that the considerations of people who are keen to participate (the workshop sample) are much the same as the broader community; and that these were not radically affected by the workshop experiences.

## Attractors

While the altruistic considerations came considerably lower down the scale in comparison to more prosaic issues, it seems that they do remain important motivators to participation.

As Figure 12 shows, contributing to the development of cures, treatments and screening techniques were the things most likely to attract respondents to participating in the study. While getting personal health benefits as a by-product of the study were attractive, they were considerably less attractive than contributing to advances in technology and knowledge.

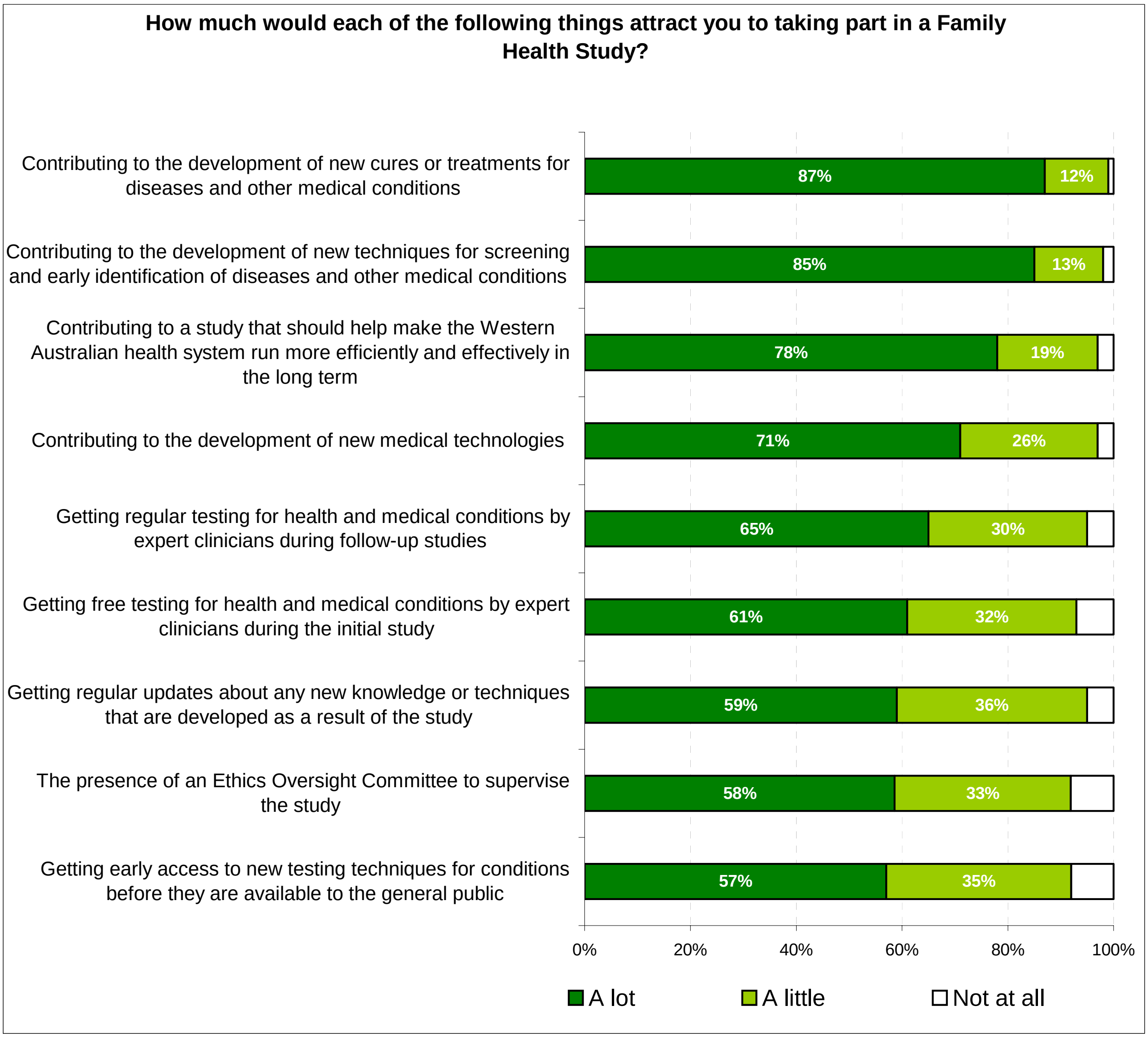
There are two other particularly interesting results in Figure 12:

- The relatively high ranking of the attraction of possibly improving the efficiency of the WA health system; and

- The relatively low ranking of the impact of an Ethics Oversight Committee.

These two results suggest that the former may be an effective component in any strategy to attract participants, but reinforces the fact that the ethical / privacy considerations may be more of a hygiene factor. Meeting participant's basic needs in this area will be critical characteristic of the study, but in itself will not motivate them to actually participate.

**Figure 12: Attractors to participation.**



### Deliberative Survey

There were several places where the deliberative sample varied from the community sample in terms of what was initially attractive to them – and one place where a substantial change seemed to take place as a result of the workshop.

Workshop participants – people who were generally very interested in being involved in the study – ranked as being more attractive:

- *Contributing to a study that should help make the Western Australian health system run more efficiently and effectively in the long term* (91% 'a lot' compared to 78%)
- *Getting regular testing for health and medical conditions by expert clinicians during follow-up studies* (82% vs 65%); and
- *Getting regular updates about any new knowledge or techniques that are developed as a result of the study*

The change that occurred was in terms of the attractiveness of *an ethics oversight committee*, which increased from 61% pre-workshop to 80% post-workshop.

There were no stand-out attractors when respondents were asked to pick the benefits that would be of most personal advantage, with no one benefit attracting more than 16% of 'top' rankings.

**Table 13: Ranking of most attractive benefits.**

| | Most important | Top 3 |
|---|---|---|
| Getting regular testing for health and medical conditions by expert clinicians during follow-up studies | 16% | 50% |
| Contributing to the development of new cures or treatments for diseases and other medical conditions | 13% | 48% |
| Getting free testing for health and medical conditions by expert clinicians during the initial study | 32% | 45% |
| Contributing to the development of new techniques for screening and early identification of diseases and other medical conditions | 5% | 36% |
| Contributing to the development of new medical technologies | 11% | 34% |
| Contributing to a study that should help make the Western Australian health system run more efficiently and effectively in the long term | 9% | 32% |
| Getting early access to new testing techniques for conditions before they are available to the general public | 7% | 30% |
| The presence of an Ethics Oversight Committee to supervise the study | 6% | 14% |
| Getting regular updates about any new knowledge or techniques that are developed as a result of the study | 2% | 11% |

Again however, the benefits picked out as being of most personal advantage were not necessarily exactly the same as the ones that appeared most highly in Figure 12, suggesting that respondents were indeed processing these two questions differently. The results across the two questions suggest that respondents recognise that there are things that would be of personal benefit to them (eg: regular and free testing), but that these are not necessarily the things that are most attractive to them.

This may or may not genuinely be the case – it is likely that some people will respond in a 'socially correct' manner to such a question. However, this does suggest that a multi-dimensional communications strategy can be utilised, targeting both the globally attractive outcomes of the study plus also the personal benefits. How this is managed might require some consideration in terms of which is given precedence and which is secondary, it seems intuitive that the personal benefits would be sold as the secondary outcome – a bonus on top of the positive global outcomes.

**Deliberative Survey**

The results from the deliberative survey were broadly similar to those from the community survey. By comparison to the community survey, workshop participants were more attracted by *regular* rather than *free* testings. The only result to change in the two waves of the deliberative survey was a small increase in the attractiveness of an ethics oversight committee.

## 3.4 Implementation Issues

### Time to participate

One of the possible barriers to participation in the study is the amount of time required for the physical testing component. However, more than two thirds of respondents indicated that they expected that getting time to complete the physical tests would be either *not very difficult* (50%) or *not at all difficult* (21%). Only 7% of respondents expected it would be *very difficult* to get time to do the testing.

Not surprisingly, but perhaps important to note, people who lived with children (especially those aged 5 and under) were a little more likely to expect some difficulty in getting the time to do the testing. Respondents aged 50+ were the leat likely to expect it to be difficult to get time to participate.

### Scheduling testing

There was quite a strong level of consensus amongst respondents for how the testing regime should be structured. There was a strong preference for testing being done:

- At a central location;
- In one longer session;
- During the week; and
- With children tested along with parents/guardians.

Preferences for testing during or out of business hours were mixed.

**Table 14: Which of the following options for conducting the physical testing would you prefer or find most convenient?**

| | | | | |
|---|---|---|---|---|
| **74%** | **Testing was done at a central location within Joondalup** | | 26% | Testing was done in your own home |
| **82%** | **Testing was all done in one long session** | | 18% | Testing was done in several shorter sessions |
| 55% | Testing was done during business hours | = | 45% | Testing was done out of business hours |
| **72%** | **Testing was done during the week** | | 28% | Testing was done on weekends |
| 23% | Children's testing was done in school | | **77%** | **Children's testing was done at the same time as parents / guardians** |

If should be noted from Table 14 that while there are strong general preferences, there are substantial minorities (in most cases around 1-in-4 respondents) who would prefer the alternative option. Thus, while these results are very strongly indicative of how the main testing procedures should be set up, they also suggest that having alternatives available may make participation more attractive or practical to a wider range of potential participants.

## Protection of personal information

### Importance of protection

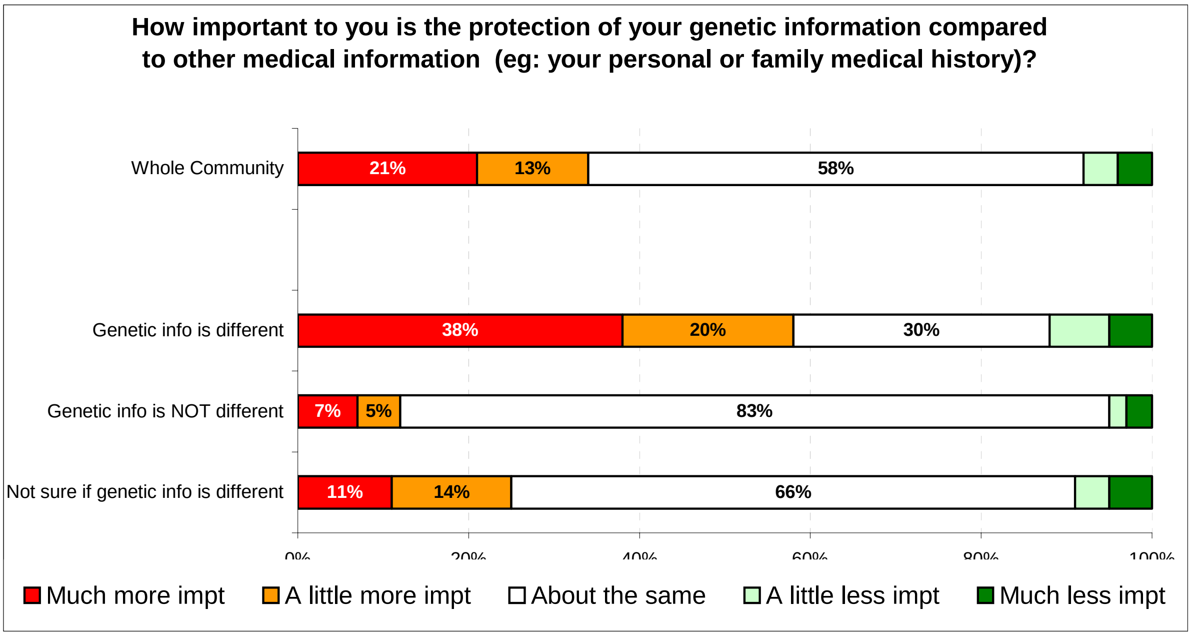
Genetic information is important to people, and to many people its protection is more important than other medical or health information.

A third of all respondents indicated that protecting genetic information was more important than other information, with 1-in-5 respondents saying it was *much more important* (the top bar in Figure 15).

44% of respondents indicated that genetic information is different to other health information, while 43% felt it is no different (and 13% are unsure). Interestingly, this result did not vary across age groups, although males were marginally more likely than females to feel that genetic information was different (48%, compared to 40% of females).

The importance placed on protecting genetic information compared to other medical and health information is shown on the bottom three bars of Figure 15. This clearly shows that people who feel genetic information is *different* also feel that it is *more* important to protect.

**Figure 15: Importance of protection of genetic information.**



**Deliberative Survey**

Participants in the workshop were, initially, a little more likely to say it was more important to protect genetic information than other health information (42% much more or a little more important, compared to 34% of the wider community). After the workshop, this figure increased further to 55%, suggesting that one of the effects of the workshop experience was to reinforce the importance of protecting genetic information beyond general health and medical information.

The proportion of workshop participants who felt that genetic information is different from other medical information increased from 42% pre-workshop (about the same as the wider community) to 61% post-workshop.

Perhaps not surprisingly, people who placed a different emphasis on the level of security of genetic information also responded somewhat differently to the various considerations and benefits of being involved in the study.

As Table 16 shows, respondents who felt that the protection of genetic information was much more important than other medical information felt that the possible benefits of the study were less important considerations compared to issues around access to data. By comparison, the small group who felt that genetic information was much less important to protect were much more likely to rank the possible benefits as an important consideration.

**Table 16: Differences in importance of considerations around participation, based on perceived relative importance of protecting genetic information.**

|  | How important to you is the protection of your genetic information compared to other medical information (eg: your personal or family medical history)? |  |  |  |  |  |
|---|---|---|---|---|---|---|
| **Issue for consideration** | **Much more impt** | **A little more impt** | **About the same** | **A little less impt** | **Much less impt** | ***Overall Top 3 rankings*** |
| ***Group size:*** | ***21%*** | ***13%*** | ***58%*** | ***4%*** | ***4%*** | ***100%*** |
| The possible benefits arising from genetic research | ↓ 39% |  |  |  |  | *50%* |
| Concerns about possible disadvantages arising from genetic research |  |  |  |  |  | *16%* |
| The possible benefits for you | ↓ 14% |  |  |  | ↑ 37% | *22%* |
| The possible benefits for your family's health | ↓ 35% |  |  | ↑ 68% | ↑ 72% | *56%* |
| The opportunity to do something for the good of the wider community | ↓ 26% | ↓ 22% |  |  | ↑ 47% | *32%* |
| Raising the profile of Joondalup in Western Australia and beyond |  |  |  |  |  | *5%* |
| Who would have access to your personal data | ↑ 53% |  |  |  | ↓ 19% | *37%* |
| Who would have authorised access to anonymous data from the study | ↑ 26% |  |  |  |  | *13%* |
| Security of your personal data | ↑ 59% |  |  |  | ↓ 20% | *45%* |
| Providing personal lifestyle information |  |  |  |  |  | *7%* |
| Comprehensive physical tests and giving blood samples |  |  |  |  |  | *15%* |

Note: Where cells are empty, this indicates that there was no major deviation from the overall rankings.

Interestingly, there was little difference in terms of which benefits were felt to be of greatest advantage. The only meaningful difference was that respondents who felt that genetic data was much more important to protect ranked the presence of an ethics oversight committee more highly than the other groups.

Responsibility for protection

Three quarters (77%) of respondents would prefer the medical and research community to be responsible for the protection of participants' personal information, in preference to the Government (through the Department of Health).

The exact proportion who preferred the medical and research community to protect the information did vary a little across sub-groups (eg: age groups). However, this did not appear to be systematic, and nor did the variations in any way change the overall preference of all groups for who should be responsible for data protection.

**Deliberative Survey**

Participants in the deliberative workshop were initially considerably more likely than the wider community to prefer the medical and research community to be responsible for protection of personal information – 91% compared to 77%.

This did not change at all during the workshop, and the figure remained at 92% in the post-workshop survey.

## 3.5 Considered Interest in Participation

The level of interest in participating in the study did not substantially change as a result of the completing the survey. The proportion of respondents who were *very likely* or *quite likely* to participate increased only slightly from 81% to 86%.

Importantly, of those who had a high pre-existing likelihood to participate, less than 2% lost interest as a result of the survey – suggesting that more detail of the project is unlikely to put people off participating.

The slight increase in overall likelihood to participate is driven by 34% of respondents who originally indicated they were *not very likely* or *not at all likely* to participate moving up to being *quite* or *very likely* to participate. Again, this small movement supports the theory that the details of the study appear to be more of an attraction than a barrier to participation.

**Table 17: How likely would you be to participate in a family health study like the one being proposed if it was to be conducted in Joondalup starting in the next 12 months?**

| | Very likely | Quite likely | Not very likely | Not at all likely |
|---|---|---|---|---|
| **Before questionnaire** | 37% | 44% | 15% | 4% |
| **After questionnaire** | 41% | 45% | 11% | 3% |

There were no changes in the degree to which parents would allow children to participate in the study after completing the survey.

# Section 4. Summary and Conclusions

## 4.1 Summary of the main results

### The samples

The community survey generated a valid and representative sample with a high degree of statistical reliability. This survey comfortably met its objective to provide a clear indication of the existing attitudes within the community.

The workshop sample for the deliberative survey was more problematic to interpret because:

1. The sample size was relatively small;
2. The sample required considerable weighting to correct structural biases; and
3. The group of people who attended the workshop were essentially people who were interested in participating in the study, and were not representative of the wider range of attitudes across the community.

Despite these issues, the deliberative survey was still a useful exercise in that it revealed something of the nature of the people who are most likely to become involved in the study, as well as some of the impacts that deeper information is likely to have on such interested people.

### Main results

#### Importance of studies

The importance of long-term family health studies such as the one being proposed in the City of Joondalup is well recognised. 96% of respondents felt that such studies are very or quite important, including 53% who felt they were *very important*.

Older people feel that such studies are more important than younger people – but even the youngest age group in the survey still felt that studies are very important. If anything, the perceived importance of the study only increased further with the additional information and detail provided in the community workshop.

#### Who benefits

Most respondents – including the older age groups - expect that the benefits of a long-term health study will be very important (37%) or quite important (51%) to their own generation. This is important, because it allows the angle of “personal benefit” to be utilised in communicating reasons why potential participants should chose to take part in the study.

#### Interest in participating

Accordingly, there is a high level of latent interest in participating in the study. 85% of respondents were at least quite interested in participating in such a study in general, and 81% would be at least quite likely to participate in a study in Joondalup beginning within 12 months. The majority of people aged under 50 would allow any children they have aged 6-18 to participate in the study as well.

#### Considerations and attractors

The issues that attract people to the study and that they would consider as important when deciding to participate are interesting, as they reveal several opportunities for developing effective communications strategies. The main considerations were:

- Security of personal data;

- Possible benefits of research, including benefits to their own family health; and
- The opportunity to do something for the good of the community.

These *considerations* were a little different to what actually *attracted* them to the study though, which were:

- Contributing to the development of new cures, screening techniques and other medical technologies;
- Getting regular and free testing; and
- Contributing to improving the efficiency of the WA Health System.

The comparative results from the deliberative survey did not alter radically, but suggested that the information from the workshop *did* have an effect on both considerations and attractors. The importance of the possible benefits from genetic research and the chance to do something good for the community both increased in importance as a consideration, presumably in the direction of encouraging participation. However, so too did the importance of considering the actual physical testing and need to provide personal lifestyle information, considerations of which might be expected to be more of a barrier to participation. The attractiveness of an ethics oversight committee also increased after the workshop.

### Implementation

In terms of implementation, most respondents felt that getting time to complete the physical testing would not be a major barrier to their participation. 71% of respondents expected getting time would be not much of a problem (50%) or not a problem at all (21%). People who live with children, especially when aged under 5 yrs, expected to have slightly more difficulty in getting time to participate.

There was a clear consensus as to how most respondents would like to see the testing regime set up:

- At a central location;
- All in one long(er) session;
- During the week; and
- Any children’s testing in conjunction with a parent / guardian’s testing.

However, there were around 1-in-4 respondents who preferred an alternative to each of these elements, suggesting that it will be important to also offer other options in order to accommodate as many potential participants as possible.

### Protection of data

34% of respondents felt that protecting genetic information was more important than protecting other health or medical information. 44% of respondents felt that genetic information was different to other medical information – and of this group 58% felt it was more important to protect than other information. If anything, the higher perceived importance of protecting genetic information was further increased as a result of the workshop experience.

Three quarters of respondents preferred to see the medical and research community have responsibility for protecting genetic information (in preference to the Government through the Department of Health).

## 4.2 Conclusions

Overall, the results of both surveys – but particularly the community survey – are very positive in terms of the proposed study.

It is perceived to be of importance to the community, and there is a very high latent level of interest in participation. Both of these results can almost be considered to be pre-requisites for actually conducting a study in which high levels of community participation are required.

That said though, there remain some important challenges. It is evident from the survey results that some of the key groups to the study organisers – younger people and families - are also the groups least likely to be interested in participation. This is not to say that they are actively dis-interested, but to note that they are less interested than the older age groups. This suggests that participation rates amongst the younger groups will probably be below the 'average' levels that might seem likely from these results, a suggestion that was starkly evident in the attendance levels at the community workshop.

It should also be noted that interest (even intention) does not equal participation. In reality, action levels are always considerably below both intention and interest (again, evidenced by the drop-out rate for the workshop). The latent interest levels identified in the survey should be considered to be a maximum possible participation rate, not a likely participation rate.

In terms of communicating the study in a manner to maximise interest and participation, there appear to be three potentially effective 'angles' which emerged from the study:

1. Personal benefits (testing, health outcomes, etc);
2. Altruism and contributing to society; and
3. Security of personal and genetic information.

It is not possible from this survey to precisely determine the inter-relationships between these, but it is perhaps not unreasonable to hypothesise that a coherent and effective communication strategy might be, in order of precedence:

- The chance to contribute to medical developments for the good of the community…
- …which in turn has direct benefits for participants (in terms of their own health and their family's health; plus the free and regular testing)…
- …and that all information is secure and there is minimal risk associated with participation.

This is based on the observation that it is the first of these that seems to be most attractive to people (and is the most "socially correct" reason to participate). However, personal benefits are inevitably going to have a strong influence in terms converting good intentions into action. While the security issue is an important consideration (and especially so for those people who feel that protection of genetic information is much more important that other medical and health information), it is probably more of a "hygiene factor" for participation. That is, it probably doesn't actually attract people to participate, but is a necessary condition for them to do so. However, it is a very important consideration for a substantial proportion of respondents, and so this part of the message still needs to be highly visible.

Additional secondary messages may also have a place. While responses to messages such as improving the efficiency of the WA health system and even raising the profile of Joondalup were relatively lower, they were still generally quite positive.

Finally, and also positively, the detail of the study does not appear to put off potential participants. Neither completing the survey nor participating in the workshop had any negative impacts on respondent's interest in participating, and in fact the effects of the workshop were almost universally in the direction of further encouraging participation amongst those people who were already highly interested. This suggests that the more information which can be disseminated to the community, the more positive the reaction to the study will be.

Overall, this initial community feedback process would seem to suggest that the community within the City of Joondalup is open to and interested in the possibility of the Family Health Study being launched. There does not appear to be any obvious barriers to the study, and the main challenge will probably be to encourage suitable levels of participation from the important younger residents segment.

# Appendix A: The Questionnaires

Questionnaires included on following pages:

- Community Survey
- Workshop Survey (Wave 1)

# Joondalup Family Health Study – Community Survey

**Please tell us what you think about the proposed Joondalup Family Health Study – to answer the questionnaire just tick the boxes that best describe how you feel for each of the issues and then return it in the reply paid envelope provided.**

**1. How important do you think it is to conduct large-scale Family Health Studies like the one being proposed?**

| | Quite important | Not very important | Not at all important |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**2. How important do you think the benefits of a large-scale Family Health Study like the one being proposed would be…**

| | Very important | Quite important | Not very important | Not at all important |
|---|---|---|---|---|
| **…For you and your generation** | 1 | 2 | 3 | 4 |
| **…For your children and their generation** | 1 | 2 | 3 | 4 |
| **…For your grandchildren and their generation** | 1 | 2 | 3 | 4 |

**3. How interested would you be in participating in a Family Health Study like the one being proposed?**

| Very interested | Quite interested | Not very interested | Not at all interested |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**4. Before completing this survey, how likely would you be to participate in a Family Health Study like the one being proposed if it was to be conducted in Joondalup starting in the next 12 months?**

| Very likely | Quite likely | Not very likely | Not at all likely |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**5. Children between the ages of 6 and 18 would be an important part of the Family Health Study. If you had children in this age range, how likely would you be to allow your children to participate in the study?**

| Very likely | Quite likely | Not very likely | Not at all likely | Not applicable |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 9 |

**6. When deciding whether to take part in a Family Health Study, how important would considering each of the following issues be to your decision?**

| | Very important | Quite important | Not very important | Not at all important |
|---|---|---|---|---|
| 1. The possible <u>benefits</u> arising from genetic research | 1 | 2 | 3 | 4 |
| 2. Concerns about possible <u>disadvantages</u> arising from genetic research | 1 | 2 | 3 | 4 |
| 3. The possible benefits for you | 1 | 2 | 3 | 4 |
| 4. The possible benefits for your family's health | 1 | 2 | 3 | 4 |
| 5. The opportunity to do something for the good of the wider community | 1 | 2 | 3 | 4 |
| 6. Raising the profile of Joondalup in Western Australia and beyond | 1 | 2 | 3 | 4 |
| 7. Who would have access to your <u>personal</u> data | 1 | 2 | 3 | 4 |
| 8. Who would have <u>authorised</u> access to <u>anonymous</u> data from the study | 1 | 2 | 3 | 4 |
| 9. Security of your personal data | 1 | 2 | 3 | 4 |
| 10. Providing personal lifestyle information | 1 | 2 | 3 | 4 |
| 11. Comprehensive physical tests and giving blood samples | 1 | 2 | 3 | 4 |

**Of the issues in the list above, which three are <u>most</u> important?**

**Most important:** ☐ **2nd most important:** ☐ **3rd most important:** ☐

**7. How much would each of the following things <u>attract</u> you to taking part in a Family Health Study?**

| | A lot | A little | Not at all |
|---|---|---|---|
| 1. Getting <u>free</u> testing for health and medical conditions by expert clinicians during the initial study | 1 | 2 | 3 |
| 2. Getting <u>regular</u> testing for health and medical conditions by expert clinicians during follow-up studies | 1 | 2 | 3 |
| 3. Getting early access to new testing techniques for conditions <u>before</u> they are available to the general public | 1 | 2 | 3 |
| 4. Contributing to the development of new medical technologies | 1 | 2 | 3 |
| 5. Contributing to a study that should help make the Western Australian health system run more efficiently and effectively in the long term | 1 | 2 | 3 |
| 6. Contributing to the development of new cures or treatments for diseases and other medical conditions | 1 | 2 | 3 |
| 7. Contributing to the development of new techniques for screening and early identification of diseases and other medical conditions | 1 | 2 | 3 |
| 8. Getting regular updates about any new knowledge or techniques that are developed as a result of the study | 1 | 2 | 3 |
| 9. The presence of an Ethics Oversight Committee to supervise the study | 1 | 2 | 3 |

**Of the issues in the list above, which three would be of the most advantage to you personally?**

**Number 1 advantage** ☐ **Number 2 advantage** ☐ **Number 3 advantage** ☐

Volunteers in a Family Health Study would be asked to provide information and undertake a series of physical tests. This would include:

- Completing a detailed survey about their lifestyle;
- Giving a blood sample (anaesthetic cream is used whenever blood samples are taken);
- A series of physical tests such as lung function tests and eye examinations.

The whole assessment would generally take about half a day to complete.

**If you were a participant in the Study:**

**8. How difficult would you expect it to be to get time to complete the physical tests?**

| Very difficult | Quite difficult | Not very difficult | Not at all difficult |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**9. Which of the following options for conducting the physical testing would you prefer, or find most convenient?**

| | | | |
|---|---|---|---|
| 1 | Testing was done at a central location within Joondalup | 2 | Testing was done in your own home |
| 1 | Testing was all done in one long session | 2 | Testing was done in several shorter sessions |
| 1 | Testing was done during business hours | 2 | Testing was done out of business hours |
| 1 | Testing was done during the week | 2 | Testing was done on weekends |
| 1 | Children's testing was done in school | 2 | Children's testing was done at the same time as parents / guardians |

**10. How important to you is the protection of your genetic information compared to other medical information (eg: your personal or family medical history),**

| Much more important | A little more important | About the same | A little less important | Much less important |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

**11. Do you feel that genetic information is different from other health information (e.g. your medical history)?**

| Yes | No | Unsure |
|---|---|---|
| 1 | 2 | 3 |

**12. If you were to participate in a Family Health Study, who would you prefer to be responsible for the privacy and protection of your personal information?**

| | | | |
|---|---|---|---|
| 1 | The medical and research community (e.g. university/ hospital ethics committees) | 2 | The Government (through Department of Health) |

**13. After completing this survey, how likely would you now be to participate in a large-sale Family Health Study like the one being proposed if it was to be conducted in Joondalup starting in the next 12 months?**

| Very likely | Quite likely | Not very likely | Not at all likely |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**14. How likely would you be to allow your children to participate in the study while they were aged 6-18 years?**

| Very likely | Quite likely | Not very likely | Not at all likely | Not applicable |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 9 |

**Please continue to the last page of the survey**

**Finally, we need a little information about you so that we can:**

- **Make sure that we have feedback from a good cross section of the community; and**
- **We can see whether different groups of people have different opinions.**

**It is VERY IMPORTANT that you provide this information, as without it we cannot include your views in the analysis and reporting. This information is not used to try to identify specific people - all responses are anonymous – but is simply to allow us to match our survey sample to the population correctly.**

**Please note**: If you completed the feedback form with input from other people, please indicate that in question 22. When asked for your age and gender details, please give ONLY those of the person who was originally sent the form. The final data set will be 'weighted' in order to make sure that it matches the age and gender profile of the community – and forms that have two sets of information can't be used for the final analysis (just as ones without any information cannot be used).

| | | | | | |
|---|---|---|---|---|---|
| **15.** | **Your Gender:** | 1 Male | 2 Female | | |
| **16.** | **Your age:** | ☐ years | | | |
| **17.** | **Your living arrangements:** | 1 Alone | 2 Couple | 3 Family | 4 Unrelated adults |
| **18.** | **Your family:** | 1 Spouse / Partner | 2 Children 5 or under living with you | 3 Children 6 or over living with you | 4 Children who have left home |
| | | **How many:** | ↓ ☐ | ↓ ☐ | ↓ ☐ |

| | | | | | | |
|---|---|---|---|---|---|---|
| **19.** | **Where you live:** | 1 Joondalup | 2 Heathridge | 3 Hillarys | 4 Greenwood | 5 Ocean Reef |
| | | 6 Woodvale | 7 Kinross | 8 Kallaroo | 9 Sorrento | 10 Iluka |
| | | 11 Mullaloo | 12 Burns Beach | 13 Padbury | 14 Craigie | 15 Duncraig |
| | | 16 Warwick | 17 Edgewater | 18 Kingsley | 19 Currambine | 20 Connolly |
| | | 21 Beldon | 22 Marmion | | | |

| | | | | | |
|---|---|---|---|---|---|
| **20.** | **Who else did this survey?** | 1 No one | 2 Spouse / partner | 3 Children | 4 Someone else |

**Thank you for completing this survey. Now that you have taken the time to do it, please don't forget to send it back to us! Completed surveys can be returned in the reply paid envelope - we need them no later than November 30th for our analysis.**

# Joondalup Family Health Study – Workshop Survey

| Survey<br>1 | Your number |
|---|---|

**Please tell us what you think about the proposed Joondalup Family Health Study – to answer the questionnaire just tick the boxes that best describe how you feel for each of the issues and then return it to your table facilitator.**

***Please make sure you have written your workshop participant number in the top right hand corner.***

**1. How important do you think it is to conduct large-scale Family Health Studies like the one being proposed?**

| | Quite important | Not very important | Not at all important |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**2. How important do you think the benefits of a large-scale Family Health Study like the one being proposed would be…**

| | Very important | Quite important | Not very important | Not at all important |
|---|---|---|---|---|
| **…For you and your generation** | 1 | 2 | 3 | 4 |
| **…For your children and their generation** | 1 | 2 | 3 | 4 |
| **…For your grandchildren and their generation** | 1 | 2 | 3 | 4 |

**3. How interested would you be in participating in a Family Health Study like the one being proposed?**

| Very interested | Quite interested | Not very interested | Not at all interested |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**4. Before participating in this workshop, how likely would you be to participate in a Family Health Study like the one being proposed if it was to be conducted in Joondalup starting in the next 12 months?**

| Very likely | Quite likely | Not very likely | Not at all likely |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

**5. Children between the ages of 6 and 18 would be an important part of the Family Health Study. If you had children in this age range, how likely would you be to allow your children to participate in the study?**

| Very likely | Quite likely | Not very likely | Not at all likely | Not applicable |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 9 |

## 6. When deciding whether to take part in a Family Health Study, how important would considering each of the following issues be to your decision?

| | Very important | Quite important | Not very important | Not at all important |
|---|---|---|---|---|
| 1. The possible <u>benefits</u> arising from genetic research | 1 | 2 | 3 | 4 |
| 2. Concerns about possible <u>disadvantages</u> arising from genetic research | 1 | 2 | 3 | 4 |
| 3. The possible benefits for you | 1 | 2 | 3 | 4 |
| 4. The possible benefits for your family's health | 1 | 2 | 3 | 4 |
| 5. The opportunity to do something for the good of the wider community | 1 | 2 | 3 | 4 |
| 6. Raising the profile of Joondalup in Western Australia and beyond | 1 | 2 | 3 | 4 |
| 7. Who would have access to your <u>personal</u> data | 1 | 2 | 3 | 4 |
| 8. Who would have <u>authorised</u> access to <u>anonymous</u> data from the study | 1 | 2 | 3 | 4 |
| 9. Security of your personal data | 1 | 2 | 3 | 4 |
| 10. Providing personal lifestyle information | 1 | 2 | 3 | 4 |
| 11. Comprehensive physical tests and giving blood samples | 1 | 2 | 3 | 4 |

**Of the issues in the list above, which three are <u>most</u> important?**

**Most important:** ☐

**2nd most important:** ☐

**3rd most important:** ☐

## 7. How much would each of the following things <u>attract</u> you to taking part in a Family Health Study?

| | A lot | A little | Not at all |
|---|---|---|---|
| 1. Getting <u>free</u> testing for health and medical conditions by expert clinicians during the initial study | 1 | 2 | 3 |
| 2. Getting <u>regular</u> testing for health and medical conditions by expert clinicians during follow-up studies | 1 | 2 | 3 |
| 3. Getting early access to new testing techniques for conditions <u>before</u> they are available to the general public | 1 | 2 | 3 |
| 4. Contributing to the development of new medical technologies | 1 | 2 | 3 |
| 5. Contributing to a study that should help make the Western Australian health system run more efficiently and effectively in the long term | 1 | 2 | 3 |
| 6. Contributing to the development of new cures or treatments for diseases and other medical conditions | 1 | 2 | 3 |
| 7. Contributing to the development of new techniques for screening and early identification of diseases and other medical conditions | 1 | 2 | 3 |
| 8. Getting regular updates about any new knowledge or techniques that are developed as a result of the study | 1 | 2 | 3 |
| 9. The presence of an Ethics Oversight Committee to supervise the study | 1 | 2 | 3 |

**Of the issues in the list above, which three would be of the most advantage to you personally?**

**Number 1 advantage** ☐

**Number 2 advantage** ☐

**Number 3 advantage** ☐

**8. How important to you is the protection of your genetic information compared to other medical information (eg: your personal or family medical history),**

| | | | | |
|---|---|---|---|---|
| **Much more important** | **A little more important** | **About the same** | **A little less important** | **Much less important** |
| 1 | 2 | 3 | 4 | 5 |

**9. Do you feel that genetic information is different from other health information (e.g. your medical history)?**

| | | |
|---|---|---|
| **Yes** | **No** | **Unsure** |
| 1 | 2 | 3 |

**10. If you were to participate in a Family Health Study, who would you prefer to be responsible for the privacy and protection of your personal information?**

| | |
|---|---|
| 1 **The medical and research community (e.g. university / hospital ethics committees)** | 2 **The Government (through the Department of Health)** |

| | | | | | | |
|---|---|---|---|---|---|---|
| **11.** | **Your Gender:** | 1 Male | 2 Female | | | |
| **12.** | **Your age:** | ☐ years | | | | |
| **13.** | **Your living arrangements:** | 1 Alone | 2 Couple | 3 Family | 4 Unrelated adults | |
| **14.** | **Your family:** | 1 Spouse / Partner | 2 Children 5 or under living with you | 3 Children 6 or over living with you | 4 Children who have left home | |
| | | **How many:** | ↓ ☐ | ↓ ☐ | ↓ ☐ | |
| **15.** | **Where you live:** | 1 Joondalup | 2 Heathridge | 3 Hillarys | 4 Greenwood | 5 Ocean Reef |
| | | 6 Woodvale | 7 Kinross | 8 Kallaroo | 9 Sorrento | 10 Iluka |
| | | 11 Mullaloo | 12 Burns Beach | 13 Padbury | 14 Craigie | 15 Duncraig |
| | | 16 Warwick | 17 Edgewater | 18 Kingsley | 19 Currambine | 20 Connolly |
| | | 21 Beldon | 22 Marmion | 23 Other (Please specify: ) | | |

**Please return completed surveys to your table facilitator – and remember to check your number is on the top-right corner**