

BMJ Open General practitioners' (GPs) understanding and views on breast density in Australia: a qualitative interview study

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ABSTRACT

Objectives To understand general practitioners' (GPs') awareness and knowledge of mammographic breast density (BD) and their perspectives around information and potential notification of BD for women.

Design Qualitative study using semistructured telephone interviews. Interviews were audiorecorded, transcribed and analysed using framework analysis.

Setting Australia.

Participants Australian GPs (n=30).

Results GPs had limited knowledge of BD and little experience discussing BD with women. There were mixed views on notification of BD with some GPs believing this information would help informed decision making about breast health and that women have the right to know any information about their bodies. While others were concerned about causing unnecessary anxiety and were worried about the uncertainty about what to advise women to do with this information, particularly in relation to supplemental breast screening. The need for an equitable system where all women are either notified or not, and also provided with publicly funded supplemental screening was raised by GPs. Overall, there was high interest in education, training and support around the topic of BD.

Conclusions Australian GPs require education, support and evidence-based guidelines to have discussions with women with dense breasts and help manage their risk, especially if widespread notification is to be introduced in population-based screening programmes.

INTRODUCTION

Breast density (BD), as measured on a mammogram, is the relative amount of fibrous and glandular tissue in a woman's breasts compared with the amount of fatty tissue. BD is classified into four categories¹: (A) almost entirely fatty, (B) scattered areas of fibroglandular tissue, (C) heterogeneously dense and (D) extremely dense, with categories C and D being classified as 'dense.' BD is one of a number of independent risk factors for breast cancer² and current estimates are that 40% of women in the breast screening population have dense breasts,³ making it one of the most

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ First study seeking to understand general practitioners (GPs') views on breast density (BD) outside the USA.
- ⇒ Findings provide important and timely insights into GP perspectives and the challenges primary care practitioners may face when discussing BD.
- ⇒ Although knowledge and views of GPs in other countries may vary, they are likely to be similar in countries where there is no widespread notification process.
- ⇒ GPs from urban areas and being younger females represented a majority.
- ⇒ Some of the GPs in this study had a special interest in women's health, therefore among the broader GP population, lack of BD knowledge may actually be greater and there may be less understanding around potential implications of BD notification.

common risk factors. Furthermore, through its masking effect, dense breast tissue lowers the sensitivity of mammography which can increase the chance of cancer going undetected.^{4,5}

The notification of BD been a topic of international discussion for some time, particularly in the USA.⁶ In 2020, the US government introduced a legislative requirement that women be routinely notified of their BD following mammography.⁷ This has escalated concern about the issue in the scientific and broader community,^{7,8} particularly given concern that evidence supporting widespread BD notification is weak, and—for any individual woman—the balance between potential benefits and harms of notification is unclear.⁹ There are no uniform recommendations for women with dense breasts in regard to supplemental screening. This is due to very limited evidence for any benefit in long-term outcomes such as advanced breast cancer incidence and mortality.^{10–12}



Irrespective of this, US women who receive a BD notification are often advised to follow-up with primary care practitioners (PCPs) including general practitioners (GPs). In countries outside the USA, widespread BD notification does not occur. However, given the US legislation and growing pressure from consumer advocacy groups to notify women about their BD, countries with population-based screening programmes are contemplating what to do.

To date, there have only been a handful of studies on GPs' understanding and views on BD,^{13–17} all conducted in the USA during or following the introduction of BD legislation. No data are available from other jurisdictions. The aim of this study was to understand Australian GPs' awareness and knowledge of BD and their perspectives around information and notification of BD, in a country where notification is not legislated. The BreastScreen Australia population screening programme invites women aged 50–74 years for free biennial mammography, and does not routinely record BD or provide supplemental testing for women with dense breasts.¹⁸ However, one state (Western Australia, WA) does notify women and their GP of BD,¹⁹ as do most private screening providers, and some consumer advocacy groups have generated public awareness campaigns and lobbied for broader notification policies. As many other countries with breast cancer screening programmes are at a similar point in the development of BD policy, understanding Australian GPs' approaches may assist in developing communication strategies for GPs and other PCPs in countries where widespread notification is not (yet) in place. The objective of this study is therefore to explore GPs' understanding and views on BD in Australia

METHODS

Design

This qualitative study used semistructured telephone interview method.

Patient/public involvement

Two consumer representatives from Breast Cancer Network Australia and Health Consumers New South Wales, respectively, were involved in advising team's BD research stream. However, they were not directly involved in developing study materials, conducting the interviews, analysing the data and reviewing of manuscript for the current GP study.

Sample and recruitment

The sample included GPs currently practising in public and private settings throughout Australia. We used a purposive sampling strategy and pursued to recruit GPs with diverse characteristics, including those with or without a special interest in breast medicine, from different Australian states and rural or urban localities. Potential GPs initially were selected among self-referrals.

GPs were recruited through several avenues including: (1) an email, with Participant Information Statement (PIS) attached, to the Royal Australian College of General Practitioners Breast Medicine Special Interest Group mailing list, (2) an email, with PIS attached, to a list of GPs who had consented to be contacted for future studies after participating in previous University of Sydney research and (3) a brief study advert on the 'GPs Down Under' Facebook group page, an online community page for Australian GPs with more than 8000 members. All avenues included study investigators' details. GPs contacted researchers (BN or HD) directly to express interest in participating and arrange an interview. On contact, the interviewer verbally explained the study and answered any participant questions. Written consent was obtained from each participant before the interview. 'Snowballing' recruitment technique, whereby participants forwarded study information to eligible colleagues, was also used. Recruitment continued until preliminary analysis suggested thematic saturation, that is, existing themes were consistently adequate in capturing recurring patterns in the participants' accounts, indicating saturation of key themes. The data saturation was agreed on by team members who engaged in continuous monitoring of data and discussion of the process. All GPs were compensated with a gift voucher (\$A100) for their time.

Data collection

The semistructured telephone interview schedule (see box 1 for a list of overarching topics and online supplemental appendix 1 for full interview schedule) was developed by a multidisciplinary team of public health and medical researchers, a GP, breast physicians and psychologists. The interview schedule was piloted with two GPs and revised accordingly.

Interviews were conducted over the telephone by two public health researchers with experience in qualitative methods (BN and HD) between June and July 2020. Interviews lasted 20–51 min and were audiorecorded, then transcribed verbatim by a professional transcriptionist. As the interviews were being conducted, the two researchers continually met to discuss the data and

Box 1 Interview schedule topic guide

- ⇒ Clinician characteristics.
- ⇒ Knowledge and understanding of breast density (BD).
 - ⇒ Source of knowledge.
 - ⇒ Implications of BD for women.
 - ⇒ Views on BD notification after each screening, including pros and cons.
- ⇒ Experience with discussing BD with women.
- ⇒ Communicating about BD.
 - ⇒ Information, communication, support and training needs.
- ⇒ Views about current BD notification/legislation.
- ⇒ Future directions.

themes arising. This helped to form the initial familiarisation process of the data and to inform the analysis structure.

Analysis

We conducted a Framework Analysis, using Excel to organise the data.²⁰ Framework analysis is a matrix-based method which uses a spreadsheet for organising and charting data.^{20 21} This method allows for easy comparison of data by cases (rows) and by codes (columns).²¹ This method was chosen for data analysis because it allowed for systematic reduction and structured analysis of data, which assists with team collaboration and transparency, while allowing for flexibility in accommodating emergent themes or reflective enquiry.²¹ BN and HD reviewed transcripts and developed a list of topics and themes identified, with reference to notes made continuously throughout the interview process. Those topics (overarching themes) and subthemes, along with the interview schedule, formed the basis of the coding framework (see online supplemental appendix 2). One additional researcher (KM) reviewed the coding framework, and changes were discussed and made accordingly. Once a framework was agreed on, HD coded all interviews, and summarised the coding of each interview into the framework in Excel. BN double-coded six (20%) interviews to ensure the framework was adequately capturing the data. Transcripts were coded deductively when the explicit meanings of the text segments were mapped onto the themes/subthemes in the priori coding framework. Data was coded inductively when the text segments reflected new or interesting perspectives, allowing for the coding framework to be revised iteratively. Any coding differences between the two researchers were discussed and re-assessed. During the coding process and again once coding was complete, BN and HD examined the framework chart to interpret the findings, which were discussed with the entire research team.

The trustworthiness and rigour of data analysis were established by: engaging with data for a prolonged period of time; keeping reflective notes throughout the data collection and analysis to record evolving impressions of the data and the course of our analytical thinking; double-coding a subportion of the transcripts; frequent debriefing with multidisciplinary team members; and using a matrix-based analysis method which allowed for thorough documentation and version control (audit trail) of data coding and theme development.

RESULTS

Participant characteristics are outlined in [table 1](#). Most participants were female, had less than 10 years' experience and worked in urban centres. There was a mix of GPs who worked at public, private or both types of clinics. Participants indicated diverse special interest areas, with

Table 1 GP characteristics

Characteristic	No of participants (n=30)
Years of experience (YE)	
<10	17
10–19	5
20–29	3
30+	5
Type of practice	
Public	10
Private	10
Both	10
Location of practice	
Urban	24
Rural	6
State	
New South Wales	11
Victoria	7
Queensland	5
South Australia	4
Western Australia (WA)*	3
Sex	
Female (F)	23
Male (M)	7
No of patients managed/week†	
<50	5
50–99	14
100+	11
Proportion of female patients aged 40+†	
<30%	7
30%–59%	16
60%–89%	5
90%+	2
Special interest in women's or breast health†	
Yes	11
No (other or no special interest reported)	19

*State which currently notifies women of their BD through the population-based screening programme (BreastScreen WA).
†Self-reported.

11 GPs having a special interest in women's or breast health.

The study findings are organised into five main themes, some with subthemes. Participant quotations are incorporated to illustrate GPs' views and experiences. We noted important differences between GPs with a special interest in women's or breast health (subsequently referred to as 'special interest GPs' and marked with asterisk *) and those without ('non-special interest GPs'), and also

between GPs from WA (where BD notification occurs) and other states. The results discuss these differences throughout.

Knowledge of BD

Most GPs knew very little about BD. The minority of GPs who did know about BD were more likely to have a special interest in women's health or breast medicine.

The main source of knowledge about BD for GPs came from mammogram reports, with all GPs from WA and a minority of GPs who had received reports from radiology services indicating seeing information about BD on mammogram reports. A number of GPs (with various characteristics) also discussed hearing about BD through professional conferences or talks given by radiologists or breast specialists.

While most participants (especially non-special interest GPs) stated that BD was not covered during medical education or training, a few did describe briefly hearing about it. There was no pattern in specialty, GP location or recency of training in determining this.

...we haven't had any sort of education that I know about where they advise GPs what to do... we know about the screening stuff, how to manage a breast lump or a clinical breast symptom. But I don't think there's been much education around breast density. (GP21, F, <10YE)

Overall GPs had limited knowledge of the implications of BD for women. For many, knowledge was limited to younger women having denser breasts and therefore being more likely to be recommended ultrasound over mammogram. Some GPs indicated some level of understanding of how BD can mask cancer on the mammographic image.

...increased breast density, there's more sort of glandular connective tissue in the breast and it can make it a bit more difficult on mammogram to detect changes or cancers. (GP20, F, <10YE)

There was also very limited understanding of BD being an independent risk factor for breast cancer.

I didn't know that was a risk factor. I've never known that. No one's ever told me that. All the guidelines I've looked at I've never seen that... (GP7, M, 30+YE)

Most non-special interest GPs perceived their own level of understanding of BD as inadequate or very basic, citing reasons such as being unaware of its clinical significance, BD not being reported on screening reports or included in guidelines, or breast screening making up a very small part of their practice.

...until this interview I didn't know that there really was anything particular to understand, other than the fact that people with dense breasts needed ultrasounds instead of mammograms, or, as well as

mammograms, to pick up their cancers. So I didn't really feel that it was an issue.... (GP4, M, 30+YE, WA)

A few GPs also believed that clinical breast nodularity detected by physical examination of the breasts (lumpy, hard or dense) was the same as mammographic BD.

Views on current landscape of BD notification in Australia

GPs' comments on the current landscape of BD notification in Australia mainly revolved around the divides between public and private patients and the practice in WA versus other states. Some GPs felt that not telling women their BD in the public system creates a 'two-tiered' system and there should be a uniform recommendation. Others felt it is 'very complicated' or 'a mess' to have different guidelines across different Australian jurisdictions, or women's 'right to know' should not depend on where they live.

it would be good if there was a general rule, either we do it or we don't do it, rather than people thinking they have an inadequate screening because the private place they can get it graded but at a public BreastScreen, they can't. (GP18, F, <10YE)

While having concerns about the ununiformed approach to notification in Australia, the majority of GPs expressed that BreastScreen Australia's decision to 'not routinely record BD or provide supplemental screening for women with dense breasts'¹⁸ must have justification to it, given it is based on the latest evidence.²² They considered that given the uncertainties surrounding the implications of BD and notification, the lack of solid evidence, and not having an equitable way of dealing with financial and logistical implications of notifying women, the decision of BreastScreen Australia sounded reasonable.

I don't think it's fair to tell someone something that they're at high risk but we have no way of dealing with it with you, if you tell someone who has no money that they've got a high risk of developing, a higher risk of developing breast cancer than their neighbour... but we can't find that for you because we can't screen you more than every two years and we can't give you a free ultrasound and all that sort of stuff, I don't think that's fair. (GP3*, F, 10-19 YE)

A few however felt strongly about women's right to know and commented that BreastScreen should at least let the doctor know.

I think then it's a medical and patient decision. Not like a government decision, it's difficult, 'cause I don't know like what the costs of that would be. Overdiagnosis is something that we have to think of. But I still think people need to, we have the right to know. (GP23, F, <10YE)

There was no pattern in the views held among special interest and non-special interest GPs or those from different states.

With regard to consumer campaigns on BD information in Australia, some GPs viewed them in a positive light, commenting that campaign messaging helped women become more aware and proactive towards their breast health. They, however, cautioned that GPs would need to be prepared with information and skills to respond to women's inquiries and direct them to appropriate resources. Other GPs had concerns as they perceived that consumer campaigns could potentially lead to overscreening and create anxiety and confusion among women, with some women potentially equating BD to breast cancer.

I think they can be quite dangerous as well, because they can frighten women maybe unnecessarily. It's better coming from their healthcare professional than from media campaigns that are unregulated. (GP5, F, <10YE)

Views on informing women of BD

There were varied opinions among all GPs in terms of the notion of specially notifying all women during population screening or on an individual basis, citing various reasons and concerns.

Specific views on notifying all women of their BD during population screening

Some GPs were not supportive of informing women at a population level because 'we don't know yet what to do if women are found to have dense breasts'. Most of those GPs preferred an individual-based approach to notifying women of their BD, based on other risk factors, rather than notifying all women during population screening. Some GPs discussed the importance of GPs (rather than patients) being informed about BD to enable them to better advise women and take it into account in relation to their overall risk. Other GPs saw it as unimportant and thought women 'would not be particularly interested'.

For those GPs who were supportive of population-level notification, their main argument was that notifying all women might benefit those with dense breasts, would ensure informed decision making and motivate them to be diligent in screening.

...there are particular patients that would benefit from that knowledge, in that it would motivate them to attend screening and to actually follow correct protocols as advised. (GP25, F, <10YE)

A few GPs argued that some women are already being told about their BD because they go through private screening providers, and that this was inequitable. They argued that implementing a policy of notification would 'level the playing field' for those going through the public screening programme.

I guess at the moment it creates a two-tier system where women who go to a public system don't know what their breast density is and women who go privately do. And certainly some women who have gone

to BreastScreen for many years don't know they have dense breasts and then they have a symptom and [you] send them off for a private mammo and you find that they've got extremely dense breasts and they can be quite upset that they've never been told about it. (GP27, F, 10–19 YE)

Given the US precedent of mandating BD notification following mammography through legislation, GPs who are both for or against population-level notification noted the different healthcare system in the USA, a country 'driven by litigation', and expressed that going as far as to legally mandate notification is 'extreme' or 'heavy handed'. They also noted the potential complexity and impracticality of such legalisation, such as determining whose responsibility it is to notify women. A few also commented that notifying women should come from a moral stance, rather than a legal one.

...my instinct is to say that that's too extreme... I guess I would have a few questions... How's it communicated? I don't know if making it a legal issue is necessarily a good thing in medicine. (GP29, M, <10YE)

Minority of GPs were supportive of mandating BD notification, with one commenting that doing so would prevent healthcare professionals 'passing on the bucks' and ensure women were told.

I think that it's good that they've got legislation that just says you have to do it. Otherwise, there's so much variation in what you do in your day-to-day practice. (GP12*, F, 10–19 YE)

Reasons why women should be informed

Similar to views expressed about population-level communication, GPs who supported notifying individual women about their BD usually argued that women should be able to make informed decisions.

I'm always in favour of letting the patient know all the information that we have available. And particularly because if there's a known risk to developing breast cancer I certainly would want the patient to have that information, so that they can make an informed decision about screening intervals and the importance of screening in the future. (GP29, M, <10YE)

GPs in favour of informing women also commonly asserted that knowing their BD and its implications would make women more proactive and vigilant towards their breast health. Some felt that the information would give women a realistic idea of their risk and might also provide extra impetus for women to get regular screening or choose an appropriate screening interval or modality.

Others suggested it is wrong to withhold information about increased risk, and stressed women's right to know, the importance of being open with women, even with the substantial uncertainties.



I guess the patriarchal thing is the best way I can think of it. Like not having some Big Brother looking after me by going, oh I know this but it's just going to confuse you so I won't tell you... I think it's important because I think if women feel like information is being withheld, then that impacts on the trust as well. (GP10, F, <10 YE, WA)

Some emphasised the importance of proper discussion and explanation of BD to women, as they argued if women are given the right amount of information and it is explained well, it will not necessarily cause anxiety.

...if we can make them understand and with the right words, and also give them out the information what they have to know, instead of giving too much information is going to definitely increase their awareness and reduce their anxiety about the problem. (GP1*, F, 10–19 YE)

One GP from WA where women are routinely notified of their BD through publicly funded BreastScreen programme commented on the letter that women receive after their mammogram and stressed the importance of the BD information being communicated by an informed GP.

...a lot of women I find don't understand the letter that they get from BreastScreen. And they either think it means nothing and everything's fine or they don't need to do anything, or they freak out that they're high risk 'cause they've gone and Googled it... So I think it's useful as a doctor for me to know, and then for me to discuss it with the patient, rather than... trying to explain it all via the letter. (GP10, F, <10 YE_WA)

Concerns about informing women of BD

The main concern GPs expressed about informing women of BD was that doing so might cause some women undue anxiety. This reflected their reservations about the fact that BD is not modifiable, uncertainties in how much of an increased risk it confers and having no clear guidelines on what to do next.

...the cons is that introducing another level of complexity that maybe people don't understand or makes them more worried, there isn't I guess the concrete guidelines how they're meant to manage it. So, it could cause more anxiety I suppose for people, if there isn't clear advice on it. (GP20, F, <10YE)

GPs were concerned that telling women about increased risk might cause them financial costs for extra examinations and might lead to overscreening, overdiagnosis or increased radiation exposure.

Perceived challenges to communicating BD information

While two-thirds of participants claimed to have had experience discussing BD with women, often in the case of non-special interest GPs, BD was briefly mentioned

within the context of explaining the modality of imaging for younger women or when it was reported on mammogram results. GPs without experience discussing BD with patients explained that none had asked about it, and they had not seen it on mammogram reports. Some also acknowledged that their own lack of knowledge of the implications of BD could have contributed to this conversation having never come up.

GPs who had experience discussing BD said this was challenging, as BD is an abstract concept that is hard to explain and poorly understood by women, especially by those with low educational and health literacy levels. While some GPs used visual aids to overcome this challenge, others worried that if they explained it poorly, this might increase women's anxiety or lead to misinterpretation.

...they can't feel it, they can't see it, unless they Googled an image of high breast density on a mammogram it can be difficult for them. (GP5, F, <10YE)

Lack of knowledge was also cited as a barrier to communication, along with how to discuss the costs associated with supplemental screening (ie, that it is not publicly funded), discrepancies between radiology reports and GP guidelines, lack of time, uncertainty in evidence, and needing to use interpreters with people who do not speak English.

I'm happy enough to say, look you've got more dense breasts, you have more connective glandular tissue. It can make it harder to see cancers, but I think it [the guidance] is not clear on telling them what to do from there. (GP20, F, <10YE)

GPs views on patient information materials were mixed, but many emphasised that the key was to have an informed GP who can explain BD clearly.

I think mainly your GP would have to really understand it and that GP can use their own language to explain to a patient, rather than you just have a formal sheet. (GP2*, F, 10–19 YE)

Information and communication needs of GPs

GPs who had little knowledge and experience of BD expressed their desire to learn more. Generally, GPs highlighted the need for more evidence on BD and associated breast cancer risk, benefits and harms of BD notification and supplemental screening, and analysis of cost-effectiveness. They also stressed the need for clear guidelines or protocols regarding further investigation and advice on breast screening if women are found to have dense breasts. Promoting BD knowledge among GPs, enhancing research communication to GPs, and a wider discussion between experts and stakeholders were also proposed as important future directions.

I guess it would be good to have a resource where you could go, ok, you've got increased breast density, what does this actually mean for the patient? And

then...the advice would be just to screen, counsel the patient on risks for breast cancer and modifiable risks, or do I change anything about their management? (GP24*, F, <10YE)

DISCUSSION

Globally there has been increasing discussion of BD, including public messaging, post-legislation of BD notification in the USA. This study found that Australian GPs felt that they had a low level of knowledge about BD, particularly in relation to it being a risk factor for breast cancer. Although GPs with a special interest in women's or breast health and those from WA (where BD information is provided in mammogram reports through the state-based screening programme) felt that they had higher levels of knowledge, important gaps in understanding still existed and there were concerns expressed by GPs about how to communicate BD information to women. Importantly, findings are similar to those from studies of PCPs conducted in the USA, where BD notification has been legislated and where women have more awareness of this issue.^{13–17}

In Australia, there is currently no formal training or guidelines about BD for GPs, but there has been some advocacy to notify women of their BD. GPs in this study indicated an overall willingness to receive further information and training in relation to BD, including how to discuss the implications of BD with women. BD information would therefore need to be implemented as part of GP training and in clinical management guidelines. Despite their interest in this information, GPs had mixed views about informing women at a population level and the implications this may have for both women and clinical practice. GPs who supported more widespread notification believed this information would help women make more informed decisions about their breast health and that no information about one's health should be withheld. Similar views have been expressed by Australian GPs in the context of PSA screening.²³ In studies from USA and South Korea, women who knew their own BD level were found to be more likely to intend to complete mammogram in the future.^{24 25} The main concern displayed by GPs in this current study was that this information may cause unnecessary anxiety and supplemental screening. GPs who expressed this view were concerned about the fact that BD is not modifiable, uncertain about how much of an increased risk BD would confer for individual women, and troubled about not having clear guidelines to inform women what to do next. The latter point is core to the controversy about BD notification—whether or not to offer supplemental screening and if so, what type and how often.²⁶ Given the limited consensus in this area¹² and lack of current guidelines, supplemental screening recommendations for women with dense breasts would currently be left to the discretion of the GP. Before and after any such guidelines exist, GP training and discussions

should be directed around how to discuss women's individualised risk factors for breast cancer, inclusive of BD, the value of breast cancer screening in relation to risk level, and the possible benefits, harms and trade-offs for women with high BD in regard to options for supplemental screening. Such GP training could be delivered via continuous professional development programmes, conferences or workshops, online or in-person learning modules, and specialist lectures or seminars. Given the recent data has shown that there is no difference in screening mammography attendance in rural and urban areas in Australia,²⁷ GP training in BD discussions could have broader implications nationwide.

GPs supported the decision by BreastScreen Australia¹⁸ to not routinely record BD or provide supplemental screening for women with dense breasts, given the uncertain evidence to support widespread BD notification. GPs also felt that BD notification may be an ethical issue if there is no publicly-funded supplemental screening, and that the current divide between public and private creates a two-tiered system. The belief that everyone should have the same knowledge and access to whatever the guidelines recommend was perceived by GPs to be a key part of the health system in Australia.

This study has both strengths and limitations. To our knowledge this is the first study seeking to understand GPs' views on BD outside the USA. Findings provide important and timely insights into GP perspectives and the challenges PCPs may face when discussing BD. Some countries are considering whether or not to notify women through population-based screening programmes given recent events in the USA and growing pressure from consumer groups pushing the 'right to know'.⁶ Although knowledge and views of GPs in other countries may vary, they are likely to be broadly similar in countries where there is no widespread notification process. Surprisingly though, recent studies in the USA have also shown similar findings.^{13–17} A substantial proportion of the GPs in this sample had a special interest in women's health, therefore among the broader GP population the lack of knowledge may actually be greater and there may be less understanding around the potential implications of widespread BD notification. As GPs were initially recruited by self-referral, the GPs in this study may not be representative of all Australian GPs. In particular many participants were from urban areas, of female gender and had relatively short duration of clinical experience. Study results should be interpreted in light of the participant characteristics. However, a strength of our recruitment was the ability to compare GPs with and without special interest in women's or breast health. All interviews were conducted over the phone, which may have had disadvantages in terms of visual cues. However, current evidence comparing the data collected from phone interviews and face-to-face interviews suggest that these two methods can be equally productive and valid in producing rich data.^{28 29} Advantageously, phone interviews also enabled us to interview GPs in other states or locations that were

geographically inaccessible or too costly to travel to for the researchers.

Overall, this study highlights the lack of knowledge about BD and uncertainty about how best to manage patients with high BD. Despite BD consumer campaigns in Australia and overseas, BD notification legislation in the USA, and the difference in public versus private screening services providing this information to women, GPs in Australia have limited experience in discussing BD with patients. Findings point to the need for substantial training and support for GPs about how best to have discussions with and manage women with dense breasts, especially if widespread notification is to be implemented in population-based screening. As GPs are likely to be the main clinicians to have these discussions in Australia, women will depend on them moving forward in this complex and uncertain space.^{30,31} Therefore, it is imperative that GPs are involved now in designing strategies and policies in relation to BD discussions and future screening protocols for women with dense breasts.

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Appendix 1. Interview Schedule

Clinician characteristics

1. Firstly could you please just confirm your role, so you're a _____?
2. Can you describe the setting where you work?
 - Urban, regional or remote area?
 - Solo or group practice?
 - Public (bulk-billing) or private?
3. How long have you been a practicing GP?
4. Do you have a special interest area of practice? (e.g. women's health etc)
5. How many patients would you see each week?
6. What proportion of your practice would you say are women over the age of 40?

Breast screening:

7. Before I get into the questions specifically about breast density, can I just ask: in general, how do you approach advising women about breast screening?

Knowledge and understanding of breast density

8. To start off, have you heard of the term breast density?
 - a. Where have you heard (or read) it from?
 - What have you heard/read about what breast density is?
 - What is your understanding of how breast density is measured?
 - Why might breast density be of interest or relevant to women?
 - b. How well do you feel you understand breast density as a clinical issue at the moment?
 - What would you like to understand better?
 - c. How important do you think breast density is as an issue for women?
Prompts: breast cancer risk, age, family history.
 - d. From your perspective, what do you think women should or shouldn't know about their density after each mammogram?
 - As a whole at a population level? Why?
 - To individual woman? Why?
 - e. What would be the pros and cons (downsides or consequences) of women knowing more about their breast density after each mammogram?
 - As a whole? Why?
 - To individual woman? Why?

Experience with discussing breast density with women

7. Have you had any experience discussing breast density with patients?

If **YES**:

- a. Could you think back to the last women you had this conversation with and describe that interaction in a non-identifying way?
 - What was the age for this women?
 - What was the women's socioeconomic background?
 - How did the subject of density come up for discussion?
- b. Is that pretty typical do you think, or are you having density conversations with a wide range of women?
 - How many times (approximately) or how often would you say you've had this discussion and what were the circumstances?
 - What was the age group for women?
 - Have these discussions been more recent or were they a while ago or have they been consistent across the years?
 - How did the subject of density come up for discussion?
- c. Could you tell me about your approach to explaining to patients what breast density is, or trying to help them understand it?
- d. How do you feel about women's ability to understand what breast density is and the implications it has for them?
- e. (*if not already discussed*) How do you approach advising breast screening when breast density is discussed?
 - How does your approach to advising breast screening compare to when breast density was not discussed?
- f. What would you say are the key challenges for communicating about breast density to women?
 - Risk factors?
 - Recommendations for supplemental screening?

If **NO**:

- a. Why do you think that conversation has never come up with any of your patients in the past?
- b. If this conversation were to come up, how would you approach explaining breast density to women?
- c. What do you think would be some of the challenges for communicating about breast density to women?

Communicating about breast density

8. Do you think primary care clinicians are adequately equipped to discuss breast density with women at this time?

9. If you felt like you needed additional information, support or training in talking about breast density, where would you go to find this?

Options might include:

- Royal Australian College of General Practitioners (RACGP) education programs like webinars and online Continuing Professional Development (CPD) courses
- RACGP conference workshop
- Other conferences
- Own reading/ research
- Speak to specialists
- Other???

- a. What information or skills development would you like to be included in any support or training that was offered?

10. Are there any communication materials in particular that GPs can use with patients and you think would work? Or do you think at this time this isn't really needed?

- Leaflets or brochures?
- Online reading or viewing materials?
- Communication or decision aids?
- Anything else?

Views about current breast density notification/legislation

As you may or may not be aware, in recent years there has been quite a bit of advocacy, largely from consumer groups, to have women routinely notified about their breast density during screening.

11. What are your views on this?

In the United States they have now passed federal law which makes it illegal for screening services not to inform women if they have dense breasts.

12. What are your views on this?

We don't have any legislation like this in Australia, and Breast Screen Australia decided after an evidence review that density shouldn't be tested or recorded.

However in Western Australia (WA), Breast Screen has been notifying women of their density for years, and private screening services often promote their ability to inform women about their breast density, and a number of Australian consumer groups have been running campaigns to inform women about density and push for notification.

13. What do you think about these broader legal, social and political issues around density?

14. What are your views on the current landscape of breast density notification in Australia?

There are also a number of consumer groups in Australia that have been using campaign messaging, for example posters in shopping centres, to inform women about what breast density is and push for widespread notification.

15. Just out of curiosity, have you seen any of these campaigns?

- a. What are your views on them?

- b. Do you think they are a good thing or not? Why?

Future directions

16. If you controlled Australian policy around breast screening specifically in terms of breast density notification, what would you do?
- Why would you focus on that message or action?
 - Who do you think that would have implications for screening or managing women?

Closing

Now we're coming to the end of the interview, but before we wrap up do you have anything else that we didn't discuss that you would like to say about breast density in general, the implications of discussing breast density with women or the current landscape of breast density in Australia? Or do you have any questions for me at this point?

Thank you very much for your time.

BD qualitative clinician interview study — analysis framework

1. Clinician characteristics
 - 1.1 Gender (male/female)
 - 1.2 Type of clinician
 - 1.2.1 General practitioner with special interest in breast health
 - 1.2.2 general practitioner
 - 1.3 Practice setting
 - 1.3.1 urban/regional/remote
 - 1.3.2 solo/group
 - 1.3.3 public/private
 - 1.4 Part-time or full-time work (*if mentioned*)
 - 1.5 Years of experience working as a GP
 - 1.6 Special interest area of practice
 - 1.7 Case load
 - 1.7.1 numbers of patients/ each week
 - 1.7.2 proportion of women aged over 40
2. Knowledge of breast density
 - 2.1 Source of knowledge
 - 2.1.1 Reports of mammogram, ultrasound
 - 2.1.2 Conferences, continuous education
 - 2.1.3 Through work (breast clinics, women's health)
 - 2.1.4 Medical education, training or fellowship exams
 - 2.1.5 Misc. (reading articles, personal experience)
 - 2.2 Understanding of clinical implications of breast density
 - 2.2.1 Impact on interpretation of the imaging & masking the cancer (harder to determine the cancer)
 - 2.2.2 Risk of cancer
 - 2.2.3 Misc.
 - 2.3 Measurement breast density
 - 2.3.1 Mammogram image
 - 2.3.2 Grading
 - 2.3.3 Physical examination/lumpy breasts
 - 2.4 Perceptions of their level of understanding of breast density
 - 2.4.1 Not adequate
 - 2.4.2 Adequate
3. Views on current landscape
 - 3.1 Complicated landscape
 - 3.1.1 Public vs private divide
 - 3.1.2 Western Australia vs other states
 - 3.1.3 Lack of evidence
 - 3.1.4 Not an issue
 - 3.1.5 Misc.

- 3.2 Views on BreastScreen Australia position
 - 3.2.1 Supportive
 - 3.2.1.1 Need more scientific and solid evidence (uncertainties)
 - 3.2.1.2 Need equitable way of dealing with it
 - 3.2.2 Not supportive
 - 3.2.2.1 Women's right to know
 - 3.2.2.2 GPs should be aware
- 3.3 Views on consumer campaigns
 - 3.3.1 View them in a positive light
 - 3.3.1.1 Increase awareness in women
 - 3.3.1.2 women become proactive/aware
 - 3.3.2 Not supportive
 - 3.3.2.1 Uncertainties
 - 3.3.2.2 Over-screening
 - 3.3.2.3 Cost-effectiveness
 - 3.3.2.4 Creates anxiety
 - 3.3.2.5 Clinicians need to be able to answer questions
 - 3.3.3 Neither
- 4. Views on informing women of BD on an individual level
 - 4.1 Specific views on notifying all women of their BD during population screening
 - 4.1.1 Supportive
 - 4.1.1.1 Women become vigilant towards breast health
 - 4.1.1.2 Addresses public vs private inequity issues
 - 4.2 Reasons why women should be informed (pros)
 - 4.2.1 Increase frequency of screening/Supplemental tests
 - 4.2.2 Women become more proactive/aware/empowered/vigilant
 - 4.2.3 Women have the right to know
 - 4.2.4 Not necessarily cause anxiety
 - 4.2.5 Misc. (clinician become aware)
 - 4.3 Concerns about informing women of BD (cons)
 - 4.3.1 Increased concerns, worries and anxiety
 - 4.3.2 Misc. (cost, inconveniences, radiation, overdiagnosis)
- 5. Perceived challenges to communicating BD information
 - 5.1 Has experience in discussing breast density with women
 - 5.1.1 Occasions when breast density discussion came up
 - 5.1.1.1 After mammogram results came back
 - 5.1.1.2 Patients bring it up
 - 5.1.1.3 After physical examination
 - 5.1.1.4 When explaining the modality of breast screening
 - 5.2 Has no experience in discussing breast density with women
 - 5.2.1 Reasons why this conversation never came up
 - 5.2.1.1 Not reported on mammogram
 - 5.2.1.2 Patients did not ask, not interested
 - 5.2.1.3 Misc.
 - 5.3 Perceived challenges to communication

- 5.3.1 Abstract concept and hard for women to understand (an image of high breast density on mammogram might help)
- 5.3.2 Patient education level (higher might understand better than lower but also depends on how the doctor explains it)
- 5.3.3 Clinicians' lack of knowledge
- 5.3.4 Finances (some women may not financially able to go for supplementary tests)
- 5.3.5 Misc. (time, rapport building etc)

6. Information and communication needs

6.1 Information needs

- 6.1.1 More evidence
- 6.1.2 Clear guidelines or protocols for what to do if women are found to have dense breasts
- 6.1.3 Cost-effectiveness analysis
- 6.1.4 GP education on breast density
- 6.1.5 Research communication to GPs

6.2 Training and support through

- 6.2.1 Learning modules/ programs for GPs
- 6.2.2 Conferences
- 6.2.3 General practice working group
- 6.2.4 Talks and speeches
- 6.2.5 Websites