

Joondalup Family Health Study Community Forum



On behalf of the Joondalup Family Health Study team, thank you for participating in this Community Forum. Your input will help us to decide how to progress with our community engagement program in the City of Joondalup. If the proposed Family Health Study goes ahead, the insights we have gained today will also help to shape a Study that will become a world-leading research resource, leading to health breakthroughs that will benefit generations to come, and will serve the Joondalup community.

The Joondalup Family Health Study is a collaboration of some of Western Australia's leading researchers and health professionals. The Study hopes to follow the long-term health of the Joondalup community, through detailed health, diet and lifestyle checks conducted at regular intervals. Health is multifaceted and as such, is affected by all of these factors, which are themselves inter-related. The Joondalup Family Health Study would seek to investigate all of these factors, and to enable a new and powerful understanding about the common diseases that affect so many of us.

The aim of this Community Forum has been to engage local residents in a dialogue about the proposed Study - informing participants about the issues from all perspectives, providing opportunities to deliberate with fellow residents, and informing the Study team about participants' hopes, concerns and suggestions. The forum will also provide the Study team with information about whether participants' views changed as a result of information and opportunities to deliberate. To achieve this:

- a) a large random sample of 7,500 Joondalup residents was surveyed by mail (to determine their views);
- b) at the beginning of the Forum participants were surveyed (to see if the Forum's views were similar to those of the larger population);
- c) participants had opportunities to listen to and question a broad range of experts and to discuss the issues amongst themselves;
- d) at the end of the Forum, participants were surveyed again (to see if views changed as a result of information and deliberation).

This information will be used to design further community engagement initiatives and will be available on the web (www.jfhs.org.au) in mid-January 2006.

Professor Lyle Palmer, Joondalup Family Health Study Team Leader

Keynote Addresses

Dr Fiona Wood	Professor Lyle Palmer
<ul style="list-style-type: none"> • Medical research can work through collaboration, communication and cooperation. • It is essential to work as part of a multidisciplinary team to allow science to the bedside, to further positively impact our quality of life. • Everyone's contribution matters. By using the available information, technology and expertise to assist us in this study, we can take responsibility for our own health, well being and education. • Health needs to be planned with short and long-term vision. The research being done now not only benefits us, but also future generations. • Medical research has already impacted on all our lives. With good community engagement, this Study will bear fruit. 	<ul style="list-style-type: none"> • Long running cohort studies are considered essential for understanding the environmental, social and genetic causes of common diseases • This Study is a long-term health study of children, adults and families, collecting health measures, lifestyle data and a blood sample. • Extensive community engagement program is being conducted to ensure both community support and design input. • Short term benefits: comprehensive free medical checks, enhanced access to clinical trials and new technologies. The Study will improve the prevention, diagnosis, and treatment of illness and the promotion of health. • The study, conducted in partnership with the community would provide a model for further studies in other WA communities, the State and Australia.

Study Hopes	Study Concerns
<ul style="list-style-type: none"> • Contribute to the understanding of what influences health, illness and how we can modify our lifestyles to stay healthier. • Cures, including alternative medicines will be found for common diseases, especially diabetes and asthma. • Prevention more than cure - starting with younger children. • Outcomes of this research will influence the health budget and an efficient health system in WA. • Access to long term expert health screening to enhance detection. • Future generations will benefit through knowledge of genetics and environment. • Educate children to the awareness of their individual health responsibility. 	<ul style="list-style-type: none"> • Use of personal/genetic data by both authorised and unauthorised people that have a negative impact on the individuals. • If the Study continues to receive Government and community support into the future, will people stay engaged? • Legal aspects keep up with the advances in genetics to avoid discrimination by governments or employers. • Privacy. • Where will collected information be stored and will it be secure? • If we discover something negative about our health via this study, do we need to disclose this to a third party? • Don't want to get into "weird science", issues that are morally, ethically or spiritually questionable, not playing God; also bias through pharmaceutical companies getting involved. • Dragging children into medical tests – do they want to know about poor health?

Panel 1: Importance of the Study and Advantages/Challenges

Professor Ian Constable

- Study participation will enhance health awareness in the community.
- Studies of this design lead to enhanced early detection of known risk factors and symptomless disease.
- Such studies generate new population data for long-term evaluation of genetic and environmental risks.
- Findings from such a study will potentially lead to new discoveries of disease-predicting genes, pharmaceutical interactions and responses.
- The generation of population data will lead to the ability to better plan of health services in the community.

Professor Jon Emery

- GPs are beginning to see the benefits arising from genetic research in their practice.
- The Joondalup Family Health Study will help identify genetic and environmental risk factors for many common diseases.
- This will enable GPs to tailor their management of people at increased risk of diseases such as cancer and heart disease to help prevent these conditions.
- The Joondalup Family Health Study will also identify genetic reasons for why people respond differently to drugs.
- This will enable GPs to tailor their prescribing more closely to the individual patient.

Ms Michele Kosky

- The community should be able to have input into the decision process of health research being conducted to ensure study benefits outweigh the risks.
- Informed consent, privacy and confidentiality are essential, in accordance with statute and law. If there is not adequate statute, this must be ensured if the study is to go ahead.
- Long term issues need to be considered to reflect the long term nature of the study.
- Intentions in terms of third party use must be defined to ensure that participants' rights are protected.
- Participants' rights should be clearly outlined so you are aware of your rights with respect to your health information.

Professor Alan Bittles

- Genes are the blue print from which we are created and these are affected by many external factors.
- Specific genetic disorders are often confined to particular families and communities, hence studies such as this facilitate its further investigation.
- Diagnostic and treatment facilities for genetic diseases are now widely available, reflecting the importance of the genetic profile of diseases in the population.
- The majority of diseases are influenced by a large number of genes, therefore, with this study we can see what genes are occurring with high prevalence in the community.
- Potential benefits of this study include the identification of high-risk families, gene products, and disease genes, leading to improved overall health and well-being in the community.

Panel 1: Questions and Answers

Will I have one test or a series and when will it take place (locations, times, days)?

All testing will be completed in one (half) day, based on the model used in Busselton. The community will be consulted to determine preferences such as testing in schools or at a central location as a family

Can we request to withdraw in the future and do they delete the information?

Participants can choose to withdraw at any time, with options on whether they want all samples to be destroyed.

What were the issues of the 21% of GPs who didn't support the Program?

The majority of GPs that didn't support the study, responded that they were uncertain. This could be due to the limited information available on the Study design at the time of the survey.

If anything is discovered is there an obligation to be informed and treated? Will counselling be available?

There will be an obligation to inform individuals if something is discovered in through Study. Counselling would be made available to the participants.

The Study team will investigate this in further detail to reflect community concerns about how the results will be fed back to the patient/GP.

Why am I only given clinical and not genetic information? Do I have right to know?

This Study is not only about genetics but about health in general. It is NOT screening for single gene diseases. Therefore, the genetic information will not be of clinical relevance. The genetic information collected will look at genes and their association with various diseases to establish how we can predict disease development and response to treatments.

What is the role of the GP in this study?

GPs won't be directly involved in recruitment of participants or in the collection of clinical information. However, if you choose, you can discuss any findings or health implications from the study with the GP.

What if there is information that a person may not want their GP to know?

Participants will have the final say on the level of involvement of their GP. There will be no sharing of genetic information to either the individual or their GP.

Will the study aid issues concerning mental illness?

Many cases of mental illness of a genetic origin. Therefore, we would strong support and a positive influence offered by the study in terms of improved awareness and breaking down fear of mental illness in the community. In addition, Pharmacogenomics (genetic influence on drug response) has a significant impact in mental illness. We would predict that there will be strong interest in this area generated by the Study.

How will it be decided if the study will proceed?

The study will proceed if there is enough support from the community of the City of Joondalup. If approximately ten percent (16 000) of the community are willing to participate, the study would seek adequate funding and move forward.

Can genetic tracking of family members living outside the area be conducted if indicated?

Yes, it can but done but there are many ethical and legal issues surrounding the issue. As such, this issue would require discussion and detailed investigation.

If the data is de-identified, how will they follow up people?

The data is coded rather than de-identified. Researchers will only have access to this coded data.

I want to be involved but family doesn't...?

You can enroll as an individual; enrollment in the study is not dependent of your family status.

Panel 2: Legal, Ethical and Other Issues

Professor Margaret Otlowski

- Researchers are legally obligated to ensure the safe custody of samples and personal information and that samples are only used in accordance with the subject's consent.
- There are clear challenges to ensuring 'informed consent' to future undefined use and subjects should be given the option of consenting to this.
- Researchers will be the legal owners and custodians of samples but participants should be informed of any proposed commercialisation as part of the consent process.
- Subjects should be advised about who will have access the databank and under what conditions.
- There is minimal risk of 'genetic discrimination' as genetic information will not be released to you or third parties.

Professor Lou Landau

- Most diseases are the result genetic predisposition and environmental exposure during pregnancy or early life. Therefore the greatest long term benefits, and potential harm, could result from research in children.
- Children have special needs as a result of their developmental status, vulnerability, and exclusive susceptibility to some disorders.
- Participation of healthy children in research without any likely personal benefit needs special consideration.
- It is unethical NOT to do research in children.
- Children participating in research need special protection related to consent/ assent, confidentiality, and emotional well being

Ms Meina Lee

- The ethical issues involved in the Study are not unique – they are shared by other large scale studies e.g. the Busselton Health Study.
- Security: health information and samples will be coded and securely stored according to Australian and international best-practice standards and regulations.
- Access: Third parties will not have access to your personal information and samples without your permission, in accordance with Commonwealth Law. Under no circumstances will genetic information be released to anyone.
- The Study plans to create a new best-practice standard for the ethical safeguarding of participant information.
- The Study is committed to openness and transparency and has measures in place for your easy access to the Study team, if you have any queries.

Ms Veronica Kerr

- Having a family history of breast cancer, Veronica was also diagnosed and treated but progressed to metastatic breast cancer.
- Following support and guidance from her GP, Veronica was enrolled in the Herceptin Clinical Trial in conjunction with chemotherapy.
- Despite an adverse prognosis, Veronica is now approaching her fourth Christmas, works full time and leads a wonderful, active life.
- Regular monitoring can allow early identification of problems, immediate intervention, and severity minimization.
- There are many considerations to being involved in a clinical trial. However, this trial has given Veronica her 'life back' and perhaps it can do the same for members of the community.

Panel 2: Questions and Answers

What security measures are in place to guarantee protection?

The Study data will be coded, with identifiable information kept separate from all other data. Any analysis will be done on this coded data. The study would be bound by stringent legislation as well as ethics oversight committees and scientific advisory boards. In addition to this, the study has measures in place to ensure that the design is over and above these regulations and best-practice guidelines.

Are there laws currently being proposed regarding personal information and privacy – for long term protection of personal information?

The Department of Health has been discussing issues related to the Privacy Act since 2003. This study should motivate them to keep up to date with health legislation.

How will this be funded? Will any companies (e.g. pharmaceutical) or corporations be involved?

It is important for the State and Federal Government to fund this study to retain community ownership. There will be no corporate interest in funding this Study which prevents the obligation to supply genetic information and samples to third parties. However, third party interest (such as pharmaceutical companies) is beneficial to encourage development and research into new treatments and therapies.

What was the protection in place for the Busselton study and is it comparative or useful for this study?

There are no unique issues that have arisen in this study compared to Busselton or other large scale studies. There will be multidisciplinary input into the Study design and all protective mechanisms will be put in place to protect participants.

If asked on an insurance form whether genetic tests have been performed am I legally obligated to say yes?

No. There will be no genetic testing performed in the Study that will be of relevance or importance to insurance companies.

How will a change of Government affect Study funding? Where do any proceeds from the Study go?

Based on past experience (e.g. Busselton), change of government has not affected Study funding. Third parties will not be able to purchase Study data, they will only have access to the results of analysis. Any proceeds will be placed back into medical research, the health system, Department of Health and the Joondalup Community.

Ethical Consent Rights:

If parents do not want a child to participate, then they will not participate. On the other hand, if parents want the child to participate, but child does not want to, they would not be coerced – the Study is entirely voluntary.

The age of consent is 18, and assent would be considered as consent. Participants can withdraw at any time.

Consent is not a legal contract, but rather a relationship of trust between researchers. However there are still protections in place.

Release of Information: What guarantees can you give that information will not be released in 50 or 100 years from now?

Based on the current guidelines for release of information, this would be unlikely. The issue of risk of information release is not unique to this study. In terms of safeguards, democracy ensures that we are well protected.

Suggestions

- Important to talk directly to the people e.g. a family fun day where information could be delivered; sausage sizzle, activities for children & families.
- Provide regular updates and feedback to the community e.g. e-mail, mail, telephone
- Hold a community forum just like today's, that is more focused on the teenage demographic, encourage younger participation.
- Send information to community groups - sporting, seniors, single people, youth groups, school activities, recreation centres.
- Encouraging people who are interested in the study from today reaching out to their families and friends.
- Holding a community forum, just like today's, that is more focused on the teenage demographic, encourage younger participation.
- Show the "proof in the pudding" - what Busselton brought to the community.
- Promotion of the Study through ECU - via advertisement when enrolment occurs, advertise to the student body through emails, get relevant faculties involved.
- Active promotion of the Study through a community health nurse and GP's
- Access for minority groups - need for translators and for information (flyers etc) to be provided in languages other than English. Information dissemination to the indigenous population could be through local community groups, new migrant centres etc.

Closing Address

Hon. Dr. Judy Edwards, MLA

- The Study is a unique opportunity for WA to be at the forefront of medical research and breakthroughs that will affect not only the health of our State, nation and the world, but also the health of our economy.
- The WA State Government's Centre of Excellence in Science and Innovation Program is providing some of the world's best health and medical researchers with great scope by committing \$100 million over four years to targeted initiatives in scientific research, including medical research.
- We need community opinion input into the design of the study - how it takes place and the information that will be collected, in order to achieve health benefits on a large scale as well as for individuals who take part in the study.
- Both the Government and the study team have a strong commitment to openness and transparency through addressing ethical, legal and social implications of the study.
- Such studies throughout the world have delivered great benefits including understanding of causes of major diseases. Your participation will produce better study results, leading to new industries as well as a healthier and better lifestyle for all of us.

Where to from here?

Everybody involved in the Joondalup Family Health Study looks forward to talking and working with you, and – most of all – becoming a valued part of the Joondalup community.

This Forum is only the beginning of our community engagement program in the City of Joondalup, and is the first of many community events and programs planned over the coming months. In 2006, we will be working closely with Joondalup General Practitioners, researchers at Edith Cowan University (ECU) Joondalup, and the Joondalup Health Campus to decide how to design a Family Health Study that would offer the best value to the Joondalup community and to Australian society.

In the longer term, we also plan to both engage the community and add value in many different areas. For instance, we plan to work with local schools and some of Australia's best education specialists to develop innovative ways to improve science education in Joondalup schools. We are also working with some of Australia's leading bioethicists and legal experts to ensure that a Family Health Study in the City of Joondalup would also set new standards for governance and for the protection of privacy and confidentiality of health information. It is likely that a Joondalup Family Health Study would define best practice for medical research studies both in Australia and overseas.

There will also be many other developments and I encourage you to visit our website at www.jfhs.org.au to keep up to date with the latest news. In addition, a more comprehensive report detailing the findings of the community survey and the two forum surveys will be published on the website.

The Study team can also be contacted at any time if you wish to discuss issues further or to inquire about the proposed Joondalup Family Health Study through:

Website: www.jfhs.org.au **Email:** queries@jfhs.org.au **Study hotline:** 9346 4782

The involvement and support of the Joondalup community in the planning of the proposed Joondalup Family Health Study is of great importance. The Study team encourages you to discuss information from the Forum with your family, friends and fellow members of the Joondalup community to ensure that the community remains actively involved in all aspects of the Study.

On behalf of the Joondalup Family Health Study team, thank you again for your contribution and for being a valuable part of the Community Forum. We look forward to meeting you again, and wish you joy for the festive season and a happy and rewarding 2006.

Professor Lyle Palmer, Joondalup Family Health Study Team Leader