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ORIGINAL ARTICLE

# Consumer attitudes towards the establishment of a national Australian familial cancer research database by the Inherited Cancer Connect (ICCon) Partnership

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**Abstract** Clinical genetics units hold large amounts of information which could be utilised to benefit patients and their families. In Australia, a national research database, the Inherited Cancer Connect (ICCon) database, is being established that comprises clinical genetic data held for all carriers of mutations in cancer predisposition genes. Consumer input was sought to establish the acceptability of the inclusion of clinical genetic data into a research database. A qualitative approach using a modified nominal group technique was used to collect data through consumer forums conducted in three Australian states. Individuals who had previously received care from Familial Cancer Centres were invited to participate. Twenty-four consumers participated in three forums. Participants expressed positive attitudes about the establishment of the ICCon database, which were informed by the perceived benefits of the database including improved health outcomes for individuals with inherited cancer syndromes. Most participants were comfortable to waive consent for their clinical information to be included in the research database in a de-identified format. As major stakeholders, consumers have an integral role in contributing to the development and conduct of the ICCon database. As an initial step in the development of the ICCon database, the forums demonstrated consumers' acceptance of important aspects of the database including waiver of consent.

**Keywords** Consumer · Inherited cancer · Database · Research

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## Introduction

Inherited cancer syndromes whilst individually rare have a significant impact on individuals and their family. Collectively, they contribute to population-based cancer morbidity and mortality due to their substantially increased absolute risk of cancer, early age of onset (< 50 years) and rapid tumourigenesis (Easton et al. 1995; Jasperson et al. 2010).

Research into the prevention, screening and treatment for individuals with an inherited cancer syndrome is often challenging as families can be geographically spread with family members cared for by different Familial Cancer Centres (FCCs) and clinical genetic services nationally. This barrier to research is exemplified by, but not unique to, Australia; Australia is the sixth largest country in terms of geographic area, although has a relatively small population of 23.13 million people (Australian Bureau of Statistics). The number of mutation carriers in Australia is estimated from population carrier estimates in the context of the Australian population size, but is not definitively known. Therefore, the contribution of inherited cancer to the Australian population cancer statistics cannot be accurately determined and health care resources are difficult to allocate appropriately.

In 2013, a national collaborative initiative, the Inherited Cancer Connect (ICCon) Partnership, was formed between all Australian publically funded FCCs, familial cancer researchers and consumer representatives and funded by the Cancer Council of New South Wales, Australia. This partnership aimed to establish a national database of all mutation

carriers identified through Australian FCCs to facilitate research and health care planning and set a national translational research agenda that was responsive to the needs of individuals and their families with inherited cancer syndromes. All clinical data held by each FCC was to be transformed into a national research resource.

The need to collaborate with consumers as research partners, on par with the clinicians and researchers conducting studies, is acknowledged but is often not the reality (McKenzie and Hanley 2007). Two decades ago, Collier et al. (1997) wrote to The Lancet stating that 'research consistently indicates that, given the same data, patients make different decisions to health professionals'. These authors were disagreeing with an assertion made by Alexandre and Strandberg (1997) that the European Medicines Evaluation Agency would benefit from understanding consumers' views on risk versus benefit for the development of pharmaceutical regulations, rather than directly including consumers as members of their regulation board. This example illustrates the schism in many clinical and research disciplines where there is delineation between consumers and committees comprised of clinicians and researchers that develop medical guidelines and undertake research. Consumers are invited to contribute as research participants, donating biospecimens, clinical data and demographic and psychosocial information, but are often not expected to participate as active and equal members on committees that develop medical guidelines and research. As the quote from Collier et al. (1997) is explaining, having consumer representation and engagement from conception of research ideas, through development and conduct of the research, avoids making (patriarchal) assumptions about consumers' preferences and achieves research and clinical outcomes that are prioritised and valued by consumers (Mitchell et al. 2015).

The ICCon Partnership purposely included consumers as equal members of the partnership, including as associate investigators on grant applications and integrated consumer views into project development. Specifically, consumer representation is genuinely valued by ICCon as demonstrated through a Consumer Advisory Panel embedded within the ICCon Oversight and Governance Committee. Consumers independent to ICCon who were patients of FCCs were also invited to contribute their views, attitudes and perspectives towards the development of the ICCon database. Consumer forums were conducted with the aim to examine consumers' attitudes towards the establishment of a national research database of individuals who carry a mutation in a cancer predisposition gene. This paper presents the findings from these forums.

## Methods

Consumer forums were organised in three states of Australia at metropolitan hospitals which have a genetic department or FCC. These included the Peter MacCallum Cancer Centre in Victoria, the Prince of Wales Hospital in New South Wales and the King Edward Memorial Hospital in Western Australia. Ethics approval was gained from each hospital to recruit patients from their embedded genetic services (PMCC 13/71L, POW 13/252, KE 2013097EW) to take part in a consumer forum at that site.

### Participant recruitment

Individuals aged 18 years or older, known to one of the FCCs, and from a family with a heritable cancer syndrome, were eligible to participate in a consumer forum. Potential participants who met these criteria and who were proficient in spoken and written English, were not undergoing treatment for active cancer and who were not experiencing any significant mental health issues were identified from the databases of each of the three genetic services. Letters were mailed by the respective state-based ICCon co-ordinators inviting the potential participants to a consumer forum in their state of residence. Interested participants replied to their ICCon co-ordinator to opt in to a local forum. The first 12 respondents for each forum were included and mailed a participant information sheet and consent form and an information brochure about database storage of genetic information.

### Data collection

Participants were asked to anonymously complete a brief questionnaire prior to the commencement of the forum. The questionnaire comprised of demographic and genetic and cancer status questions. These data were collected for descriptive purposes only and due to the anonymous nature of the responses were not able to be linked with participants' responses in the forums.

The conduct of the forums was guided by a modified version of the nominal group technique used to collect qualitative data about the participants' attitudes towards the establishment and use of the ICCon database. The nominal group technique is a structured procedure involving sequential stages, which provides participants with the opportunity to generate their own ideas on the topic, share their ideas in a group setting with balanced participation from all forum members, group and categorise similar ideas, discuss and refine ideas and finally rank the resulting refined ideas into a priority list that reflects the contributions of the participant group (Van de Ven and Delbecq 1972). We used a modified version of the nominal group technique excluding the ranking of ideas into a priority list, instead of aiming to finish with a detailed collection of ideas that had been discussed and refined by the group.

The consumer forums were facilitated in person by two of the authors (LF and MAY) and were digitally audio-recorded with the participants' consent. The recordings were

transcribed verbatim, and the transcripts were subject to a quality control process (LT) to ensure accuracy of the transcription. The transcripts were de-identified by removing any identifying information about the participants.

### Data analysis

The data were thematically analysed using an inductive approach to look for similarities, consistencies and differences within and between the forums. The authors (LF, MAY and LT) coded the transcripts independently then compared their findings to ensure consistency in the themes arising from the data. The iterative analysis process aimed to stimulate the emergence of ideas, concepts and categories that could be organised into themes.

## Results

Three consumer forums were conducted between November 2013 and September 2014, and a total of 24 participants attended the forums, with eight participants in each forum (Table 1). The forum was 1 h in length in Victoria and 90 min each in New South Wales and Western Australia.

The overall findings from the forums included that participants were, without exception, enthusiastic about the establishment of the ICCon database, were willing to waive active consent for their de-identified information to be stored and were generally willing for "*as much information as possible to be stored in the database*" about each individual. The main ideas commonly voiced that tempered their enthusiasm for inclusion of their data were that participants were concerned about the use of their information by third parties for commercial benefits, and that their views and perspectives may only be reflective of the 'genetic carrier population' but not the general population who have not had any contact with the familial genetic services in Australia.

**Table 1** Participant description

| | Number (%) | Mean (range) |
|---|---|---|
| Gender | | |
| Female | 16 (67) | |
| Male | 8 (33) | |
| Age (years) | | 56 (25–75) |
| Partnered | 19 (79) | |
| Children | 18 (75) | |
| Education | | |
| Secondary school year 10 or below | 1 (4) | |
| Secondary school to year 11 | 1 (4) | |
| Secondary school to year 12 | 0 (0) | |
| Bachelor degree | 9 (38) | |
| Graduate degree/diploma | 6 (25) | |
| Postgraduate degree | 7 (29) | |
| Genetic test | | |
| *BRCA1/2* | 11 (46) | |
| Lynch syndrome | 7 (29) | |
| Other | 6 (25) | |
| Mutation carrier | | |
| Yes | 20 (83) | |
| No | 3 (13) | |
| Unknown | 1 (4) | |
| Previous cancer diagnosis | | |
| Yes | 15 (63) | |
| No | 9 (37) | |

### Establishment of the ICCon database

Participants overwhelmingly expressed positive attitudes towards the establishment of the ICCon national database and perceived that currently FCCs operated in relative isolation to one another.

> "At the moment we have all these FCC's and there's more than one FCC in some States. They have these little FCCs because you can have one at Prince of Wales [metropolitan hospital], you can have one at North Shore [metropolitan hospital] and they all just sit by themselves and no one talks to each other." (Female 2, NSW)

> "I think we need to have a national database. I don't like… I don't like the FCC being in every state because information needs to be shared on a countrywide basis." (Male 3, WA)

Participants saw a need for the database that would be a national repository of aggregate data that could provide evidence of clinical outcomes. In some instances, participants were surprised that such a database did not already exist in Australia.

> "I was really surprised that there wasn't a database. Like I would just assume that all this information is pooled and that when I ask a question, if I have this treatment, what are the statistics? How do you get that information if it's not all collated together?… I would have just assumed that there was a national [database] and we worked internationally, so for me it is kind of a surprise that it's not already in existence." (Female 3, VIC)

Positive attitudes of participants were influenced by the perceived benefits that may be generated by the ICCon database. Participants were hopeful that research outcomes derived from

use of the database might result in improvements in health care for individuals who carried a germline mutation. Whilst participants were specific in identifying beneficial health outcomes for themselves and their families, many of the perceived benefits were more general for the carrier community by contributing towards a broader understanding of the implications of testing positive for a pathogenic cancer-causing mutation.

> "I think the presence of the database will promote research and information about, or promote the knowledge of the *BRCA* gene. My older sister died of ovarian cancer and it must be 20 years ago now. My brother mentioned if only we'd known, if she'd known then, she could have been alive now. So it's very important that we increase the knowledge of the condition." (Male 2, NSW)

> "I have a similar thing about benefits and the better understanding of the cancers and the links across types of cancers… breast cancers and ovarian cancer. I had an incident with bowel cancer and it appears to be linked as well. I think that would be… ultimately there might be better outcomes for treatment and perhaps precautions about being aware of those links across the cancers." (Female 6, NSW)

Participants had "*no concerns on what data is collected*" (Female 2, VIC) and wanted the database to contain a comprehensive compilation of personal and familial information relating to cancer so that beneficial research outcomes could be achieved.

> "I think that every possible type of data should be collected, absolutely everything that's in the hands of the clinicians already, the family trees, who's had it [cancer] and who hasn't, at what age, what death age, what age did they get it [cancer], what type, what age the children are tested, absolutely everything. The more information that can go in, the more that can come out, I think." (Female 1, NSW)

Some participants also suggested that the ICCon database could be linked with other national clinical (e.g. Medicare and the Pharmaceutical Benefit Scheme) and research databases in order to facilitate the compilation of other cancer-related medical and clinical information. This was to enable the inclusion of screening information used for cancer surveillance, such as the frequency that individuals engage in screening and the outcomes, as well as the types of cancer treatments.

> "Or if you've had cancer or a tumour or if you've taken medication" (Female 4, WA)

Furthermore, many participants suggested that the database could include a more extensive collection of data, such as lifestyle information, biological tissue samples and "*left handedness… all medical history*" (Male 1, VIC). These suggestions stemmed from ideas that if more wide-ranging data were collected, research using the database could be more far reaching.

> "I think it's always better to ask for more data and therefore we have a much… ICCon then has a lot more powerful resource for researchers to use" (Female 3, NSW)

Participants did not discuss the feasibility of including these types of information. Nor did they appear to be aware that given the information populating the research database is collected in clinical genetic settings, the collection of additional data such as lifestyle and personal characteristics is likely to be unrealistic given the clinical focus on provision of care by the clinics.

> "I would also like to see lifestyle data… I look at it that it's a unique opportunity to actually collect as much data as possible and we should link to as many things as possible. It's better to get it all upfront because going back you're just not going to get the same thing. I think lifestyle data would be a good thing and as [name] suggested, treatment choices, gene mutation and then I'm sure we could do bloods and tissue samples, as well." (Female 3, NSW)

### Managing participants' consent when using the ICCon database

All participants bar one were comfortable to waive active consent for their de-identified data to be included in the ICCon database. The only participant to voice concern about waiving consent based their apprehension on their prior experience of losing control of informing their children about the familial genetic information due to their other family members' open conversations in social settings. Nevertheless, for all other participants, the waiver of consent was not viewed as an issue.

> "I felt that you know in terms of the data being put in there, I felt for me it wasn't really an issue at all if the data was going to be… only able to be re-identified by coming back to the FCC. So I would really say go for waiver of consent." (Female 1, *VIC*)

The following excerpt is from the WA forum:

> Male 4: "So the way I understand it… you've got all this information in there [ICCon database], each packet of information is identified by a number, it's person XYZ, so surely that should be available for you… to do a research project without having to go to find out who

XYZ is to ask them can I use that to do this? I thought that was the whole idea; upload it all into a database so that researchers have got access to it."
Facilitator 2: "So if the research only needs the data in the database… they should just go ahead?"
Female 1: "Yeah."
Female 4: "Yeah."

Many participants were cognisant of the distinction between waiving consent for their de-identified information to be included in the ICCon database and giving informed consent (or opting in) if additional identifying data were sought for research purposes. Participants also understood that for identifiable information to be obtained about them and from them, researchers would have to contact the relevant FCC with approval from an ethics committee in order for the FCC to contact the participant for project-specific consent.

"who would have access to the database and… if it's not identifiable I don't mind, I don't care, so that wouldn't concern me at all. Probably only be consulted if it was going to be identifiable and have that choice to participate." (Female 2, *VIC*)

Participants were clearly able to delineate and describe different situations when they felt active consent was necessary, in particular, if further information was required for research from participants that was not already stored in the ICCon database.

### "Power in numbers": opting in or out of the ICCon database

Participants expressed understanding that there is "*power in the numbers*" (Female 1, NSW) and that if individuals were asked to opt in, the database may not gain a critical mass of population to enable rigorous research.

"It's the power in the numbers. For any research that people do, to look at a database the bigger your numbers the more conclusions you can draw from it so it's very powerful to have something like this and then have lots of numbers and then just to be able to, you know, 'cause otherwise its chance. It's losing the numbers." (Female 1, NSW)

"Opting in is a lot worse… if you lose 10 or 20% of people you have gained not a 100% of what we already have." (Female 2, NSW)

There was some discussion that individuals attending FCCs in Australia should be given the option to 'opt out' of having their data included; however, this was not repeated throughout all forums. Some participants did not perceive the need to opt in or out of the ICCon database but instead automatically have "*everyone*" from the FCC included to facilitate beneficial research. Without the inclusion of the whole FCC population, the ICCon database may be reduced to "*a bit of a toothless tiger*" (Female 2, VIC).

### External access to the database for commercial benefit

The greatest concern expressed by participants was that third parties, such as insurance and pharmaceutical companies, may seek to access the information contained in the database for commercial benefit. Participants were particularly concerned that if life or health insurance providers gained access to patients' genetic mutation status through the ICCon database, they would use it to discriminate against this population.

"I'm thinking of the sort of privacy issues and what can happen if it gets into the wrong hands. So you know insurance companies in particular and employers. You know health funds, superannuation funds with life and TPD [Total and Permanent Disability insurance], all that sort of stuff" (Male 4, WA)

"I do have concerns about having incredible data there about what my personal response has been to carrying a genetic mutation because of the potential for misuse of that information particularly by insurance companies." (Female 4, VIC)

"On the concern side, the information could be misused. One set of people… I have in mind is like private health insurers. I think that could, or anyone involved in health insurance… privacy, particularly to do, I suppose, with insurance" (Male 1, *NSW*)

### Consumer representation

Participants in the NSW and VIC forums perceived the need for consumer representation in any forums where decisions were made about accessing and using the data contained in the ICCon database.

"... it was at the backend that I had concerns that the accessing of that data at every level needed to involve consumers." (Female 4, VIC)

Furthermore, participants in the forums were direct in querying how many consumers would be included on the steering committee and making recommendations that there should be more than one consumer on committees.

"Will there be a steering committee and how many consumers will be on it?" (Female 1, VIC)

"On that ICCon sub-committee I think you must have at least one consumer as well… At least one, two is usually better." (Female 3, NSW)

## Discussion

Individuals who have received genetic counselling and testing for inherited cancer syndromes at Australian genetic services and FCCs are major stakeholders of the ICCon database. For this reason, it was imperative to examine their views and perspectives on the establishment of the first national Australian research database comprised of their personal, clinical and genetic information. The finding from the consumer forums that participants were enthusiastic about the establishment of the ICCon national database was clearly associated with their desire to see improvements in health and health care for themselves and their families. The anticipation of beneficial outcomes from biobank research has been frequently described as the basis for individuals' motivation for participating (Mitchell et al. 2015). Altruism has been postulated to contribute towards motivation to participate in research, particularly where participants' contribution may benefit the welfare of their group. In this case, participants identified their family as benefitting from their participation and were still positive, but less specific, about the benefits to the wider population with inherited cancer syndromes, therefore demonstrating a predominantly altruistic motivation for their participation (Caporael 2001; Quinn et al. 2013). Furthermore, the participants' enthusiasm about the ICCon database is consistent with other studies demonstrating that consumers commonly possess positive attitudes towards genetic research due to the belief that it will benefit society (Kerath et al. 2013).

The alternatives to seeking explicit consent at entry to a research study include waiving consent or offering an opt-out approach. These alternate enrolment processes presume participation on behalf of a potential research population, and the opt-out method then offers participants the opportunity to actively decline their inclusion. Waiving consent is ethically justifiable; in Australia, this relies on the research project meeting the requirements for waiving consent set out by the National Health and Medical Research Council (National Statement, Chapter 2.3.9). Participants in the forums discussed the consent processes involved in ICCon and considered waiving consent acceptable for their information held by their local FCC to be included in de-identified form in the ICCon database. They understood they would be approached to consent prospectively to any research that required identifiable or more detailed information to be collected. The participants' support for this aspect (waiving of consent) is integral to the success of the ICCon database, as the rigour of research findings generated from data held in the ICCon database would be potentially compromised if patients were uncomfortable with the database and revoked consent (Hansson 2009).

There is limited research examining participants' acceptance of different consent approaches to research, specifically regarding the acceptability of waiving consent. Studies from the USA have examined participants' preferences towards different models of consent for databases and biobanks (Ewing et al. 2015; Kaufman et al. 2012; Platt et al. 2014). Preferences regarding opt-in or opt-out models of consent were sought from patients prior to the establishment of a database of one million veterans' genomic, lifestyle, military-exposure and health information (Kaufman et al. 2012). A random sample of 451 veterans indicated that 50% preferred either model, 29% preferred the opt-in model and 14% preferred the opt-out model (Kaufman et al. 2012). Similar to the veterans study where the majority of participants were comfortable with an opt-out model, our findings that participants accept waiving consent indicates a general level of comfort and trust in the establishment and conduct of the ICCon national research database.

Other models of consent include broad and narrow consent. In the USA, participants from two studies preferred a broad method of consent (consenting once, prospectively, to have their information included in a database and then the database can be used for multiple research purposes) compared to participants asked about a narrow model of consent (consent each time their information is used for a new research project) (Ewing et al. 2015; Platt et al. 2014). Whist these findings are not directly applicable to the ICCon database model that involves a waiver of consent, it is striking that the participants again exhibited trust in the conduct and use of the database by preferring a broad model of consent. The broad model of consent would allow the researchers, with ethics approval, to conduct research using a large cohort of participants without having to contact every individual in the database for every project, which would reduce efficiency. ICCon participants will not be asked to provide active prospective consent but rather a waiver of consent has been sought and granted by human research ethics committees and gives ICCon participants the option to withdraw their data at any time from the ICCon database if they wish, i.e. the opt-out option exists for the ICCon database.

Whilst forum participants are in favour of waiving consent, variations have developed at a regulatory level between states in Australia regarding the implementation of the ICCon database. This has arisen because the state-based human research ethics committees (HREC) governing FCCs have considered the implementation of waiving consent differently as it relates to the opportunity for ICCon database participants to choose to opt out of the database. Most HRECs agreed with a passive

notification of mutation carriers about the existence of ICCon database whereas a minority required more active notification about the ICCon database (by direct mail out) of mutation carriers who had been identified as carriers by the FCC within the previous 2 years.

The primary concern of forum participants in this study pertained to privacy and confidentiality of research data and is congruent with concerns raised in other studies (Etchegary et al. 2013; Etchegary et al. 2015). This concern particularly focussed on insurance companies (Etchegary et al. 2015) and how these companies may use this information to the detriment of the participants and their families. Concern about the use/misuse of genetic information by insurance companies is not restricted to research participation and is a clear barrier to an important number of people making choices around accessing genetic testing in the clinical setting (Alderfer et al. 2015; Bernhardt et al. 2011; Keogh et al. 2009).

It is unsurprising that the responses from the participants in the consumer forums regarding the establishment of the ICCon database and waiving consent were positive, given these participants are recipients of care from genetic services and were willing and motivated to attend a forum afterhours at a local, metropolitan hospital. However, this population's experience of genetic counselling and testing is the reason they were the most appropriate group to provide (mostly) realistic feedback about their concerns and the boundaries within which they perceived the database should operate.

The main limitation of this study is the small sample size with only one forum conducted in each of three states of Australia. The findings from these consumer forums are only relevant to the ICCon database, and whilst the participants frequently expressed similar attitudes and concerns to other studies, we cannot assume that the broader mutation carrier community would be similarly inclined. Also, due to the qualitative methodological approach employed to collect data, only English-speaking individuals were able to participate. It is unknown whether individuals and their families who are not fluent in spoken English and living in Australia have different expectations and attitudes towards a national research database derived from previously collected clinical genetic information.

## Conclusion

Consumer representation in the development, establishment, maintenance and use of the ICCon database is integral to ensure research outcomes generated from the database are responsive to patients' needs and beneficial to individuals and their families with inherited cancer syndromes. These consumer forums established that participants were accepting of waiving consent to have their clinical data included and used in de-identified form for research, but wanted the opportunity to consent when further information was required for research not included in the ICCon database. This demonstrated consumers' understanding of the nuances of consent processes and the delineation between research using data already stored in the ICCon database and research requiring identifying information. Establishment of the ICCon database is an international first offering a unique opportunity to conduct research nationally with families with inherited cancer syndromes. Consumers' enthusiasm and support for this initiative, and ongoing involvement in the ICCon Partnership, herald a productive and responsive research partnership that aims to generate consumer-centred outcomes.

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**Compliance with ethical standards** Ethics approval was gained from each hospital to recruit patients from their embedded genetic services (PMCC 13/71L, POW 13/252, KE 2013097EW) to take part in a consumer forum at that site.

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**Conflict of interest** The authors, Laura Forrest, Letitia Thrupp, Lara Petelin, Kate Richardson, Lyon Mascarenhas and Mary-Anne Young, declare that they have no conflict of interest. Gillian Mitchell received honoraria from AstraZenica for attending an advisory board and associated travel costs in 2014 and 2015.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional human research ethics committees and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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