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ORIGINAL ARTICLE

Principles of patient-centred care and barriers to their implementation: a case study of breast reconstruction in Australia

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Abstract

Purpose "Patient-centred care" is widely promoted as an ideal goal of health care systems, but is often difficult to achieve in practice. This article has three aims: to develop an original set of generalisable patient-centred care principles (PCCPs); to identify barriers to the implementation of these principles in a real-world setting, using breast reconstruction (BR) services in Australia as a case study; and to document examples of successful patient-centred care in relation to BR.

Methods Semi-structured interviews ($n = 90$) were conducted with 31 breast and plastic reconstructive surgeons, 37 breast cancer health professionals and 22 women who underwent mastectomy as part of their breast cancer treatment and were dissatisfied with their BR experiences.

Results Ten broad PCCPs were derived from our participant interviews. These principles comprised the following: maximising patient choice, access to services, patient and family support and appropriateness of information; minimising patient costs and physical and psychosocial morbidity; and facilitating informed decision-making, interdisciplinary patient management and evidence-informed practice. While the major barriers to the implementation of these PCCPs in relation to BR were resource driven, surgeon-related factors were also identified.

Conclusions These PCCPs highlight areas of need but also provide examples of high quality patient-centred care. They may help to guide a national discussion about minimum standards of BR practice, while allowing for some necessary regional and cultural variation. They also have the potential to be applied more widely to the provision of a range of health services within Australia or internationally.

Keywords Patient-centred care · Patient preferences · Breast reconstruction · Models of care · Australia

Background

Defining patient-centred care

"Patient-centred care" is widely promoted as an ideal goal of health care systems, but is often difficult to achieve in practice [1]. This is because it requires an integrated health system that is flexible enough to make the patient's individual needs paramount. One of the earlier definitions from The US Institute of Medicine defined patient-centred care as "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions" [2]. Research conducted by the Picker Institute, an international charity, and Harvard Medical School led to the development of Picker's Eight Principles of Patient-Centred Care in 1987. These have been updated over the years (see Box 1) and since 2002 the Picker Institute has worked with the National Health Service (NHS) in the UK to design patient experience surveys [5].

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Box 1 Picker's eight principles of patient-centred care

1987 version [3]	2018 version [4]
Respect for patient's preferences	Involvement in decisions and respect for preferences
Coordination and integration of care	Effective treatment delivered by trusted professionals
Information and education	Clear information, communication and support for self-care
Physical comfort	Attention to physical and environmental needs
Emotional support	Emotional support, empathy and respect
Involvement of family and friends	Involvement of, and support for, family and carers
Continuity and transition	Continuity of care and smooth transitions
Access to care	Fast access to reliable health advice

Patient-centred care principles related to breast reconstruction in Australia

Traditionally, disease-specific "best practice" recommendations were embodied in clinical guidelines, and most countries have their own breast cancer management guidelines [6–8]. The latest complete set of published Australian clinical guidelines for early breast cancer dates back to 2001 [9] and is currently being updated. In the meantime, topic-specific guidelines have been produced to reflect the latest evidence in specific areas [10]. Cancer Australia has also published a Statement titled *Influencing best practice in breast cancer* [11]. This Statement is intended to complement the nationally endorsed *Optimal care pathway for women with breast cancer* [12], by highlighting what "ought to be done" in breast cancer care to "maximise clinical benefit, minimise harm and deliver patient-centred care" [11].

Number 11 of the 12 practices covered by the Cancer Australia Statement declares that it is "Not appropriate to perform a mastectomy without first discussing with the patient the options of immediate or delayed breast reconstruction" [11]. The *Optimal care pathway* document notes that patient-centred care is one of the "key principles" that underpin this pathway [12]. It defines patient-centred care as "healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers" and notes that it is "increasingly being recognised as a dimension of high-quality healthcare in its own right" [12]. These two publications [11, 12] have highlighted the growing importance of patient-centred care, at least at a rhetorical level. Previous research has documented significant variation in breast reconstruction (BR) uptake between different states and territories and between hospitals situated within metropolitan and non-metropolitan areas [13]. Much of this variation is related to hospital-based factors such as where individual surgeons work and what type of BR, if any, they offer [13, Feng et al., 2019, Patterns of immediate breast reconstruction in NSW Australia: a population-based study, In Press, ANZ J Surg]. These findings confirm that barriers to affordable and timely access to BR are multifactorial and require a combination of responses to address them. Further information about BR in the Australian setting is provided in Appendix 1.

Clinical practice guidelines and optimal care pathways are important tools to support evidence-based best practice treatment and management of a particular disease. Although these tools discuss the importance of patient-centred care, more specific principles are required to guide the implementation of patient-centred care in practice. This article has three aims: to develop an original set of generalisable patient-centred care principles (PCCPs); to identify barriers to the implementation of these principles in a real-world setting, using BR services in Australia as a case study; and to document examples of successful patient-centred care in relation to BR, in order to identify favourable conditions for the implementation of patient-centred care in practice.

Methods

This article reports on findings from the Improving Breast Reconstruction Equity of Access through Stakeholder consultation and Translation into policy and practice (I-BREAST) study.

Participants

One hundred and two participants were invited to take part in a single face-to-face or telephone interview with KF, an experienced qualitative health researcher. Twelve invitees (four surgeons and eight breast care nurses (BCNs)) declined to participate in the study, giving a response rate of 88%. Interviewees included 31 breast and plastic reconstructive surgeons and 37 breast cancer health professionals with primary appointments at 42 hospitals across mainland Australia. In addition, women who underwent mastectomy as part of their breast cancer treatment were purposively sampled to obtain the views of women who self-identified as being dissatisfied with their BR experiences ($n = 22$). While we realise that many women will be satisfied with their BR experiences, the reason for focusing on women who had negative experiences was to identify if there were specific problems that need to be addressed.

Selection criteria comprised the following:

- Surgeons who either performed both mastectomy and BR themselves or in combination with plastic surgeons (convenience sample of 22 breast/oncoplastic and 9 plastic reconstructive surgeons).

Table 1 Barriers to the implementation of principles of patient-centred care[a, b]

Barriers identified	Quotes from participants
Principle 1: Facilitate informed/shared decision-making	
Surgeon does not encourage shared decision-making	[The surgeon] *was the rudest wo/man I've ever met in the whole world. I think we saw her/him for about 10 minutes. I tried to ask her/him some questions … S/he threw a couple of implants, literally threw them into my lap and said, "What do you think of them?" I said, "Yeah." S/he had a bit of a poke around … and then s/he said, "These are my out of pocket expenses. See you later."* [W15, Major city] *… s/he can be a bit reserved, s/he can be a bit hard to get information out of. S/he's more of the older-style specialist where you pretty much follow what s/he tells you.* [W11, Outer regional]
Surgeon not willing to refer	*The surgeon immediately told me that I had nothing to worry about because s/he'd already booked me in for a mastectomy in two days' time. … I then went back to the breast surgeon and s/he spoke to me in the waiting room, in the reception area, and I demanded a referral* [to a surgeon] *in Melbourne.* [W14, Inner regional] *… that's what makes me really angry, that these surgeons are treating it as a business and they realise that because they're not doing the other surgery that they're potentially losing customers, so they treat it as a business only and they withhold information. That's negligible.* [W14, Inner regional]
Patients under pressure to make quick decisions to fit in with surgeon's timetable	*… that real rush of—this is Thursday night, this is about 6 o'clock at night on a Thursday, and s/he was like, well, I'll be going away in two weeks' time, but I can book you in on this Tuesday* [for a mastectomy only]. [W1, Major city] *… so two days before the surgery, I was sitting there trying to do the financial planning and that was overwhelming, far too much for me, so, you know, at ten o'clock at night, I had to call the plastic surgeon and say, "I'm just not doing it, I'm cancelling the whole thing, because it's too much; I just can't make these decisions—I'm not thinking clearly, I can't make the decision."* [W5, Major city]
Inadequate information provided	*… this is why I don't really like to think about it too much because I just felt, at that point, I was so ill informed and they just did whatever. And in that sense, that's why I feel let down.* [W17, Major city] *There wasn't a discussion* [or] *any information available from my breast surgeon about what these* [BR] *options were. Even at that stage, I couldn't walk away with a handful of bits and pieces, and say, well I've got this information I can look at it at some stage. I didn't have that … I walked away from the hospital, had nothing, no contacts no nothing.* [W6, Major city] *I think it would have been much easier to have been given information about reconstruction as an option and how it relates to the initial surgery for the breast cancer at the time of diagnosis. I think it should be part of the package in terms of the type of information people are given.* [W14, Inner regional]
BCN not comfortable raising the possibility of BR for their patients	*But still very, yeah, one of them* [surgeon] *in particular is quite old-fashioned, and a bit authoritarian, a difficult person to liaise with on an even level.* [HP4, Inner regional] *… two surgeons don't necessarily like me seeing them* [the patient] *before they operate …I think they like to be in charge and they don't like to think that I've got anything to offer the person.* [HP24, Inner regional] *It's very difficult when I see someone if they say, "Look, I've seen X and he's doing a mastectomy and I don't really know how I'm going to cope with this." … because I know from experience if I say, "Look, okay, you could get a second consult, you could see this person, he will offer you X, we could do that." It can get really messy for the patient then because she needs to get another referral from a GP to see this other doctor. It does tread on toes, they* [the surgeons] *don't like it being done, the woman can feel like, she's not supporting the original doctor … But I very rarely do that because … my experience tells me the patient won't actually change surgeons, they'll actually stay with them.* [and then the initial surgeon says] *"Well, the patient wants to stay with me anyway," so it is quite difficult to negotiate that area.* [HP13, Major city]

Table 1 (continued)

Barriers identified	Quotes from participants
Photos not available or inadequate	*"I said 'Well, what are they going to look like … and he shows me a picture of somebody else, and it's like … well that looks fantastic, but he should have showed me 20 of them, that this can go wrong and this can go wrong'."* [W13, Outer regional]
Not encouraged to speak with former BR patients	*… really they're the questions … how long until you can go swimming? Or you can go and do this and that? Can you go to the gym? Do you feel weak in the stomach and all that sort of thing? Breast care nurses can't tell you that—they can tell you from "generally, usually, sometimes," whereas an actual person can say, "No, I was okay at this point."* [W17, Major city] *"I'm not sure how much women are accessing mentoring or peer support from other women who have been through the experience and I think that might have been helpful for me, but that wasn't—I wasn't offered it at the time."* [W14, private patient, regional area; had BR in capital city].
Principle 2: Maximise patient choice	
Surgeon does not offer BR	*I said, "Well, what about reconstructive surgery?" and he just said, "Well, we don't offer that here," and went on to try and book me in to go ahead with the mastectomy.* [W1, Major city]
Demarcation issues	*… you know, someone says they are better than the other—surgery is full of it. Not a lot of cohesion, particularly between specialties. That professional jealousy of—some of the breast surgeons had wished they had got into plastics and so there is a bit of that goes on.* [S32, Major city]
Difficulties coordinating surgeons/theatres	*… trying to get two* [surgical] *teams on the same day with the same free time and a theatre that's available, that is the biggest challenge.* [HP37, Major city] *I just think they [IBRs] don't look as good … so I will do it if somebody makes me but I'd rather not.* [S25, Major city]
Principle 3: Maximise equity of access to services	
Metropolitan versus non-metropolitan	
Services not available locally	*Well, North Queensland seems to be getting nothing. We're up the top of Australia, we seem to get nothing. It seems to go to Southeast Queensland, all the money; the funding … every* [public] *hospital from here to Brisbane, none of them do reconstruction surgery. That's a lot of hospitals.* [W22, Outer regional] *I've got a young lady; she's got four kids—she's not even thirty yet. They don't have any family here—they do have family in* [capital city]*, so she's going to have to relocate her entire family* [there]. *Her husband's going to stay up here and work while she has her radiotherapy—so, I guess, she's lucky that she does have that family support in X, but the oldest two are going to have to be taken out of school and the younger ones are going to lose their day care places—it's just a huge logistical thing for them—poor people.* [HP6, Inner regional]
Poorer quality care locally	*Well I actually believe that I am alive and well because I didn't stay and have my treatment here locally, I sought a second opinion by a breast surgeon in X, one of the best in the state, and ended up being cared for by a multidisciplinary team, which wasn't available here at the time either, and I think I had amazing treatment and the treatment I had I think was far better than what it would have been—than what it was going to be here locally, and I honestly think that's what kept me alive, what saved me … It also made me feel angry because I … was bitterly disappointed to then discover that there were substandard services being offered locally … and you could really only access it, in my opinion, at that time, if you were in the private system and not the public system, and I felt that inequity was totally deplorable.* [W14, Inner regional]

Table 1 (continued)

Barriers identified	Quotes from participants
	... we formulated the policy around breast surgery in X and making sure that the patient was fully informed about the reasons why they should go away [for better treatment options]. [HP22, Remote]
Difficult to attract health professionals	*... there's only so many trained nurses that live in this area, so you don't have that big pool of nurses to call on. Lots of the nurses in the hospital say, well, we're so short staffed and they're not putting any on ... But not everyone wants to come and live in X.* [HP25, Inner regional] *... we have difficulty attracting* [plastic surgeons] *to a regional area ... We can't get their wives past the [local landmark] ... it is usually for family reasons; the family doesn't want to come to X.* [S23, Major city] *I think people want to live in big cities, particularly the younger people, for education, for children, their families are based there. Now with husband and wives both working, they very much rely upon grandparents and family to care for children.* [HP36, Outer regional]
Difficult to travel for BR	*... Someone from* [small country town] *deciding to have a mastectomy because they can't afford to be away from the farm, they're actually essential, especially around harvest time. They make a decision to have a mastectomy.* [S21, Inner regional] *... but somebody who is very elderly, or a lot of Indigenous women won't travel further than [remote town].* [HP22, Remote]
Public versus private	
Public DBR waiting list clock starts after one year post-treatment review	*Well I was only put on the waiting list 12 months after surgery, which puts me 12 months behind, and then they said, well it doesn't matter because it's still going to be seven and a half years, and I said, "Well, why should I have to wait any longer than anyone else? When did you guys decide that I'm not as important as anyone else, and why has it suddenly gone from two years to seven and a half years?"* [W7, Major city]
If patient dropped off public waiting list, through no fault of their own, they go back to the end of the queue	*I put my name down for X Hospital, they explained that, you know, you're category 3 which means that you won't be a priority and you could be waiting two to three years and that they would advise me when my appointment came up to see the specialist, and arrange it. So I returned to work and then I naturally assumed that they would advise me, so after about two years I rang them saying, okay, can you let me know where the status is, and they said to me, we sent you a letter out and you never responded, so we removed your name from the list. I said, "I did not receive anything. Shouldn't you really chase that up?" Basically, there was no arguing with them.* [W2, Major city]
Not enough plastic surgeons and resources in the public system	*... s/he had a contract to do what was supposedly one recon in the public a month ... I think s/he did nine in the last year ... but to get on her/his list basically they open the books at the beginning of the year, everybody in town that wants to have a public reconstruction rings and they get a 10 minute appointment and then s/he categorises them or something and puts them on the list and the rest have to wait and ring back next year.* [S15, Major city] *... there's two surgeons; we don't really, when you look at it per hour, we don't actually get paid that well, even though the out of pocket costs might seem a lot. I can do 10 skin cancers in a day, go home* [make a lot more money that way?] *Absolutely, realistically.* [S13, Major city]. *The AeroForm expander that I had in, only private patients can have that; public* [patients] *are still having saline expanders at this point.* [W14, Inner regional]

Table 1 (continued)

Barriers identified	Quotes from participants
Principle 4: Maximise support for patients and their families	
BCN not available	*We don't have a breast care nurse in the public. So, I'm a cancer coordinator and I look after breast cancer, gynaecological cancers, lung cancer, melanoma, sarcoma, urogenital and prostate cancers.* [HP34, Major city] *… it just would have been nice to have more knowledge… but my only knowledge was the surgeon that's it. And because I was so panicked you know I didn't sort of seek out, I didn't know who else to go to.* [W21, Major city]
BCN not aware of patient	*There's no MOU with the private hospital. There's no agreement or anything … Sometimes I get calls from the nurses at the private hospital who say "I've got this patient about to go home. She needs to see a breast care nurse." … So it's very* ad hoc. [HP13, Outer regional] *… the neo-adjuvant patients weren't ever being referred, and there were some cases I came across, and we would see them just before surgery when they came on the theatre list, and you'd start talking to them and saying, well where have you been for the last six months, and they've been going through treatment and we weren't aware of them.* [HP1, Major city]
Surgeons do not refer patients to BCN	*… we don't get referrals directly through from surgeons unless there's extreme psychosocial needs … we follow through the theatre lists and that's where we get referrals. So, it can, sometimes they're put on two weeks in advance, sometimes it's just the night before, the day before, depending on when they've seen the surgeon* [HP1, Major city]
Surgeons do not refer patients to other services	[if the general surgeon had signed this form you would have been entitled to discount travel?] *Yeah, and when I rang to make an appointment they said, "Well, s/he does mastectomies so…* "[You *don't* need to go anywhere*?] Yep. To have this [benefit] and think, "This is an entitlement, this is good, this will help," and then someone going, "Nah, we're not going to sign that … I could do some of it." That's not good enough.* [W8, Outer regional]
Travel support inadequate	*I couldn't have done it* [without staying at my sister's house]. *Because we couldn't have afforded to—we went to back one income earning, we had three kids, they were all under the age of four. There was absolutely no way I could have done it without my sister, no way. And I know that 100 per cent. Even with assistance on public transport, like if I was travelling today I'd be seeing money for it in two and a half months. By the time you were getting it you're already spending it again sort of thing. Definitely not possible unless you had some sort of extra support.* [W16, Outer regional]
Principle 5: Maximise use of appropriate communication techniques and information materials	
No culturally appropriate information available	[what resources do you have available? Do you have anything in different languages?] *Not a lot. We've got Breast Cancer Network of Australia, and Cancer Australia, they have Vietnamese, Arabic, Greek, Italian, Chinese. They usually come with families but we do use an interpreter. We don't rely on family interpreting; an interpreter is always booked for people who don't speak English … Because usually when they come here, they're being told something important or they have to sign a consent, so it's a bit of a legal thing.* [HP29, Major city] *I saw a lady, Indigenous, quite young, never been to X before and never left her family before and was sent to the* [radiotherapy centre] *and then back to X, which is the accommodation, with a bit of paper. It's got a picture of a radiation machine, and a picture of somebody having some medication put into their arm and a few other pictures, and that was their effort at trying to explain what was going to happen. She didn't even know where her cancer was.* [HP13, Outer regional]
No low literacy information available	*… it is about lower expectations, lower health literacy, not being so used to dealing with medical specialists and maybe not having the confidence. And even knowing what questions to ask. … a lack of access to the Internet really does contribute to a lower health literacy rate. I mean it's lack of access to information. I mean in the communities there are no libraries*

Table 1 (continued)

Barriers identified	Quotes from participants
	or anything like that. You have to travel—so I mean even here I had to travel an hour and a half just to go down to X to have a look in their library and see what they might have on breast cancer. [HP18, Outer regional]
Interpreters not available	*… for Aboriginal languages, we have struggled to maintain an easy and available interpreter service … there's nine major language groups and lots of other sub-language groups, and most people understand one of nine and so there is an interpreter theoretically available for each one, but in a hospital at any one time, there's usually only one for one of the language groups and that does make it, you know, if they're not easily available it doesn't happen often. So often we're speaking in their second or third language and … that's sub-optimal culturally.* [S17, Outer regional]
Lack of confidence in accuracy of interpreters	*You're just assuming you're getting a good service. Although, just recently, I had a patient who said to me—the daughter was in with the interpreter and the mother and she said that woman is not interpreting what you're saying to my mother. It's always a worry when the interpreter talks more than what you've said. And they don't always—and the woman says something to them and they have a conversation, but they don't actually say to you what they just said.* [HP28, Major city]
No access to similar women with BR experience	*I think my most important thing is to help other ladies. I don't want them to ever be in the position where I was. It's like stumbling in the dark.* [W2, Major city; Greek volunteer for BCNA] *There's too much travel I think. My cousin's mob, I think they were trying to get more services down there. But I know when I was getting treatment, like chemo and all that, I'd see all the other remote mob from the remote communities, like Tennant Creek, and they'd have to be living in Darwin, away from their homes for a long time. I know there was a few of them, and it's a bit lonely, away from home, that's for sure.* [HP20, Outer regional; also breast cancer patient]
Principle 6: Minimise patient costs	
Large out-of-pocket gaps for private patients in surgeon's rooms and for theatre/hospital costs	*So s/he flies up there once a month and does a few implants … one* [patient] *was very unhappy … her surgeon recommended … this plastic surgeon … And she didn't have a lot of time to think about it and … they had got no information about how much it was going to cost and so then by the time she found all of this out, she was only a couple of days out from her surgery …* [Do you know how much she did pay out of pocket?] *I think it was like 10 grand all up—it was just something ridiculous … that was just for the expanders.* [HP6, Inner regional]. *Some people, you have to borrow to have it done. Terrible out of pocket price, so not everybody who comes can afford it; they've either had to tap into superannuation or something to—or mortgage, if they've got it, to get the reconstruction done. Not many people have a lazy $10,000.* [HP16, Major city]
Medicare and PHI rebates do not keep up with actual costs	*The problem for women, the only complaints I have about money in BR, is tissue-based reconstruction and the extraordinary out-of-pocket costs for that, which to some extent, I can understand because you're there all day doing one operation that doesn't pay much through Medicare, but it leaves a huge gap.* [S1, Major city] *…The kind of mine field of private health insurance is just awful. It is very complicated and not well explained.* [S13, Major city]. *I was privately insured top hospital and then I went to see the surgeon, said, "Yes I'm privately insured, I can go to a private hospital," and then not long before the surgery I found out the extra costs it would, for the anaesthetist and the extra bills for the surgeon, and I'm like isn't that all covered? And it wasn't and I couldn't afford to pay for the extra. So, I ended up choosing to go to a public, a public hospital with a private surgeon, like a privately insured in a public hospital or something, but it was dreadful.* [W21, Major city]

Table 1 (continued)

Barriers identified	Quotes from participants
Some surgeons choose to perform multiple operations	[The breast surgeon] *said, "I'll do a skin-sparing mastectomy and then two days later, the plastic surgeon will come in and put an expander in, and it has to be done that way, in case you have necrotic skin flaps, and then you'll come back for some expansions and then you'll come back and have the expander exchanged for a permanent implant." Then she saw the plastic surgeon who concurred with all of that … Then she said "Why can't I just go do this direct-to-implant thing and have it all done in one day?"… They said, "Well, if you want that option, you'll have to go back to X." So, she did … Three operations. You know, the … total figure is over $35,000. It's ridiculous.* [S21, Inner regional] *I see an enormous amount of over servicing of patients and I see also influences on basically monetary grounds … I do see quite a bit of you know wastage of tax payer's money, because ultimately Medicare, and some of the fee for service potentially looks … I can question sometimes the influence of it potentially interfering with you know soft clinical decisions.* [S27, Major city]
Surgeons charging more than AMA rates	*Well, $20,000 or $25,000 for a [unilateral] reconstruction I think is pretty standard from some prominent plastic surgeons.* [S21, Inner regional] *Like, I know that we're highly trained people and I know that we need to be remunerated, but there's got to be a cap on these things.* [S7, Major city] *But if you go to X, they have a plastic surgeon that flies in … And s/he'll brag about making $100,000 a day … Her/his gaps are enormous … for implant reconstructions, s/he'll charge a $20,000 gap. Just like that. Supply and demand … there's no one else doing it.* [S2, Major city]
Principle 7: Minimise short and long-term physical and psychosocial morbidity	
Surgeon needs to be adequately trained and experienced in BR	*… you need a certain volume. So that you're doing them regularly. The problem is it's a high risk procedure, the complication rates are high. You need to be able to deal with the problems when they arise. So I wouldn't be supportive of an occasional implant being popped in by rural generalists, because of those other issues. It's not necessarily the technique of it, but it's just the lack of the support, the lack of the decision-making structure. The lack of being able to consider all of the different options. The lack of being able to deal with complications.* [S7, Major city] *… so he is flat out and it's simple logistics of he doesn't want to do an* [oncoplastic] *operation before he would get trained to do it, and it's just logistics of timing, like finding time to actually go and get trained and he certainly cares enough that he wouldn't just go gung-ho in and doing something without getting the proper training.* [HP25, Inner regional]
Careful patient selection for BR procedure required	*Making the correct decision. Putting them* [implants] *in, that's just fine. Who owns the complications, you know? And then was that the best thing to do at the time?* [S5, Major city] *… they didn't actually see the women before they made these decisions and a lot of the women were okay, you know with a BMI of 30 you can look all different shapes with a BMI of 30* [HP3, Major city] *If the referring doctor notes to consider BMI, will look at each case—they may carry their weight in their thighs. But don't send me a "barrels on legs*". [S3, Major city] *… how old you are is how many years you have in you until you would die from your body running out and there are people therefore who at 40 only have 15 years left, there are others who are 80 and have 20 years left … And because of that it's very much on the individual, but we're pretty good at judging that—how someone walks down the corridor, how they sit down, how they talk, you've got a reasonable idea, that's how I see it.* [S8, Major city]
Autologous BR not performed by two plastic surgeons working as a team	[do you work with another plastic surgeon?] *… in public we don't have that luxury. In the private always … it's a long arduous surgery so you don't want to do it alone.* [S23, Major city] *… doing it single sided by yourself, you know, you are doing microsurgery at the end of the operation and you've been operating for 5 hours. And also the aesthetics of it, you have sort of got to, you know, shape the breast which I think is one*

Table 1 (continued)

Barriers identified	Quotes from participants
	of the most important parts and if you're a bit tired and you just can't be bothered, you are not doing it justice. You know, that's when you sort of need the two of us. And the micro takes less time with them. I mean whilst someone is raising the flaps, someone finds the vessels, it's quicker, it's better for the patient. [S13, Major city]
Inadequate follow-up of longer-term BR issues.	*... so I don't see anyone till the middle of the year, it should be nice to see someone. It's, sort of, reassuring to go and see people along the way. All of a sudden it's like, "No, come back in like seven months."* [W20, Major city] *... and they ushered me out the back door; they don't want to see me again basically.* [W7, Outer regional]
Inadequate mentoring of junior surgeons	*... and we have fellows here but they don't come for specialist training, they come to be broad-based generalists. So they come through and I teach them too, but they're not with me for a year or two, and because my practice is only one third breast, it's not like having a specialist breast unit training.* [S17, Outer regional]
Principle 8: Foster interdisciplinary patient management	
No breast cancer-specific MDT meeting established.	… it's a general surgical oncology MDT, so it's all cancers treated by general surgeons and it's just in the last year or so, it's becoming oversubscribed, so sometimes there's a delay of two weeks before you can get somebody on. [S17, Outer regional] … the one general surgeon, s/he's got a bit of an odd view of what multidisciplinary care is. [HP22, Remote]
Not all appropriate clinicians able to attend	… But our problem is the radiologists and there's only two in town and they can't provide any more radiologists to attend a meeting at the moment. [S17, Outer regional] The thing that we're trying to get on board here at the moment is our own radiologist and pathologist. That's what we require and that's what we have available in X and that why we still use the X MDT if we have a really complex case. [HP26, Inner regional].
Surgeons based outside of major hospitals have limited access to the more experienced clinicians and decision-making processes	*I actually took a patient to their breast MDT a week ago, because we haven't got the skill mix for me to have that discussion, to support me in the decision-making here ... I think it's training input and skill mix. Number* [of cases], *I know, in the past have been proven to make a difference to outcomes, but I think it's more to do with the complexity of cases; the team approach and the true MDT setting.* [S22, Inner regional]
Principle 9: Promote communication between care providers	
Not all relevant clinicians are regularly informed of patient outcomes and progress	*... even though sometimes the GP gets the letters and so forth, I don't always get—I have to go and do some more homework to get that information and put it in their notes and follow-up. And, yeah, so there's a lot of following up going on.* [HP33, Remote] *And when I have sent [plastic surgeons] a patient that may have had a problem, it disappears to Melbourne; so, I lose them completely. If they're then talking about further surgery to the other breast I end up not being involved ... I've had a few scenarios where that has happened [loss of oncological follow-up].* [S22, Inner regional] *S/he [plastic surgeon] was quite derogatory too about the country; that our doctors up here wouldn't be able to manage this and they wouldn't be able to manage that and the country doctors are hopeless.* [W53, Inner regional] *There's still a few GPs in town that despite the fact that we've got three good surgeons, they think that the only place women can be treated for breast cancer is in* [major city], *so they just refer them straight to* X [that city]. [HP6, Inner regional]

Table 1 (continued)

Barriers identified	Quotes from participants
Principle 10: Encourage evidence-informed practice	
Patient-reported data not collected or not used to inform practice	*And let's not forget that seeing a reconstruction on a photograph that looks great, the patient may not necessarily be that happy because of chronic pain, because of all sorts of things. And so I think that there can be a lot more research looking at quality and patient satisfaction after their surgery. Not just the cosmetic appearance of the reconstruction.* [S24, Major city]
Clinical outcomes data not collected or used to identify and address problems	*They* [plastics] *don't collect data. They're not that mindset. You need to be oncologically trained to be used to collecting lots of data. And, plastic surgeons don't collect lots of data in general.* [S21, Inner regional] *There's no survival outcome on my results, where there is on a breast surgeon's results so if there's no survival meaning in it then why bother with the nightmare of keeping a database on it?* [S31, Major city] *…nobody really knows how many delayed reconstructions are being done. I mean, we all assume it's a very small proportion but we don't really know.* [S10, Major city] *My audit's not up to date. Well I pay someone. But they left [laughs]. Now I'm paying someone else.* [S2, Major city] *I never go back to my BQA patients, I never update them … what I put in at about the time of diagnosis is as far as I ever get with it.* [S25, Major city]
Inadequate education of GPs and patients	*There are clearly GPs who are giving people bad advice, usually, because of lack of education. I think GPs only see about a dozen women with breast cancer in their life.* [S29, Major city] *I didn't know that I was going to have mesh, I didn't even know what mesh was, I just didn't have any of that information … and I wouldn't know how to ask for that either.* [W17, Major city]
Surgeons do not follow latest clinical guidelines/evidence	*But for the most part, if they are having radiotherapy to the chest wall it's kind of like well you can't have immediate reconstruction. That tends to be the way it goes.* [HP3, Major city] *… certainly if there is any potential for radiotherapy … after a mastectomy, then they certainly wouldn't be doing an immediate reconstruction.* [HPs 28/29, Major city] *They don't do many core* [biopsies], *which I think is a bit crazy. Everything is still pretty much FNAs in their practice. One of their surgeons there I know is resistant to doing vacuum assisted biopsies* [because of the cost]. [S15, Major city]

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[1]. Pusic AL, Klassen AF, Scott AM, Klok JA, Cordeiro PG, Cano SJ. Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q. Plast Reconstr Surg. 2009 Aug;124(2):345–53

AMA Australian Medical Association, *BCN* breast care nurse, *BMI* body mass index, *BQA* Breast Surgeons of ANZ Inc. Quality Audit, *BR* breast reconstruction, *CNC* clinical nurse consultant, *DBR* delayed BR, *DCIS* ductal carcinoma in situ, *IBR* immediate BR, *MDT* multidisciplinary team, *GP* general practitioner, *PHI* private health insurance, *PROMs* patient-reported outcome measures

[a] No individual hospitals or participants are identified

[b] Regions classified according to the Australian Statistical Geography Standard (ASGS) 2016. Australian Bureau of Statistics. 1270.0.55.005—Australian Statistical Geography Standard (ASGS): Volume 5—Remoteness Structure, July 2016. Latest issue 16/03/2018 http://www.abs.gov.au/ausstats/abs@.nsf/mf/1270.0.55.005 [accessed 12 April 2019]

- Health professionals who worked with women undergoing mastectomy for breast cancer in centres that did and did not offer BR (purposive sample of 37 health professionals, mostly BCNs with selection informed by an earlier survey of BR practice in their local area).
- Women who had undergone mastectomy for breast cancer, were interested in BR, and self-identified as being dissatisfied with their BR experience (purposive sample of 22 women).

Recruitment

Surgeons were identified through personal contacts, recommendations by other surgeons and comments by BCNs about particular issues in their local areas. Surgeons who did not perform BR were not invited to participate.

Health professionals (mainly BCNs) were initially identified via a Human Research Ethics Committee [HREC]-approved survey sent to BCNs in January 2016 via the membership lists of the McGrath Foundation, the NSW Breast Cancer Interest Group and the Breast Cancer Network Australia. This same survey was posted on the Reclaim Your Curves (RYC) website in May/June 2016, resulting in further BCNs volunteering to participate.

Women were recruited from a variety of sources including suggestions from surgeons and BCNs, as well as an invitation to participate in the study posted on the BR advocacy RYC website[14].

Recruitment of participants ceased when the study authors agreed they had reached a satisfactory level of data saturation (i.e. the same issues were being identified in subsequent interviews). The role of interview respondents by jurisdiction is provided in Appendix 2.

Interview processes

Interviews were conducted between May 2015 and May 2017 with written informed consent obtained from all participants. Face-to-face interviews took place at a convenient location for the respondent, with KF interviewing in seven capital cities and four regional centres. Telephone interviews were conducted with patients and health professionals in an additional 18 locations across mainland Australia. Interview duration ranged from 9 to 103 min (mean = 43; median = 41).

Data management

Interviews were digitally recorded and de-identified. They were uploaded and transcribed verbatim for data analysis by an independent transcription company that had signed a confidentiality agreement. Each participant was assigned a sequential reference number, with a prefix of W for women, HP for health professional and S for surgeon to ensure confidentiality. Responses from interviewees were grouped into broad topic-based categories, agreed on by all authors, to reflect the range of views on particular issues. Where data was relevant to more than one topic, it was included in all relevant categories. Appendix 3 provides the topics discussed by each group of respondents. This article is based on participant responses to the “Models of care”, “Support”, “Information”, “Cultural differences”, “Waiting times” and “Patient choice” categories.

Data analysis

The interview data provided evidence of situations where patient-centred care was non-existent or severely compromised. It also provided examples of high quality patient-centred care in certain locations. Through our evaluation of the variation in standards across different locations in Australia, the authors derived ten PCCPs that could be used to guide ideal provision of BR services. We then grouped participant quotes that demonstrated practical barriers to the implementation of each of the ten principles (Table 1). Finally, we grouped examples from the interview data of high quality patient-centred care under each of the principles to demonstrate that these ideal practices are possible within the Australian health system where resources are available and clinicians are willing to optimise patient-centred care (Table 2).

Ethics approval

Ethics approval for the I-BREAST study was granted by the Human Research Ethics Committee of St Vincent’s Health Network Sydney (18/099).

Results

Box 2 presents the ten PCCPs the authors derived from their overall evaluation of the interview data.

Box 2 Ten principles of patient-centred care

Principle 1: Facilitate informed/shared decision-making
Principle 2: Maximise patient choice
Principle 3: Maximise equity of access to services
Principle 4: Maximise support for patients and their families
Principle 5: Maximise use of appropriate communication techniques and information materials
Principle 6: Minimise patient costs
Principle 7: Minimise short and long-term physical and psychosocial morbidity
Principle 8: Foster interdisciplinary patient management
Principle 9: Promote communication between care providers
Principle 10: Encourage evidence-informed practice

Table 2 Examples of high quality patient-centred care in Australia[a]

Principles	Examples
1. Facilitate informed/shared decision-making	Second or third appointments prior to surgery; patient accompanied by others for support and to act as "another pair of ears"; encourage list of questions; DCIS patients can take more time for decision-making. Patient able to access information at home and discuss with others. Include written estimate of costs. Refer to BR decision aid available on the BCNA website. Women able to view poor, average and good outcomes from full range of BR techniques in their own time. Patients provided with a list or database of women who have completed BR and are happy to discuss their experiences—matched with age, circumstances, type of BR etc. Alternatively, women are referred to other resources such as BreaCan which organise opportunities for women to have a conversation with "somebody who's walked in the same shoes" and also provides an online navigator site for women to view photos and consider decision-making issues surrounding breast reconstruction. BCN can negotiate/interpret/represent on patient's behalf if needed. Patient decides on level of involvement in decision-making. Surgeon offers referrals for second BR opinion. Communication training for surgeons. Surgeon's communication skills make the woman feel she is supported in her decision. Use of a discussion prompt list to aid full discussion. Nurse-led BR clinic where a BCN has undertaken additional training in breast reconstruction and provides one-on-one conversation with patients considering BR to ensure they know exactly what to expect.
2. Maximise patient choice	The patient has access to a surgical team that offers mastectomy and both implant-based and autologous BR options. Prompt referral from breast/oncoplastic surgeon to plastic reconstructive surgeon for discussion of autologous options. The surgical team is willing and able to offer IBR or DBR. Has the support of radiation oncologists and medical oncologists to perform IBR. Hospital has adequate resources and staffing. Joint public clinics with breast and plastic surgeons, attended by BCNs. Plastic breast reconstructive surgeons with weekly lists in the public. Breast/oncoplastic surgeon performs oncology surgery on plastic surgeon's operating list. Neo-adjuvant chemotherapy and radiotherapy available.
3. Maximise equity of access to services	Patients can access necessary investigations, clinicians' consultations, BR of their choice and additional support services in a timely manner with minimal out of pocket costs. From these interviews, all of these criteria were only available at four large public hospitals located in metropolitan areas.
4. Maximise support for patients and their families	BCN sees patient before mastectomy to offer support, let them know what to expect and address any outstanding queries. May sit in with surgeon on initial consult in the private sector or be present in public clinics. BCN available to follow-up any oncology-related concerns. Access to a specialist BR nurse. This could be a BCN with BR knowledge, interest and expertise or a clinical nurse consultant (CNC) position with no specific oncology training, but works closely with BCN. This role takes responsibility for coordination of joint breast/oncoplastic and plastic lists. Available to discuss any BR-related concerns. Specialist BR nurse offers the following additional services: •free nipple tattooing •dressings for patients with delayed wound healing •expansions of temporary expanders •a nurse-led follow-up clinic •an additional survivorship clinic for longer-term issues •3 dimensional laser scans to assess asymmetry and for BR modelling. •a timeline of the BR process for patients •quarterly consumer fora for patients to provide feedback about what could be improved. •BR awareness evenings to inform new patients and families •regular office hours for advice, help, talk through decision-making, etc. Nurse-led survivorship clinics which provide a point of contact for patients once their active treatment has finished. It provides the opportunity for one-on-one discussion of "everything that's happened to them and to talk about what's next and how we manage all that can be associated with that". All patients routinely get seen by a psychologist, a breast care nurse, and a lymphoedema specialist pre-surgery. Subsidised accommodation available for family/support people near to hospital.

Table 2 (continued)

Principles	Examples
	State and territory-based patient travel schemes provide significant reimbursement of travel and accommodation costs for the patient and their support person, with minimal fuss and paperwork. Written information designed for particular ethnic/cultural groups or different literacy levels.
5. Maximise use of appropriate communication techniques and information materials	Utilise national resources from respected cancer bodies. Use of interpreters as needed; involve family members for translation of information if helpful to patient. Access to other women from similar ethnic/cultural backgrounds to discuss their experiences, possibly in their native languages.
6. Minimise patient costs	BR is available free of charge in public hospitals. Surgeons charge AMA rates. Offer one-stage IBR where possible. SLNB performed at same time as mastectomy (not earlier, even with neoadjuvant chemotherapy cases). GP, BCN or social worker referral to state/territory-based patient assistance travel schemes for women required to travel for BR. BCN referral to additional funding/support sources if required (e.g. Cancer Council, Breast Cancer Care WA).
7. Minimise short and long-term physical and psychosocial morbidity	IBR performed within 30 days of initial surgical consultation (Category 1 surgery). Clinically eligible women added to the public DBR waiting list as early as possible. Check with patient if they are still interested, still suitable for planned surgery and have not dropped off hospital waiting list. Women considering BR have routine appointments with psychologist. Women are clinically suitable for the type of surgery they have agreed to. Unsuitability not based on age or BMI only. Surgeons are clinically competent to perform that surgery. They have undergone specialist training and have practical experience in a large number of cases. Less experienced surgeons work under the supervision of highly qualified and experienced surgeon to ensure high quality training. Plastic surgeons work in pairs to reduce operating time for free flap procedures. Routine follow-up and referral to non-surgical specialties as required (e.g. physiotherapist for lymphoedema treatment). Survivorship clinic to pick up on long-term issues, including impact on the family.
8. Foster interdisciplinary patient management	Multidisciplinary Team (MDT) meetings have representation from all key clinicians involved in treating the patient, including plastic surgeons. Respectful acknowledgement of different views with consensus on best treatment options. Pre-operative MDTs to discuss potential eligibility for neo-adjuvant therapy (chemotherapy, radiotherapy or endocrine therapy); likelihood of requiring post-mastectomy radiotherapy; and options for IBR. Post-operative MDT to discuss all new cases, recurrences and metastatic patients presented in a breast cancer-specific meeting. Options for DBR discussed. Metropolitan hospitals linking with regional hospitals to provide MDT expertise and support. BR-specific MDTs to allow for joint discussion between breast and plastic surgeons of all cases suitable for BR. BCN-run clinics for GP shared care that see people who are low risk, early breast cancer and have finished their treatment. BCN does a treatment summary, collects all clinical information and discharges that group of patients back to their GPs.
9. Promote communication between care providers	Documentation of MDT consensus, and any dissenting views, on patient treatment. This information provided to members of the patient's care team, including their GP. Oncological follow-up by a general, breast or oncoplastic surgeon who performed the mastectomy, with surgical follow-up by the surgeon who performed the BR. Written communication between both and with the GP is essential. GPs invited to attend MDTs when their patients are being presented.
10. Encourage evidence-informed practice	Collection of PROMs data on patients to inform practice, identify problem areas and support patients. For example, patient responses to BREAST-Q quality of life questionnaire [1] have been used to lobby for DBR to be considered a Category 2 procedure to be performed within 90 days.

Table 2 (continued)

Principles	Examples
	BreastSurgANZ Quality Audit—all members of BreastSurgANZ are required to provide minimal data sets on their patient's clinical, investigation and treatment data, including BR. There is no equivalent audit for plastic surgeons. Target rates for BR for patients with in situ and invasive disease are used as a High Quality Practice Indicator. Open disclosure of complication rates. Patients have access to research trials that may benefit them or provide an opportunity for them to help others. Regular education seminars for hospital staff. BR awareness sessions for general public and women with breast cancer. Clinicians and health professionals are encouraged: to attend and present their research at appropriate conferences and meetings; to regularly review appropriate journal articles, e.g. through a journal club; and to undertake further training, e.g. BCN practicums. Increased use of neo-adjuvant chemotherapy and radiotherapy in clinically appropriate women. Review evidence of benefits of neo-adjuvant endocrine therapy.

[1]. Pusic AL, Klassen AF, Scott AM, Klok JA, Cordeiro PG, Cano SJ. Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q. Plast Reconstr Surg. 2009 Aug;124(2):345–53

AMA Australian Medical Association, *BCN* breast care nurse, *BCNA* Breast Cancer Network Australia, *BMI* body mass index, *BQA* Breast Surgeons of ANZ Inc. Quality Audit, *BR* breast reconstruction, *BreaCan* Gynaecological and Breast Cancer Support Service, *CNC* clinical nurse consultant, *DBR* delayed BR, *DCIS* ductal carcinoma in situ, *IBR* immediate BR, *MDT* multidisciplinary team, *GP* general practitioner, *PHI* private health insurance, *PROMs* patient-reported outcome measures

[a] No individual hospitals or surgeons are identified

Table 1 presents the ten PCCPs and the practical barriers identified by our participants to the implementation of each of these principles, while Table 2 provides examples of successful implementation of the ten PCCPs in relation to BR.

Discussion

Interviews revealed examples of high quality patient-centred care in several metropolitan and regional hospitals, including public hospitals. However, challenges were also identified. Barriers to patient-centred care included problems of inadequate levels of staffing and resources, even in metropolitan and regional areas that could be reasonably expected to be well staffed and well resourced. However, the majority of the 42 hospitals represented in these interviews did not provide services that met all 10 ideal principles for patient-centred care and some of them would struggle to meet any.

It is not possible to discuss all the barriers that were revealed through these interviews, but we will mention a few items that, if implemented more widely, are likely to make a significant difference to the care women receive. Firstly, BCNs are clearly vital for the delivery of patient-centred care as evidenced by the poorer quality care patients received when BCNs were not available.

Secondly, the provision of specialist BR nurses is still a rarity in Australia, but the extra services they offer have the potential to add tremendous value to patients, surgeons and BCNs, as our findings and those from the UK have shown [15]. Specialist BR nurses have the knowledge to offer fully informed discussion, provide referrals as necessary and perform a range of practical tasks such as seroma drainage, inflation of expanders and nipple tattooing in a continuous care model of support. Specialist BR nurses can also collect, collate and analyse patient-reported outcome measures as a means of quality assurance and to inform clinicians of areas that could be improved, as well as to lobby for improved services. One particular benefit of having specialist BCNs is the potential for nurse-led survivorship clinics, which care for the patients once the active treatment phase has ceased.

Pre-operative MDT meetings are also scarce in Australia, with the majority of hospitals discussing their patients' adjuvant treatment post-operatively. If women have opted to have IBR, then it has already been performed prior to any MDT discussion, with the surgeon being responsible for this decision. The exception is for women considering neo-adjuvant treatment, but in these cases, discussion often involves more informal talks between relevant multidisciplinary team members in order to fast-track chemotherapy treatment and BR is often not discussed in the MDT setting. Some hospitals do hold regular pre-operative MDT meetings which allow for a wider discussion of BR possibilities among clinicians prior to mastectomy. Where breast, oncoplastic and plastic surgeons attend, this could facilitate a more collegial approach to BR discussion, especially if it is open to other local surgeons as a mentoring tool for decision-making. Such cooperation can only benefit patients.

In addition to resource-based barriers to patient-centred care, this research has identified surgeon-based issues. Clinicians need to learn to be better communicators and listeners. Patient-centred care cannot exist in situations where the views of patients and their supporters are not valued. The use of a prompt list to guide BR discussion between surgeons and their patients is likely to be useful, as a reminder against omitting items that are important to the patient, or assuming they understand those issues [16]. Surgeons also need to be prepared to work collaboratively and in the patient's best interests, even in situations where this may potentially disadvantage them financially. They should be prepared to engage with more junior surgeons to help develop their skills so that future patients will benefit from the time they have committed to mentoring. Surgeons also need to recognise the potential negative impact demarcation between surgical sub-specialties can have on patient care (Flitcroft et al., "On the frontiers of change": breast surgeons' views on demarcation between surgical sub-specialties in Australia, under review).

Finally, it is vital that clinicians keep up to date with the latest advances in breast cancer treatments in order to offer their patients treatment options tailored to their specific needs. Patient-centred care must be based on the best and latest evidence, requiring surgeons to keep up to date with clinical trials and relevant publications in order to provide their patients with the latest information. One example is the growing evidence that radiotherapy after implant or autologous reconstruction is oncologically safe, even for older women, does not delay treatment and provides cosmetic outcomes that women are largely satisfied with [17–22]. Furthermore, there is growing evidence of the benefits of neo-adjuvant radiotherapy (NART) in the setting of immediate autologous reconstruction. Tansley et al. [23] predicted superior outcomes from their resequencing of adjuvant radiotherapy in 2013, and their own and subsequent studies appear to confirm it is oncologically safe with a low side effect profile even during BR [24]. NART has also been reported to achieve significant downstaging in some patients with high risk, locally advanced breast cancer regardless of tumour phenotype [25]. Hughes and Neoh noted this treatment sequence allows patients to have an immediate gold standard reconstruction without an increase in surgical morbidity: "It affords the benefits of IBR without concern in delaying adjuvant therapy and appears to be safe from an oncological perspective" [26].

Limitations

The semi-structured questionnaires used in this research are not validated QoL assessment instruments. However, to our knowledge, there are no validated questionnaires available to capture women's or health clinicians' views on BR in their local area. It is also possible that some practices may have changed since 2015 when the first interviews were conducted.

Conclusion

We have compiled a list of 10 patient-centred principles that we believe, if implemented, would facilitate the delivery of high quality patient-centred care for women requiring or choosing mastectomy and interested in BR. We realise that achieving some of the ideal BR practices nominated here will not be feasible for many breast cancer services, at least in the short term. However, we believe it is important to identify what an ideal system would look like, so that with time, the care of these patients will improve and become more attuned to patient preferences. These patient-centred principles may form the basis for a national discussion about minimal standards of BR practice, while allowing for some necessary regional and cultural variation. Arguably, women living in rural and remote areas of Australia have different and more difficult access issues to deal with. Further research exploring specific BR models of care for these women is underway.

Policy implications

We have discussed the usefulness of these ten generic PCCPs in identifying barriers to and exemplars of patient-centred care in relation to BR. Their strength lies in their potential as a helpful framework to guide analysis of unmet needs in a range of other health care services. For example, these generalisable principles could be used to benchmark the patient-centredness of existing programs in areas of chronic disease such as other cancers, cardiac disease, diabetes or lung disease.

Acknowledgements We are grateful for the assistance of the Consumer Advisory Panel (CAP) who advised on the interview component of this study. CAP members provided input into draft questionnaires and participant information to be sent to women with breast cancer, breast care nurses (BCNs) and breast surgeons. We also thank the interview participants.

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Compliance with ethical standards

Conflict of interest All authors declare they have no conflicts of interest. KF has full control of all primary data. This data has not been deposited into a public repository to protect the anonymity of interview respondents. The journal may review de-identified data if requested.

Appendix 1. Issues concerning access to breast reconstruction in the Australian setting

Breast reconstruction (BR) is available in public and private hospitals in metropolitan and regional areas of Australia. Medicare Australia offers treatment as a public patient in a public hospital without cost to the patient, so BR performed by a surgeon appointed by the hospital is free of charge [27]. Medicare also covers 75% of the Medicare Benefits Schedule (MBS) fee for services and procedures for private patients in a public or private hospital [27], although the majority of surgeons will charge more than the schedule fee for BR (the "gap") due to a lack of reasonable indexation of Medicare and health fund rebates over a number of decades.

Waiting times for delayed BR (DBR) are longer in public hospitals due mainly to limited availability of operating theatre time for these procedures, which are classified as Category 3 (non-urgent) surgery. National surgical waiting time guidelines state that Category 3 surgery "is desirable" within 12 months of being placed on a hospital waiting list [28], but wait times of up to 3–5 years are not uncommon [16]. If a woman has immediate BR (IBR) in a public hospital, then she can fast-track the initial reconstruction which, when performed at the same time as the mastectomy, should be completed within 30 days of the initial surgeon's visit (Category 1).

In June 2015, 47% of the Australian population had some form of private patient hospital cover [27], but over 70% of BR is undertaken in private hospitals [13]. Waiting times for BR in private hospitals is minimal; however, significant out-of-pocket costs are associated with this surgery as the fees the surgeons charge are not regulated and even women with the top level of private health insurance face substantial additional costs for the surgeon, assistant surgeon and anaesthetist. The Breast Cancer Network of Australia (BCNA) has recently reported on out-of-pocket costs associated with breast cancer treatment [29]. The Minister for Health has responded by promising to introduce a more transparent system so that consumers can compare costs for common breast cancer tests and treatments against Medicare rebates before their surgery, as well as offering a guarantee that a Coalition government will provide full Medicare rebates for any breast cancer tests and treatments that are recommended by the Medical Services Advisory Committee [30].

Box 3 describes the two main models of surgeon involvement in BR in Australia.

Box 3 Main models of surgeon involvement in BR in Australia

Model 1: Breast cancer surgeon plus plastic reconstructive surgeon

This model involves a cancer surgeon (general or breast) who performs the mastectomy and axillary node surgery, working in tandem with a plastic surgeon who performs all of the BR—implant or autologous, and immediate or delayed. No oncoplastic surgeons are involved in the care of these patients, and plastic surgeons are unlikely to be involved in the multidisciplinary team (MDT) meetings. Breast and plastic surgeons tend to be co-located within the same hospitals/clinics.

Model 2: Oncoplastic breast surgeon +/− Plastic reconstructive surgeon

This model involves an oncoplastic surgeon performing both the cancer surgery and either IBR or DBR. For IBR, they may use a direct-to-implant technique. For either IBR or DBR, they can insert an expander (as stage one of a two-stage process). The second stage involves the replacement of the temporary expander with a permanent implant in a separate operation. Oncoplastic surgeons may also perform immediate or delayed pedicled flaps such as a latissimus dorsi (LD) flap, with or without an implant, or a pedicled transverse rectus abdominus myocutaneous (TRAM) flap. Plastic surgeons are not involved with the management of these patients unless the patient prefers a procedure outside the skill set of the oncoplastic surgeon, most typically a deep inferior epigastric perforator (DIEP) or other free flap reconstruction.

Appendix 2

Table 3 Table of participants in the I-BREAST study

Respondent group	Role	ACT	NSW	NT	QLD	SA	VIC	WA	Australian total
Surgeons (*n* = 31)[a, b]	Oncoplastic surgeon	2	9	1	2	2	5	1	22
	Plastic surgeon	0	3	0	2	1	2	1	9
Health professionals (*n* = 37)[c]	Breast physician	0	0	0	1	0	0	0	1
	Breast care nurse	1	15	2	5	2	4	3	32
	BR coordinator	0	0	0	0	1	0	0	1
	Cancer care coordinator	0	1	0	0	0	0	0	1
	Community health nurse	0	0	2	0	0	0	0	2
Patients (*n* = 22)	Public patient[d]	0	3	2	2	2	2	0	11
	Private patient[d]	0	4	3	0	2	2	0	11
Total		3	35	10	12	10	15	5	90

[a] Most surgeons had appointments in both the public and private sector. For the purposes of this study, their principal place of work was allocated as the surgeons' main operating hospital; 17 hospitals were public and 7 were private. Surgeons in the capital cities of five states and two territories of Australia were included, along with those from major regional centres in the two most populous states—two in Victoria and three in New South Wales (NSW)

[b] Sixteen of the 31 surgeons were male

[c] All health professionals were female and 17 of the 37 (46%) were located in hospitals or community centres where BR was not available in the public system at the time of interview. Three health professionals had also received BR following mastectomy for breast cancer. They were not included as patients in the study because they were familiar with BR options through their own practice. One was satisfied with her BR, while the other two were not, but had decided against further surgery

[d] Based on where patient had breast reconstruction performed (may differ from where they live) or mastectomy performed if NBR

Appendix 3

Table 4 Interview content topics

Topic	Surgeons	Patients	Health profs
Quality of life factors:			
Aesthetics of BR—importance to patients and surgeons, assessment of, and satisfaction with outcomes	√		
Body Image—importance to patients		√	√
Satisfaction—patient satisfaction with surgeon, care received, information provided, role in decision-making & surgical outcomes		√	√
Support—available to patients and health professionals		√	√
Clinical factors			
Comorbidities—of patients as contraindications to BR	√	√	√
Complications—of patients' medical and surgical treatments	√	√	√
Diagnosis, treatment, follow-up, impact—how patient was diagnosed, what treatment & follow-up they received and its impact		√	
Neo-adjuvant chemo—impact on BR options	√	√	√
Radiotherapy—as contraindication to BR, impact on BR, neo-adjuvant RT	√	√	√
Decision-making factors			
BR discussion—when and what information; patient role in	√	√	√
Communication—with surgeon; power differentials; level of comfort		√	√
Cultural differences—language, customs, preferences, interest in		√	√
Decision-making—factors important to; how informed it was		√	√
Expectations—of patients and surgeons and differences between them	√	√	√
Information—provided to patients on types of BR, pros and cons; unmet informational needs		√	√
Patient choice—options available, role in decision-making, barriers to	√	√	√
Reasons—patient reasons for considering BR		√	√
Regrets—patient regret about choices, decisions, treatments and outcomes		√	
Health system factors			
Access to BR—options, waiting times, geographical limitations, costs, other barriers	√	√	√
Advocacy for BR—role of surgeons, health professionals and patients in	√	√	√
Models of care—referral processes, public versus private, who patients see and when, treatment regimens	√	√	√
Research data—how influential was research in surgeon's decision-making; how did they collect and use data	√		
Training—type and level of training of surgeons and other health professionals	√		√
Waiting times—to see surgeons, to have surgery, public versus private, reasons for delays	√	√	√
Workload—of health professionals, as a barrier to patient care and expansion of role			√
Surgeon-related factors			
Interest in BR—how surgeons became interested in BR	√		
BR options—what was available and/or offered	√	√	√
Demarcation—between breast, oncoplastic and plastic surgeons; views on who should do what	√		
Proportion & type of BR—how much BR surgeons performed and what types	√		
Surgeon caseloads—how many cases per year of X type of BR is enough to be considered competent?	√		
Surgeon preferences—for type of BR, working with colleagues	√		
Why low BR rates?—what factors do surgeons see as contributing to a low BR rate in Australia	√		

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