2020

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This article was originally published as:
Best, M., Butow, P., Jacobs, C., Juraskova, I., Savard, J., Meiser, B., Goldstein, D., Ballinger, M., Bartley, N., Napier, C., Davies, G., Thomas, D., Tucker, K., Schlub, T., & Newson, A. J. (2020). Advanced cancer patient preferences for receiving molecular profiling results. *Psycho-Oncology, Early View Online First*.

Original article available here:
10.1002/pon.5446

This is the peer reviewed version of the following article:

Best, M., Butow, P., Jacobs, C., Juraskova, I., Savard, J., Meiser, B., Goldstein, D., Ballinger, M., Barley, N., Napier, C., Davies, G., Thomas, D., Tucker, K., Schlub, T., and Newson, A.J. (2020). Advanced cancer patient preferences for receiving molecular profiling results. *Psycho-Oncology, Early View Online First,* doi: 10.1002/pon.5446

This article has been published in final form at: -

https://doi.org/10.1002/pon.5446

# Advanced cancer patient preferences for receiving molecular profiling results

**Running title: Patient preferences for receiving molecular profiling results**

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**KEYWORDS**

Cancer, genetic testing, molecular profiling, oncology, patient preference, personalised medicine, results, bioethics, qualitative research, attitudes

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1002/pon.5446

**ABSTRACT**

**Objective**

This study aimed to discern preferences for receiving somatic molecular profiling (MP) results in cancer patients who have given consent to undergo testing.

**Methods**

We conducted a mixed-methods study to explore patients' views on which MP results they would like to receive and why. Advanced cancer patients (n=1299) completed questionnaires after giving consent to participate in a parent genomics study and undergoing MP. A subset of patients (n=20) participated in qualitative interviews.

**Results**

Almost all (96%) participants were interested in receiving results which would direct cancer treatment (i.e. were actionable). A smaller majority wanted to access results which were not actionable (64%) or were variants of unknown significance (60%). Most (86%) were interested in finding out about germline findings, though not as a priority. Themes identified in interview data were: 1) Cancer is the focus; 2) Trust in clinicians; and 3) Respect for a right not to know.

**Conclusions**

The majority of advanced cancer patients undergoing MP prioritised results which would lead to treatment options. They trusted their oncologists to help them navigate the results return process. While there was interest in knowing about other results, this was a lesser priority. Nevertheless, given high levels of interest in receiving all results, ethical aspects of not providing uninformative results requires further research, including a consideration of patient rationales for desiring this information and what health professionals can and should do to support patients in the absence of meaningful information being available.

## BACKGROUND

Precision medicine is advancing in oncology, with increasing use of genomic testing to identify cancer risk and guide treatment.(1) Testing in the advanced cancer setting includes somatic molecular profiling (MP), involving panel testing of solid tumours to identify cancer-specific gene mutations, which can be linked to cognate therapies.(2)

MP can identify variants that: a) inform treatment (clinically actionable), b) do not inform treatment (non-actionable), c) are of uncertain therapeutic significance (VUS), or d) have a germline origin (and therefore have relevance to the patient's family). If a clinically actionable result is returned, the relevant treatment may or may not be accessible to the patient.

Research evidence is mixed regarding patient preferences for receiving MP results. While the promise of novel treatment attracts cancer patients to genomic testing, (3, 4) germline findings can be perceived as burdensome by patients due to incapacity caused by progressive disease, (5) and there is some confusion about non-actionable findings. (4) Concerns have also been expressed about low genomic literacy in patients leading to misunderstanding of results, generating anxiety and uncertainty about the future. (3) It is important to understand the perspectives of patients regarding MP results, in order to support them adequately during testing. This mixed methods study aimed to examine the preferences for receiving results of advanced cancer patients who were actually undergoing MP (under a research protocol) in order to access novel therapies.(6)

## METHODS

Participants were recruited to the Molecular Screening and Therapeutics (MoST) cancer genomic study, which is recruiting adult patients with pathologically confirmed advanced or metastatic solid cancers (of any histological type) who have exhausted therapeutic options.(6) Participants undergo MP and, if an actionable variant is found, are enrolled in a related therapeutic trial if available. Participants can elect to receive actionable, non-actionable and/or germline results at the time of consent, and to allow germline results to be returned to family members in the event of the participant's death.

The Psychosocial Issues in Genomics in Oncology (PiGeOn) Project is a longitudinal, mixed methods psychosocial sub-study for MoST which aims to examine the psychosocial and behavioural impacts and ethical issues for MP.(7) Patients give written consent to this study and the parent study at the same time. Both studies were approved by the St Vincent's Hospital Human Research Ethics Committee (Reference HREC/16/SVH/23).

Data collection

From the PiGeOn study, this paper focuses on participants' preferences regarding MP results. All participants were asked to complete a questionnaire just after consent was given (prior to MP), which included a hypothetical question regarding whether they would like to receive *actionable*, *non-actionable, variants of unknown significance (VUS) or germline* results. A subset of participants were invited to participate in a semi-structured telephone interview within 1-2 weeks of giving consent. Purposive sampling was used to ensure a heterogeneous sample. Interviews were conducted by one researcher (NB) and continued until data saturation was reached. Questions asked included which results participants would like to receive and why, and the expected impact of results. See Interview Schedule (Supplementary Table 1). Questions were developed iteratively to develop themes identified during the study analysis. Demographic details were collected by the parent study.

Analysis

Demographic data were tabulated and summary statistics used to describe questionnaire results (Tables 1 and 2, respectively). Analysis of variables potentially associated with the desire to receive each type of result was performed using logistic regression using IBM SPSS Statistics Version 25. Variables investigated included age, sex, education, urban versus rural/remote place of residence, English as first language, medical-science occupation, whether participants had biological children, whether any first degree relatives were diagnosed with cancer, time since diagnosis and cancer incidence (rare, less common, common). See Supplementary Tables 2-5.

Interviews were recorded and transcribed. Using thematic analysis (8), data was coded and formed into focused codes which were applied to further transcripts, and developed into themes. Data collection and analysis occurred concurrently as themes were refined and applied to the data. Any differences between researchers were resolved through discussion and negotiated consensus. Rigor was derived from successive discussions and review of the coding process by researchers until theoretical coding was complete. The varied academic backgrounds of the researchers ensured reflexivity, and comparison of qualitative and quantitative results provided triangulation of data.

## RESULTS

Participants in the MoST study (n=1299) were evenly distributed in gender (52% female), with mean age of 56 years, and mixed cancer diagnoses with an average Eastern Cooperative Oncology Group (ECOG)

rating between 0 and 1. The qualitative cohort (n=20) had a mean age of 57 years, 45% female, with mixed cancer diagnoses and an average ECOG rating between 0 and 1.

**Quantitative results**

Of the 1299 MoST questionnaire participants, 1252 (96%) indicated a preference to receive actionable results, 836 (64%) elected to receive non-actionable results, 601 (60%) would like to receive VUS, and 1119 (86%) wanted to receive germline results which could inform family risk (see Table 2).

Logistic regression indicated that patients who were more interested in being informed about actionable gene variants had an English-speaking background ($p$ = .038), biological children ($p$ = .034) or a first degree relative with cancer ($p$ = .031). See Supplementary Table 2.

Patients' higher educational background and remote/rural location were significant predictors of wanting to be informed about non-actionable gene variants ($p$ = .002) and ($p$ < .001) respectively. Living in a remote area was a significant predictor of wanting to be informed about VUS ($p$ = .003). See Supplementary Tables 3 and 4.

Younger patient age, parental status and having a relative with cancer, were all significant predictors of wanting to receive information about germline results that could inform family members' risk ($p$ = .020), ($p$ = .005) and ($p$ = .034) respectively. See Supplementary Table 5.

**Qualitative results**

Three themes were identified in the transcripts: 1) Cancer is the focus, 2) Trust in clinicians and 3) Respect for a right not to know. Perspectives were significantly influenced by the patient's clinical situation.

**1. Cancer is the focus**

a) Cancer information first

All participants interviewed prioritised receiving information about variants linked to possible cancer treatments. They were concerned that non-actionable information might confuse them. Interest was also expressed in receiving results in a staggered way, with cancer information prioritised.

> *I think most important for somebody with cancer is to get that treatment information to them as pure and understandable as possible Conflating it with non-relevant – non-treatment information at the first port [of call] is not a good idea. Male 42 years*

However, this did not mean that participants were not interested in other results. When giving consent, participants were told there was a chance of receiving a germline result. Interviewees realised that, although not necessarily important for themselves (given their advanced cancer), such information would likely be of interest to their family. As such, most did want germline information, but not as a priority.

> *Personally, for me, I would like to know. Already my brother has got bladder cancer and he had another skin cancer there was a high possibility at one stage that we might be a cancer family I've got a huge family, but everybody is very involved in knowing as much information as possible So for me personally, more information the better. My two girls would like to know too if there's a family link. Female, 60 years.*

Testing was not seen to be a waste of time, even if a new therapy was not found, as results were generally considered to be beneficial for research and cancer patients in general (which could include other family members in the future).

> *We sort of thought if it doesn't help me it might help someone else. Female, 58 years*

b) VUS

Participants were asked whether (hypothetically) VUS should be returned if revealed in MP. Participants generally understood that a VUS might be identified, given the early stage of research in this area:

> *My understanding is that, yes, if you find something within my DNA testing that you don't quite understand, I realise that that is why because the advances are happening so quickly it's hard to keep up. Female 75 years*

Despite this, many participants were optimistic that VUS results would prove useful at some point. Thus, the explanation of potential uncertainty did not always impact their desire to hear the result.

> *I guess I would be a bit disappointed, but think well, nothing ventured nothing gained. And even...the fact that you've actually tested the tumor some lightbulb might switch on somewhere in a few years and be like, I had another one like that and it might come to some cure down the track. Female 58 years*

Despite not having been mentioned during the consent process (and not being required under Australian research guidelines), several patients assumed that VUS findings would continue to be monitored into the future.

> *Perhaps, if I survive long enough, then they might understand it and so, some benefit will come from it. It can't get any worse [and they should continue to check] as long as the cancer remains within the community. Male, 51 years.*

Participants were willing to pay for this ongoing investigation of their results.

However, not all participants felt the need to hear about non-actionable results, generally because they did not perceive they would be useful.

> *I think that is really taking it a step too far. There's no point in it you can have too much information. Male, 42 years.*

**2. Trust in clinicians**

As all participants had advanced cancer, they had relationships with a community oncologist as well as the research team, and had confidence that the clinicians were 'keeping an eye' on them and ensuring they received all relevant information.

Several participants said they would rather receive information and support from their own familiar oncologist (rather than the study oncologist). Participants trusted their own doctors to tell them only what was important, thus avoiding unhelpful results.

> *For me, yeah [I can have too much information]. You know, I have great faith in the team that looks after me and so, I don't need to know all the ins and outs. Male 55 years*

However, in view of the low chance of an actionable result, other clinical support was seen as an important requirement at the point where results were communicated. For one participant:

> *Because the potential outcome [accessing a new treatment] is slim, and because people, by the time they get to you, might be getting more and more desperate about some kind of solution, I think access to social work, and that kind of more emotional support, would be a good thing for people. Male 64 years*

**3. Respect for a right not to know**

Receiving personal results was considered vital by many participants, because most had joined the study to explore potential access to a 'last-hope' therapy. When asked whether participants should be able to undergo MP but decline to receive any personal results (a question that drew on a purported 'right not to know' one's germline genetic information), the initial response was that this attitude was incomprehensible.

> *I think it kind of defeats the purpose. Male 41 years*

However, most participants accepted that others could hold different views, and have different needs and responses, and respected their decision to refuse results. Clinicians were expected to ensure that the best outcome was achieved for such patients.

> *Not knowing the person, it might send them all off on a different tangent mentally, and emotionally. That's the difficulty... I'd have to rely on the team talking to somebody that knows the person you'd have to rely on the team talking to the family doctor about that. Female, 67 years.*

Participation in the study even when results were declined was also seen as worthwhile in that it still contributed to research and would build knowledge.

> *If people chose that, that'd be fine having more participants than less is definitely a better outcome [for research purposes]. Male 41 years*

When asked whether a person should be told their results, despite refusal, if a result was found to be potentially lifesaving, the response generally changed. More respondents adopted a clinical paradigm (although this was a translational research project) and felt doctors had an obligation to inform such a patient on the grounds of a perceived duty of care to the individual, or to the community.

> *I think it's part of the duty of care, to try and give them the best option they could even if they didn't want to receive the information. Male 41 years*

> *That's the whole public health thing, isn't it?.. You might not want it but I have information that will save the public health system money, will save your life, will improve our quality of life. Male 42 years*

Concern that the family could miss out on receiving results if a participant refused was also expressed:

> *I wonder can you give it [the result] if the family says, "can we have it"? Female 67 years*

**DISCUSSION**

We conducted a mixed-methods study to explore advanced cancer patients' views on which genomic results they would like to receive after undergoing MP, and their broader views on this. We found that most participants were interested in receiving results which would provide further treatments options for their cancer. Other results, such as germline findings, were also of interest if they were perceived to have utility, particularly for participants with children and those with a family history of cancer, but not as a priority. A subset of participants noted that more information is always better, with hopes of future breakthroughs, while some feared the psychological impact of burdensome information. Perspectives were significantly influenced by the need for hope in these patients with advanced disease, who had exhausted available treatment options.

Our paper on motivation for participation in the PiGeOn study (9) reflected the overwhelming need this cohort had to find new treatments. MP was felt to be an important aspect of cancer management that should be widely available in the clinical context. Other previous research has similarly found that hope for new therapy makes MP attractive to patients, alongside concern about negative results.(4) These findings suggest the need for information and decision tools to support physicians in communicating realistic prospects of benefit from MP, to minimise possible patient distress.

Interest in obtaining results expressed by those with children or a first degree relative with cancer highlights the heightened motivation for avoiding cancer that personal experience is known to generate.(10) This study and others have, however, found that advanced cancer patients may perceive conveying risk information to relatives as burdensome.(4) Incomplete family communication of germline genetic information in this setting is well documented,(11) despite the so-called 'duty to warn' genetic relatives.(12) Here, relevant aspects of this debate are whether it applies in a research context (13) and to findings that are essentially 'incidental' to the main purpose of the test.(14) There is also recognition that specific issues can arise concerning the sharing of information with relatives once a patient has died.(13-15)

Some participants showed interest in receiving VUS, often assuming future utility. This preference gives rise to the question of whether a perceived right to know generates an actual right to know – especially in situations where resources are constrained. Arguments for granting research participants wider access to their genomic data have been made,(16) but this would need to involve a consent process that promotes genuine reflection on the rationale for wanting this information. Processes must also take account of differences between people's abilities to process and cope with this information.

This cohort expected that any VUS identified would continue to be reviewed over time. Participants were willing to pay for this information. A recent policy statement from the American College of Medical Genetics and Genomics(17) suggested physicians do their best to recontact patients with updated information. As a research study, this program has no obligation, under Australian regulations, to continue to interrogate data after the project ceases(18). However, the translational nature of this work – with personalised therapy as an intended output - also exemplifies the collapsing distinction between research and practice. Thus, the question of whether researchers should continue to interrogate participant data needs more investigation. Additionally, future consent protocols should include a discussion with participants as to whether or not results will be updated over time, based on the individual treating oncologist's intentions and relevant guidelines.

Our participants expressed great confidence in their oncologists**'** filtering of complex results so that only relevant information was passed on**.** Given their dependence on healthcare professionals to interpret genomic test results, oncologists' genomic literacy is of concern. (4) This suggests that care should be taken in deciding which findings to generate and report. Efforts to educate oncologists regarding understanding and communicating genomic test results of all kinds are ongoing.(19)

Study Limitations

This study contained a qualitative element which is not intended to be generalizable. Other cohorts may respond differently.

Clinical Implications

This study examined advanced cancer patients' views on which genomic results they would like to receive after undergoing MP. Clinicians should clearly articulate which results will be generated in order to manage patient expectations. Consideration should be given to prioritising actionable findings, and supporting patients who do not receive them.

**Conclusion**

This mixed methods study reports insights into the preferences of advanced cancer patients regarding receiving MP results. While perceived utility was an important discriminator in what was seen as valuable for this cohort, there were a variety of responses. In view of these, it is important to ensure engagement with patients about test validity and utility, their expectations and ensuring their choices reflect well-considered preferences. This can be aided by having quality consent processes, which encompass

provision of relevant information in a manner sensitive to participant distress and desire for additional treatment options, and access to professional support. As the perceived utility of genomic tests can reduce after receiving results,(20) and in view of known challenges in implementing consent processes,(21) we suggest that patient preferences are relevant to, but not determinative of, a decision to return uninformative results in this context, where the focus is on cancer treatment. The nature and value of the information should guide result return. Additionally, the ethical aspects of returning uninformative results requires further research, including consideration of patient rationales for desiring information and what health professionals can and should do to support patients in the absence of meaningful information being available.

**Acknowledgements**

Members of the PiGeOn Project include named authors, plus Judy Kirk, and Mary-Anne Young. This project was funded by the National Health and Medical Research Council of Australia, and the Cancer Institute of NSW.

**Conflicts of interest statement**

The authors have declared no conflicts of interest**.**

**Data availability statement**

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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**TABLES**

**Table 1: Demographics**

| **Characteristics** | **Total participants (n=1299)** | **Interviews (n=20)** |
|---|---|---|
| **Age (years):** | | |
| Mean (SD) | 56.02 (14.23) | 57.05 (11.44) |
| Median (IQR) | 58 (21) | 58 (15.5) |
| Range | 18-90 | 41-77 |
| **Time since Diagnosis (years)** | | |
| Mean (SD) | 3.11 (4.08) | 2.1 (2.4) |
| Range | 0-40.40 | 0.1-7.8 |
| | **n (%)** | **n (%)** |
| **Gender:** | | |
| Female | 670 (52) | 9 (45) |
| **Highest level of education completed:** | | |

| | | |
|---|---|---|
| Primary school | 16 (1) | 0 (0) |
| Year 7 or 8 | 35 (3) | 0 (0) |
| Year 9 or 10 | 212 (16) | 2 (10) |
| Year 11 or 12 | 219 (17) | 1 (5) |
| Vocational Training | 242 (19) | 7 (35) |
| University did not graduate | 17 (15) | 0 (0) |
| University graduated | 546 (42) | 8 (40) |
| Missing | 12 (0.9) | 2 (10) |
| **Accessibility and Remoteness Index of Australia (ARIA):** | | |
| Urban (versus rural/remote) | 1170 (90) | 13 (65) |
| **Culturally and Linguistically Diverse (CALD) background** | 291 (22) | 1 (5) |
| **Medical-Science Occupation** | 90 (7) | 2 (10) |
| **Has biological children** | 974 (75) | 19 (95) |
| **Has a first degree relative diagnosed with cancer** | 639 (49) | 6 (30) |
| **Cancer Incidence** | | |
| Rare | 891 (69) | 13 (65) |
| Less Common | 174 (13) | 5 (25) |
| Common | 234 (18) | 2 (10) |
| **Cancer Diagnosis (ICD-10)** | | |
| Bone and soft tissue | 244 (19) | 2 (10) |
| Brain | 139 (11) | 1 (5) |
| Colorectal | 122 (9) | 0 |
| Pancreas | 113 (9) | 2 (10) |
| Breast | 67 (5) | 1 (5) |
| Uterus | 67 (5) | 2 (10) |
| Ovary | 53 (4) | 1 (5) |
| Unknown primary | 50 (4) | 2 (10) |
| Lung | 47 (4) | 2 (10) |

| | | |
|---|---|---|
| Prostate | 36 (3) | 0 |
| Other | 361 (28) | 7 (35) |
| **ECOG score** | | |
| 0 | 655 (50) | 8 (40) |
| 1 | 576 (44) | 11 (55) |
| 2 | 54 (4) | 1 (5) |
| 3 | 4 (0.3) | 0 (0) |
| Missing | 10 (0.8) | 0 (0) |
| Mean (SD) | 0.54 (0.59) | 0.65 (0.59) |

**Table 2: Survey results- What sort of gene variants you would like to be informed about?**

| **Preference** | **n (%)** |
|---|---|
| **All results (N = 1007)** | 505 (50) |
| **Gene variants that <u>can guide</u> treatment for my advanced cancer** | |
| Yes | 1252 (96) |
| No | 3 (0.2) |
| Maybe | 22 (2) |
| Don't know | 17 (1) |
| Missing | 5 (0.4) |
| **Gene variants that <u>can NOT guide</u> a treatment for my advanced cancer** | |
| Yes | 836 (64) |
| No | 144 (11) |
| Maybe | 173 (13) |
| Don't know | 124 (10) |
| Missing | 22 (2) |
| **Gene variants that <u>no-one knows</u> anything about** | **(**N = 1007) |

| | |
|---|---|
| Yes | 601 (60) |
| No | 110 (11) |
| Maybe | 127 (13) |
| Don't know | 145 (14) |
| Missing | 24 (2) |
| **Gene variants that provide information about my <u>family members' risk</u> of developing cancer** | |
| Yes | 1119 (86) |
| No | 43 (3) |
| Maybe | 63 (6) |
| Don't know | 78 (6) |
| Missing | 17 (1) |