

kConFab Stakeholders Survey

Results 2011

Invitations Sent: **139**

Total Responses Received: **47**

Please tick areas of specialty (as many as apply)

Clinical geneticist - 5 (10.2%)
Consumer - 0 (0.0%)
Epidemiologist - 4 (8.2%)
Genetic counsellor - 6 (12.2%)
Medical oncologist - 3 (6.1%)
Radiation oncologist - 0 (0.0%)
Pathologist - 3 (6.1%)
Researcher who is a CIA on a kConFab research project - 9 (18.4%)
Researcher (not a CIA or student or Post Doc or RA) - 14 (28.6%)
Surgeon - 1 (2.0%)
Other - 4 (8.2%)

Select your state of residence

Australia - ACT - 0 (0.0%)
Australia - NSW - 12 (25.5%)
Australia - SA - 1 (2.1%)
Australia - QLD - 9 (19.1%)
Australia - TAS - 1 (2.1%)
Australia - VIC - 12 (25.5%)
Australia - WA - 0 (0.0%)
New Zealand - 2 (4.3%)
Asia - 0 (0.0%)
Canada - 0 (0.0%)
Europe - 1 (2.1%)
UK - 1 (2.1%)
USA - 3 (6.4%)
No Answer - 5 (10.6)

Section 1. Committee members

Question 1

Are you a member of a kConFab Subcommittee or the Executive committee?

Yes - 20 (43%)
No - 27 (57%)

Questions 2 – 13 only applicable to those who answered 'Yes' to the above

Question 2

Do you use the kConFab homepage to obtain kConFab updates such as meetings, mutation classification, reviewing applications?

Yes - 11 (55%)
No - 7 (35%)

Question 3

Rate the kConFab management structure

Excellent - 7 (35%)
Good - 11 (55%)
Neutral - 0 0%
Fair - 0 0%
Poor - 0 0%
No Answer - 2 (10%)

Comments

- Needs tighter governance structure re terms of ref of subcommittees, reporting, auditing, attendance/involvement of committee members.
- It appears to be well organised.

Question 4

Rate the kConFab system for review of research projects

Excellent – 10 (50%)
Good - 7 (35%)
Neutral - 1 (5%)
Fair - 0 (0%)
Poor - 0 (0%)
No Answer – 2 (10%)

Question 5

Could the delivery of new projects for review be passed on to you in an improved manner? (e.g. online access)

Yes -6 (30%)
No -12 (60%)
No Answer – 2 (10%)

Comments

- The assessment of projects needs to be transparent and VERY objective (to avoid claims of bias etc). Ideally, it would not need to involve the exec at all i.e. selection of criteria assessed by tick box, and sign off by exec officer.
- email is fine
- email is convenient
- An online system may be easier but the current system works fine.
- There is too much time spent on the creation and assessment of projects. My view is that there needs to be some rationalization of the process.
- I like the email delivery.
- email is actually easier and quicker for me. But i agree with web reviewer for the mutation classification committee, to streamline consolidation of comments
- Possibly online unless this adds considerable cost to the process
- An online approval process would be an advantage . Although not essential.

Question 6

Do you review all proposals passed on to you?

Yes - 11 (55%)
No - 7 (35%)
No Answer – 2 (10%)

Question 7

Would you prefer a limited number of applications per year for review?

Yes - 9 (45%)
No - 9 (45%)
No Answer – 2 (10%)

Question 8

Do the committees need to be..

Enlarged -1 (5%)
Stay the same - 12 (60%)
Other suggestions -5 (25%)
No Answer – 2 (10%)

Other suggestions

- Suggest a governance review re number purpose membership etc of all committees.
- some need to be bigger others fine
- if there are bottlenecks then we should deal with them. one issue is how to deal with non-participating members who do not resign...
- A smaller managerial group would suffice with transparency such as minutes and decisions available to all members on the website
- Not all members in committees are active would be better if they became active or stood down

Question 9

Do you think there should be a limit on how many amendments are allowable per project per year?

Yes -4 (20%)

No - 14 (70%)

No Answer – 2 (10%)

Comments

- depends on type of amendment, large=new application
- ideally managed semi-automatically as an admin function rather than frontal lobe involvement by exec members
- whatever is best for the science should be allowed - at least to be considered
- If a project needs to be amended, it should be considered as needed. I haven't noticed that this a real problem.
- Some projects appear far too often. I think that a maximum of two amendments a years is sufficient.
- it depends on the reason for multiple amendments. if we are wanting to do competitive science we need to do research in a timely fashion

Question 10

Are you satisfied with the system to renew existing projects?

Yes -14 (70%)

No -4 (20%)

No Answer – 2 (10%)

Comments

- see above
- Provided we ask about publications, and discontinue unproductive projects
- need reminder of when project is about to lapse.
- i think we need to ensure that there has been adequate progress on some projects
- The fees to renew data-only request projects seem excessive
- Not directly affected by this.

Question 11

Do you feel that you have enough feedback about the final kConFab Executive decision for projects that are reviewed?

Yes -10 (50%)

No - 8 (40%)

No Answer – 2 (10%)

Comments

- not sure
- I do not receive regular outcomes on grants - it would be a good idea.
- it might be interesting to get a summary after final approval to see if - how many responded yes - how many responded with q – how many did not respond (altho i know we are not necc expected to) I just wonder how many people do not bother to read applications and we cannot distinguish this from "happy with the application"
- Maybe I'm not on the database and data access committee any more, but if I am, I don't receive any feedback at all.
- Not directly affected by this
- I generally don't recieve much feedback.

Question 12

Do you feel that we need to engage more with consumer groups?

Yes - 4 (20%)

No - 14 (70%)

No Answer – 2 (10%)

Comments

- This is a scientific endeavour, not an educational or advocacy activity.
- never enough
- It is hard to see how this would work or who would benefit, especially with the lab based studies.
- There is already a good deal of engagement with consumer groups
- There is enough engagement as it is.
- think we could engage better with the ones we currently engage with.
- Don't know.
- Rotation of consumer advocate post at Exec level would be best

Question 13

Do you feel that we need to engage more with funding agencies?

Yes - 12 (60%)

No - 6 (30%)

No Answer – 2 (10%)

Comments

- Not sure they understand how critical these resources are.
- not sure
- I think it is useful to engage with funding agencies in the current climate of competitive funding, both the infrastructure and project based funding. I think an improved understanding of priorities of funding opportunities can only be beneficial.
- Already so as much as we can
- Not entirely clear what this means
- The process of grant funding has gone from the sublime to the ridiculous. There is far too much time put towards getting funding rather than actually doing useful work. KConFab should engage with such agencies to streamline the process of funding and make it more available - Australia is non-competitive in this aspect, having only one submission for grants per year. It is high time proper thought be put into this and a debate created to develop an appropriate funding scheme for 2011. KConFab could and should play a major role.
- i think that nhmrc needs to know how good we are and perhaps it could be a mission of our consumer rep and appropriate consumer groups to act on our behalf to make a noise about how good we are.
- Don't know
- Only if you want to keep kConfab viable. Is there an exit strategy (succession planning) for when the project will end?
- It would be good if approaching external funding agencies was not necessary and that secure on-going government funding was available.

Section 2. Researchers

Have you ever accessed kConFab data or biospecimens?

Yes - 25 (53%)

No - 17 (36%)

No Answer – 5 (11%)

Questions 14 – 28 only applicable to those who answered 'Yes' to the above

Question 14

How many times have you applied to kConFab for data/biospecimens (not including amendments)?

	1	2	3	4	5	6+
As a CIA	6	2	3	0	0	3
Not as a CIA	6	6	0	0	0	2

Question 15

How easy was it for you to obtain the policy on how to gain access to biospecimens and/or data?

Very Easy - 11 (44%)

Easy - 9 (36%)

Neutral - 1 (4%)

Difficult - 1 (4%)

Very Difficult - 0 (0%)

No Answer - 3 (12%)

Question 16

Would you prefer to make an application to kConFab using an online application form?

Yes - 14 (56%)

No - 8 (32%)

No Answer - 3 (12%)

Question 17

What was your level of satisfaction in dealing with the management team in being able to fine tune your application for submission?

Very Satisfied - 16 (64%)
Satisfied - 5 (20%)
Neutral - 1 (5%)
Dissatisfied - 0 (0%)
Very Dissatisfied - 0 (0%)
No Answer - 3 (12%)

Question 18

Do you have any additional comments regarding the kConFab management?

- Always a pleasure to deal with.
- Always helpful and efficient
- Excellent job.
- Bloody brilliant

Question 19

What was your level of satisfaction with the review process?

Very Satisfied - 15 (75%)
Satisfied - 6 (24%)
Neutral - 1 (4%)
Dissatisfied - 0 (0%)
Very Dissatisfied - 0 (0%)
No Answer - 3 (12%)

Question 20

Do you have any additional comments regarding the review procedures?

- I do have some concerns about the interpretation of ethical issues, with apparent inconsistent application of the "non-breast cancer gene" rule for projects with essentially the same endpoint.

Question 21

If your project(s) was approved, what was your level of satisfaction with the process of supplying data?

Very Satisfied - 17 (68%)
Satisfied - 5 (20%)
Neutral - 0 (0%)
Dissatisfied - 0 (0%)
Very Dissatisfied - 0 (0%)
No Answer - 3 (12%)

Question 22

If your project(s) was approved, what was your level of satisfaction with the process of supplying biospecimens?

Very Satisfied - 13 (52%)
Satisfied - 5 (20%)
Neutral - 3 (12%)
Dissatisfied - 0 (0%)
Very Dissatisfied - 0 (0%)
No Answer - 4 (16%)

Question 23

Are there any modifications to the access policy you would like to suggest?

- The only area I would like more assistance with from the management is understanding what peripheral data is already available on the samples that I am using (pathology, molecular, genomic) and how to access this. An online database of information linked to samples would be helpful. Samples have always arrived very fast.
- More space at PMCC, more staff and hence more speed
- supplying biospecimens N/A to this study

Question 24

How important is kConFab overall to your research on familial breast cancer?

Very Important - 15 (60%)
Important - 5 (20%)
Neutral - 2 (8%)
Unimportant - 0 (0%)
Very Unimportant - 0 (0%)
No Answer - 3 (12%)

Question 25

Would your research be compromised without the kConFab resource?

Yes - 20 (80%)
No - 2 (8%)
No Answer - 3 (12%)

Question 26

Would a broader resource be of use to your work? (i.e. CRC, pancreatic, prostate, melanoma)

Yes - 14 (56%)
No - 8 (32%)
No Answer - 3 (12%)

Question 27

Are you aware of the kConFab Administration fee scheme?

Yes - 18 (72%)
No - 4 (16%)
No Answer - 3 (12%)

Question 28

If you are aware of the scheme, do you think the currently yearly Administration fee scheme is fair and reasonable?

	Yes	No
For Australian Investigators	14	4
For International Investigators	18	2

Section 3. Members

Are you a member of kConFab?

Yes - 29 (62%)
No - 9 (19%)
No Answer - 9 (19%)

Questions 29 – 40 only applicable to those who answered 'Yes' to the above

Question 29

Have you used the kConFab homepage in the last 6 months?

Yes - 23 (80%)
No - 6 (20%)

Question 30

If so, how many times?

- Approx 6
- 25
- 2
- 6
- twice
- 5
- 5
- 6
- 3
- 1

- at least once a month
- once or twice
- 3
- >25
- 12

Question 31

Do you find the design of the homepage practical and useful?

Yes - 26 (90%)

No - 3 (10%)

Question 32

If 'no' to either Q.29 or Q.31, please state why

- Please note that the answer to this question is irrelevant. I haven't used the home page so I don't know if it is useful - but there is not option to say "not applicable".
- No real reason to do so and unaware of its existence.
- Not applicable
- n/a
- feels dated. Mixes scientific, clinical, and lay support.

Question 33

If 'yes' to either Q.29 or Q.31, please state the sections of most use to you

- Mutation database
- BIC database
- FCC contact details Mutation pathogenicity details
- Home, progress, data access
- conference information recently. Previously have used recruitment information. However, I do find the site a bit cluttered on the home page
- unclassified variants page
- I've used it to access the Epi questionnaire
- mutation classification projects publications stats
- Collection update Classification of mutations Eligibility criterion Application forms etc Conference information/registration
- Conference details
- Applications, publications - heaps of them
- member list information regarding applications to kConFab information on kConFab progress and project lists
- mutation classification
- N/A
- annual conference info

Question 34

What forms of communication from kConFab do you find useful?

	Yes	No
Email	29	0
Telephone	13	16
Combination of email and telephone	14	15
Would another communication format suit you better?	0	29

Question 35

Newsletter

	Yes	No
Do you read the annual kConFab newsletter?	20	9
If you do read the newsletter, do you find it informative?	20	9
Do you ever access the newsletter via the homepage?	10	19
Have you ever contributed articles or ideas to be published?	6	13

Question 36

Have you attended the annual kConFab meeting?

Yes - 26 (90%)

No - 3 (10%)

Question 37

If 'yes', how many times have you attended?

- 4
- 5
- 1
- 6
- numerous
- 4
- 2
- 7
- 7
- every year since it started
- 4
- 4
- 2 or 3
- All
- 6

Question 38

Would an online video link to the meeting be of use to you?

Yes - 15 (52%)

No - 14 (48%)

Question 39

Would an online link to the posters after the meeting be of use to you?

Yes - 22 (76%)

No - 7 (24%)

Question 40

Would an online link to the kConFab Annual Reports be of use to you?

Yes - 17 (59%)

No - 12 (41%)

Question 41 includes comments from all 3 sections.

Question 41

Are there any other comments you would like to add?

- kConfab has been a trailblazing project in Aust and NZ in many ways. Good governance has been a major factor in it's success in my opinion.
- I am very supportive of kConFab. I am open to new ideas of communication but am limited by my own knowledge of what is available.
- it would be a tragedy if NHMRC did not choose to support this world-class resource. it has directly contributed to me initiating an international collaborative effort, and participating in at least two other international collaborative networks. I think the user pays scheme is mere resource shifting for NHMRC and not worth the bother of implementing. more paperwork for little gain. And then it has to be justified in an NHMRC project application - who are they kidding? I think the management of kconfab is the best i know of, and i have accessed data and biospecimens from several different resources.
- No other comments, just thanks for your ongoing support of my research.
- I understand that the NHMRC is essentially walking away from a genuine commitment to support KConFab and I think this is a disgrace. I am not a committee or organizational member but I believe KConFab is an national icon that has advanced national and international collaboration that should be fully supported.
- Good job!!
- I consider kConFab a very valuable resource even though I do not access it as much as I should.
- Should I become a member of KConFab?
- Fantastic
- presentations to be available after conference
- this is a bad survey asking for answers that are not applicable
- Keep up the good work
- keep doing the great work that has made this consortium an internationally acclaimed example of how a consortium should operate
- long live kConFab