

Appendix 4.6 – Consumer and carer views of community pharmacy

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Research Paper

Consumer and carer views of Australian community pharmacy practice: awareness, experiences and expectations

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Abstract

Objectives To explore consumer awareness, experience and expectations of Australian community pharmacy practice, from the perspectives of consumers with chronic health conditions, carers or both.

Methods Semi-structured in-depth interviews were undertaken in four diverse regions of Australia. The constant comparison method was used for analysis purposes.

Key findings Ninety-seven interviews were conducted. Participants had limited understanding regarding the role of community pharmacy staff and the Pharmaceutical Benefits Scheme (PBS). Pharmacists were viewed primarily as medication suppliers, and the services provided by pharmacy, such as Home Medication Reviews, are predominantly unknown. Confusion still exists with respect to generic medications, medication pricing and how the PBS safety net system works.

Conclusions There is public uncertainty about specific aspects of Australian pharmacy practice. This is despite the introduction of newer professional services targeting chronic health conditions and extensive marketing campaigns involving pharmacy. If community pharmacy is to better assist consumers with chronic conditions, there needs to be improved community awareness of the professions current scope of practice and the system it works within.

Keywords chronic conditions; community pharmacy; knowledge; patient education; role

Introduction

There has been an increasing demand at an international level for pharmacists, like any other health professional, to assist with combating the increasing rates of chronic health conditions.^[1] Some countries have seen the introduction of public health^[2,3] or disease management services^[4] within community pharmacies, extending their role in assisting consumers to become more informed about their medication(s). In 2011, the Australian Government initiated remuneration for community pharmacists to provide specialised services, such as primary health care for diabetes, cardiovascular disease and mental health conditions.^[5] These are examples of chronic health conditions, which are long-term ailments. The above initiatives are particularly important for consumers with a chronic health condition(s) who are more likely to utilise community pharmacies and need to effectively manage their condition(s) long term.

Given the evolving role of community pharmacy, many studies have been conducted that either focus on consumer's awareness of and views regarding the provision of pharmacy services,^[3,6–10] or the community pharmacist's role.^[11–14] There appears to be a low level of consumer awareness and demand for the provision of public health or disease management services.^[3,9,10] A consistent finding is that consumers generally perceive the pharmacist's role solely as medication providers and advisors on medication use.^[11–13,15,16] When exploring the role of community pharmacists in Scotland, Gidman and Cowley identified that the general public's opinion was divided on their role in services beyond medication supply and the management of minor ailments; services such as health promotion and opportunistic screening.^[11] The authors recommended that a larger study be undertaken with a more diverse population to explore these views further, particularly given the limited qualitative research

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on consumer attitudes about community pharmacy.^[11] There is minimal research focusing on the consumer's view of pharmacy as a whole;^[17,18] studies have mostly focused on the pharmacist's responsibilities or a particular service, involving either the general public or participants with a specific chronic health condition.^[3,7,9,11,12,14] Considering the breadth of chronic conditions that consumers can have, a study that focuses on this population as a whole, regardless of the condition they have, is needed.

Since the introduction of a more active approach in chronic disease management, what was previously known about the general public's knowledge of Australian pharmacy is outdated. Although there have been social marketing initiatives to improve public awareness of various aspects of pharmacy practice, to our knowledge there are no evaluations of their impact on consumer knowledge of pharmacy practice. The non-profit organisation National Prescribing Service (NPS) MedicineWise provides educational resources and conducts extensive media campaigns aimed to make all Australians 'medicine wise'.^[19] Their 2012 national consumer survey demonstrated that further work was needed to increase the public's knowledge of the NPS as an organisation and the resources they provide, such as tools to identify a medication's active ingredient(s).^[20] Although their work is vital in educating consumers about the Quality Use of Medicines, the organisation does not exclusively promote the role of pharmacy in the health system.

The community pharmacy sector needs to appreciate and understand consumers' current knowledge of pharmacy, including the services provided and role of community pharmacy staff, as this can affect how consumers view the role of community pharmacy. If there are any gaps in this knowledge, then an increased effort needs to be made now to improve consumer understanding about what community pharmacy can do. This is important so that the public can fully utilise the services offered by community pharmacies, to better manage their chronic health conditions. This study aimed to explore the current awareness, experience and expectations of Australian community pharmacy practice, from the perspective of a range of consumers with chronic health conditions and from various backgrounds. To capture the multicultural population of Australia, participation included those from culturally and linguistically diverse backgrounds and Aboriginal or Torres Strait Islanders.

Method

To enable the researchers to explore the unique perspectives of the individual, a qualitative approach utilising semi-structured in-depth interviews was chosen.

Eligibility

To incorporate a range of different perspectives,^[21] participants were recruited from four diverse Australian regions: the rural and semi-rural regions of Mount Isa (Queensland) and Northern Rivers (New South Wales), and the metropolitan areas of Logan-Beaudesert (Queensland) and Perth (Western Australia). Participants had one or more chronic health conditions, including those who were newly diagnosed within the

past 6 months, were an unpaid carer for someone with a chronic health condition, or both, i.e. a carer and had a chronic health condition.

Procedure

A University Human Research Ethics Committee granted ethical approval (PHM/12/11/HREC). Previous stakeholder research on a similar topic informed the development of an interview guide.^[22,23] Feedback on the interview guide was sought from the research team that comprised: chief investigators, senior researchers and a consumer researcher (CC) to ensure the project was consumer focused. A Reference Group including healthcare stakeholders from various cultural backgrounds also reviewed the guide to ensure cultural appropriateness.^[24] Questions focused on the participant's experiences with their community pharmacy and the staff, the roles of community pharmacy staff, and how community pharmacy could better assist them to manage their conditions. To encourage a standardised interviewing technique, two researchers (SM, AS) conducted the first 10 interviews, trained two other researchers (CC, CM) in this process and transcribed the first 20 interviews to refine the interview guide and familiarise themselves with the data. Consequent interviews were conducted individually or in pairs (SM, AS, FK, CC, CM) during May–October 2012, depending on the participant's location and preferences, such as religious beliefs and cultural needs.

Interviews averaged 50 min in duration, were audio-recorded and conducted either via telephone ($n = 48$) or face-to-face ($n = 49$). All but two interviews, which were not audio-recorded as per participant requests, were transcribed verbatim and a sample of transcripts was checked for accuracy purposes. Participants were primarily coded depending on whether they were a consumer (C), carer (CA), consumer/carers (CC) or consumer with a health professional background (CH). Participants were also coded according to whether they had self-identified as an Aboriginal or Torres Strait Islander (IND) or from a culturally and linguistically diverse background (CALD).

Data analysis

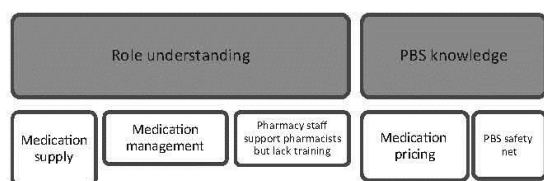
The qualitative data analysis package QSR NVIVO 9® (QSR International Pty Ltd., Doncaster, Victoria, Australia) and a constant comparison method were used for analysis.^[25,26] Initial coding of data into themes was conducted by three researchers (SM, AS, FK), who did not code the interviews they personally conducted. Initial coding was also discussed with the consumer researcher (CC) to minimise researcher bias, and an analysis framework was established. After initial coding, further interviews were explored to develop sub-themes, leading to category refinement. The constant comparison method, which represents the interrelated process of data collection and analysis, allowed participants to influence the study findings in an essential way than if analysis was completed after data collection had finished.^[27] Reliability of the coding was ensured by a research team member (MK) who checked the coding for randomly selected samples of data. The analysis process was frequently discussed and reviewed between the researchers and with the research team to ensure data credibility and trustworthiness.^[28] Data

Table 1 Participant data

| Participant characteristics | | n | % |
|-----------------------------|---|----|------|
| Carer/consumer | Consumer (C)† | 70 | 72.2 |
| | Carer (CA) | 8 | 8.2 |
| | Carer/consumer (CC)† | 19 | 19.6 |
| Location | Logan/Beaudesert (QLD) | 41 | 42.3 |
| | Mt Isa/North West (QLD) | 15 | 15.5 |
| | Perth (WA) | 20 | 20.6 |
| | Northern Rivers (NSW) | 21 | 21.6 |
| Race/cultural background | Aboriginal or Torres Strait Islander (IND) | 23 | 23.7 |
| | Culturally and linguistically diverse (CALD) e.g. Asian, Middle Eastern, European, Pacific Islander | 19 | 19.6 |
| | Caucasian | 55 | 56.7 |
| | Chronic condition(s)‡ | 10 | 11.8 |
| | Two or more | 75 | 88.2 |

†Four consumers and one consumer/carers had a health professional background.

‡Data for consumer (C) and carer/consumer (CC) participants only.

**Figure 1** Key themes from the data.

saturation was established when participants' experiences and perspectives became recurring with previously collected data.^[29]

Results

Participants

A total of 97 interviews were undertaken; the mean age was 57.2 years (range, 16–83 years) and the majority of participants were female ($n = 65$, 67.0%). There were a range of cultural backgrounds and chronic health conditions such as cancer, diabetes, cardiovascular, mental health, musculoskeletal, neurological, renal and respiratory conditions (Table 1).

Themes

Two overarching themes were identified: role understanding, i.e. what participants know about the role(s) of pharmacy and its staff, and Pharmaceutical Benefits Scheme (PBS) knowledge (Figure 1). To promote access to medications, the Australian Government introduced the PBS; a range of medications are listed on a national formulary and subsidised for Australian residents. In this study, pharmacists were primarily viewed as medication suppliers, with medication management, such as confirming medication appropriateness and providing advice, recognised as a secondary role. Participants

acknowledged that pharmacists and pharmacy support staff, including pharmacy and dispensary assistants, had vastly different roles; support staff assisted pharmacists by helping with consumer enquiries and were deemed to have limited training. Under the theme of PBS knowledge, there was confusion about how the safety net system worked; when consumers reach a certain monetary threshold from PBS medication use, the Australian Government further subsidises these medications for the rest of the financial year. This confusion also extended to price differences between community pharmacies and the promotion of generic medications, which are of similar quality, safety and efficacy to the original brand, i.e. they are bio-equivalent.^[30]

Role understanding

When describing what the pharmacist's role was, the majority of participants commented that this predominantly, or only, involved medication supply:

... I've never thought of a chemist being able to help me with asthma or diabetes ... it's a mental block I've got about chemists, all they do is give you the tablets. (C_1053)

This was particularly the case for elderly consumers who were more inclined to seek medical advice from their doctor:

I would tend to go to the GP first. I suppose it's built into my system after 50 years of doctors. (C_003)

Though it is a professional expectation that pharmacists provide current and relevant medication information to consumers,^[31] the pharmacist's medication supply role did not necessarily align with an expectation of counselling for all participants:

... I got that great advice from the pharmacist there who took the time, stepped right out and talked to me and in fact, I thought 'Oh gosh, she better go back', I started to worry. (CA_1057)

No ... they just handed the drugs over there was ... no mention of how to use it ... I wouldn't have really expected it at that time, now I would. I think they should. (C_008)

When participants discussed the pharmacist's role, some recognised the importance of counselling when initiating a new medication:

... that's been really, really good because they've [pharmacist] asked if this is the first time you've ever taken it ... and they've stood there and really explained the side effects and about it ... (C(IND)_1082)

The value of medication counselling was also re-enforced for consumers with repeat prescriptions. Limited counselling was acknowledged for repeat prescriptions or when participants were, or had been, health professionals and knowledge was assumed:

... I guess they've just always assumed that ... I'm already taking the medication and already know ... it would be nice if whoever's taking the script just says, 'Are you familiar with and comfortable with taking the

medication? And if not would you like to have a chat to our pharmacist.’ (CH_1045)

Pharmacists also had an important role to ensure medication safety, by providing medication management services such as dose administration aids, which are dose packaging units to assist consumers to take their medication, and checking for drug interactions:

If I go to buy vitamins or something, I say, ‘Oh look, will that interact?’ Which a lot of people don’t and they sort of say, ‘Oh God . . . that’s not a good one with Warfarin.’ (C_1072)

However, it was a challenge to explore the pharmacist’s role further, with some commenting that they were unsure what the pharmacist’s skill set or responsibilities were. Others were unaware of the services available from community pharmacies, including those newly funded by the Australian Government.^[5] This limited knowledge could be because these services were not offered by their regular pharmacy, they visited various pharmacies, failed to notice offered services because they had no need of them, or they utilised their doctor instead:

I don’t think they offer that service [blood pressure monitoring] at all over the counter. That should be strictly your responsibility at home or the physician’s visits. (C_1085)

Home Medication Reviews (HMRs) can also optimise safety for consumers at higher risk of medication misadventure, a service where an accredited pharmacist conducts an in-depth review and evaluation of a person’s medication usage in their own home.^[32] However, some consumers had never been offered, or heard of this service:

I had no idea what I was in for, sort of thing, and had never heard of it [HMR], didn’t even know it even existed. (C_1175)

This was particularly the case in rural communities with no local pharmacy, and was acknowledged as a desirable service for consumers with chronic health conditions.

Participants also commented on the role differences between pharmacists and pharmacy support staff:

The pharmacist, to me, is a person that distributes a medication and puts the dosage and your name and everything on it, and the assistant is the one that actually serves it to you. (C(IND)_1097)

Although most participants verified that pharmacy support staff assisted consumers with non-prescription medicine requests and helped the pharmacist, there was limited recognition of the role of dispensary assistants to complete the technical work of prescription supply. One participant was quite averse to the situation, believing that pharmacy support staff were underqualified:

. . . sales assistants from the general floor are being used in the pharmacy department to actually take the medicines off the shelf and put them in the box and then the . . . pharmacist checks . . . them. But, I don’t feel as safe with that one. (C_015)

There was limited knowledge about the responsibilities and training of pharmacy support staff. Furthermore, given that this consumer was of an older age range, her initial experience with community pharmacy is likely to be a vastly different interaction from how pharmacy is practiced today, such as the pharmacist working beyond the dispensary.

Pharmaceutical Benefits Scheme knowledge

Some consumers were unaware of how the PBS safety net system worked. There was confusion as to what they had to do in order to obtain discounted PBS medication prices:^[33]

. . . I never reached or never been involved with the safety net before . . . out of the blue I said . . . can you tell me a bit more about this . . . ? So the chemist herself came down to talk to me and asked me where I had been, what I’ve done . . . (CH_007)

The participant was unaware that she had to keep an official record of their purchased PBS medications. Others were not aware of their rights regarding medication dispensing and safety net history. The following participant described receiving a more personalised service elsewhere, yet chose to stay at their regular pharmacy because their medication history was stored there:

. . . they do all my safety net card and they’ve got all the records of when I’ve had all the meds [medication] that I’ve had dispensed, so that is the big draw card as to why I always go back there . . . (C_1052)

There was significant discussion regarding the use of generic medications, which are generally cheaper^[34] and therefore highly valued by some consumers:

. . . if it’s the same thing and you can save yourself ten or fifteen dollars, to me I’m like why not . . . (C_1107)

Another believed that generic medication should be chosen for the sole purpose of saving the Australian Government money:

. . . it costs them [the government] a fortune I know for drugs, I suppose it’s better if we all co-operate a bit anyway. (C_1059)

Conversely, others expressed frustration with generic medications and were particularly annoyed when community pharmacy staff continually asked if they wanted a generic brand. There were numerous reasons for declining substitution: risk of allergies to excipients, the impression that health professionals were promoting generic brands to generate profits, or uncertainty regarding their quality or composition:

. . . I’m not too sure that the generic might be of the same standard or quality as what you’re prescribed originally . . . (C_1025)

As generic brands may look completely different to the original product, other participants were concerned about, or had experienced medication confusion as a result of brand substitution:

Table 2 Additional quotes to illustrate themes

| | |
|---|---|
| Role understanding | |
| Medication supply | <i>I don't even know what they [community pharmacy] offer. Really, I just go there to get pills.</i> (C_002) <i>Fill out those scripts.</i> (CA(IND)_1146) <i>You go to a doctor ... they then give you the medication, then you go to the chemist ... their job is to give you the medication.</i> (C(CALD)_1069) |
| Medication management | <i>... they're there to help to make us better and to pass on the information that the doctor's prescribed ... I think they help to make sure you understand what the medication is for and how to take it.</i> (CC_1034) <i>... I've never really had a community pharmacist say, 'Oh do you need to know more about this medication?' Now look probably because my pharmacy knows me very well, they know I'm a registered nurse that might be part of it as well.</i> (CC(CH)_1049) <i>I would like the pharmacist to see you as a person and actually automatically sort of say, 'Oh look, when you come in here do you want me to organise, always look at your current meds [medication] and what we're suggesting for you?' ...</i> (CC_1166) |
| Pharmacy assistants lack training | <i>Well I usually do ask to speak to the pharmacist, I don't know whether that sounds a bit snobby or not ... rather than explain everything to someone and I've heard her say, 'I don't know, I'll have to ask someone else.'</i> (CC_1034) <i>I wanted to get some throat lollies and because I'm a diabetic I go in and she [pharmacy assistant] just give me these things with a high sugar. And I just said, 'Well I can't have them, I'm a diabetic.' And, 'Oh is that a problem?' I said, 'It is, I need to take Difflam® or whatever it was.' So here's a lady they had employed and had not trained her, not her fault ...</i> (C_1150) <i>... your pharmacist is, sort of, deal with your drugs, that sort of, qualified. Where you get, yeah your chemist staff is unqualified as such, they learn through experience ...</i> (C_1060) |
| Pharmacy assistants support pharmacists | <i>So the main person there is the chemist, the one who's giving you the medicine, themselves. But all the sales ladies there, they're just there to ask what you want, what you need, which one do you want, which one do you need.</i> (CC(CALD)_1067) |
| PBS knowledge | |
| Medication prices | <i>I can tell you about, the medicine I buy here for \$14.95 I can buy in [location] for \$8.95. A lot of the non-prescribed medicines I get here are between \$6.00 and \$15.00 dearer. I've complained and I've complained and they tell you it's freight. Well I do a lot of freight in my business; it's not freight, it's greed ...</i> (C_1150) |
| Generic brands | <i>... they wanted to give me some bloody generic brands ... I said, 'No, you haven't got the proper brand?', 'No we don't stock it.' I thought well gee, you really should stock the bloody original one first and then have the generic brand as an option. You can at least give the patient the option ... When you're used to a tablet that's orange ... then they give you a bloody white one, you just think, 'Jeez, what's that one? Have I doubled up on that one ...'</i> (C_1059) |

You know even a different packet the old people will say no, you're trying to poison me that's not the right tablet ... (C(IND)_010)

Confusion and frustration also extended to pricing differences between pharmacies:

... all pharmacists vary; they're not all the same price in a lot of things that you get ... some things are eight or nine dollars difference. Now to me, if it's the same supplier why aren't those, the medication that you get all the same? (C_1042)

Due to the depth of the interviews, further comments on these themes are provided in Table 2.

Discussion

Participants in this study had limited knowledge about the role of community pharmacy beyond medication supply and advice, especially in relation to new roles and services. There was also a narrow understanding of the Australian pharmacy system, with confusion about the push for generic medications,

how medications are priced and in what ways PBS safety net information can be documented and stored.

There are some limitations to this study. Qualitative research methods were used to explore the perspectives of a large number of carers, and consumers with varying chronic illness(s) and social backgrounds. Hence, the findings cannot be generalisable to pharmacy consumers with minor or acute ailments. The study is also specific to the Australian context. Furthermore, self-reported data can be influenced by participant and interviewer bias,^[35] although the latter was minimised by using a standardised interview framework to guide data collection and analysis.

Although consumers with chronic health conditions are more likely to utilise community pharmacies, i.e. in comparison to consumers with minor ailments that are less likely to require continuing medication, participants had difficulty discussing how pharmacy could better help them. It is concerning that they were unsure about what community pharmacy can do beyond the provision of medication. This is best exemplified when a participant worried about taking up the pharmacist's time for counselling purposes, thereby preventing them from dispensing medication. This preconception that

consultation times are not necessarily part of the pharmacist's role was also identified by Twigg *et al.*^[12] It reflects a lack of consumer knowledge of the pharmacist's skill and responsibility to ensure medication safety; it is not just about providing the right medication, but using the medication correctly. Considering that the World Health Organization estimated that half of consumers worldwide used their medications incorrectly,^[36] community pharmacy staff have an important role in medication management. Given there was evidence of limited counselling for consumers with repeat prescriptions, continual improvement in the provision of medicines information is essential and concurs with other study findings.^[18,37] Therefore, community pharmacy staff need to assess their daily practice to ensure that they are providing a professional service to consumers, which would subsequently increase consumer awareness, and expectations of, their role/s.

HMRs aim to optimise patient medication safety, yet recent studies have identified that eligible non-recipients of the HMR service were mostly unaware of this program^[38] and that further community promotion is needed.^[39] Our findings also identified that some participants, particularly those in rural areas with no local community pharmacy, have never heard of or been offered the HMR program. This is both disappointing and concerning given the acknowledged benefits of this service,^[38,39] and that participants with chronic health conditions are at higher risk of medication misadventure. The findings that consumers are unaware of the range of available professional community pharmacy services,^[6] or do not expect additional services,^[18] is also an international concern. Whilst new medication use review services such as MedsCheck can promote medication management in Australian pharmacies,^[40] it also provides a suitable opportunity for pharmacists to inform high-risk people about HMRs, thereby increasing awareness of pharmacy services in general.

Consumers are still confused about generic medications. This uncertainty also corroborates existing literature, with a recent Australian study finding that, compared with consumers with acute ailments, those with chronic conditions were less likely to accept brand substitution.^[41] The authors indicated that this could be due to concerns around efficacy.^[41] Subsequently, community pharmacy staff need to do more than ask consumers 'would you like the generic brand?' Although educational campaigns have been implemented in Australia,^[19] pharmacy staff need to provide ongoing public education about generic medication. Consumers need to understand why the Australian government is encouraging the use of generics, and that given the recent PBS reforms, pharmacists are provided limited remuneration for dispensing medications.^[34] This need for consumer education also extends to medication pricing; participants were frustrated and unsure why there were differences in medication pricing between community pharmacies. This reflects unfamiliarity with the PBS pricing structure and how pharmacists are remunerated; pharmacists are not paid on the basis of providing medication advice and have tried to maximise profits in other ways, such as discounting medicines to improve customer traffic.^[42]

It is likely consumers new to the Australian health system, or those who have just started using PBS medication, are

unfamiliar with how the PBS system works. This is also reflected in another similar health system.^[43] However, even a consumer participant who was a health professional was unclear about the process of reaching the PBS safety net. Community pharmacy staff should proactively ask consumers if they are aware of the PBS safety net threshold, explain what it is, and confirm eligibility. Consumers also need to understand their rights to their personal information. Participants should not have to settle for a pharmacy solely on the basis of their record keeping skills, particularly if the consumer believes the pharmacy is offering a less personalised service. Some participants were both unaware of the ease in which their medication history can be acquired and given to another pharmacy, or that they can obtain medications from other pharmacies and how this can be easily documented for safety net purposes.

Implications of the findings for policy and practice

Irrespective of previous, extensive marketing campaigns regarding pharmacy or medications, this study emphasises that consumers still have poor or limited knowledge about pharmacy practice and medicines. This was highlighted with generic medications. Although the NPS MedicineWise has conducted campaigns about this topic,^[44] there are still consumers who are unsure about what they are and the reasons why community pharmacies offer generic medications. There is a clear need for policymakers, government departments, consumer health and pharmacy organisations to further evaluate why such marketing campaigns are not reaching all consumers who utilise medication. There may be a need for greater use of simultaneous mass media campaigns and a coordinated grass-roots approach. In addition, further exploration is needed to identify other factors influencing the apparent lack of knowledge of community pharmacy's role/s. Whilst this article cannot provide these answers, community pharmacy staff can certainly be better utilised in marketing the pharmacy's role.

Community pharmacy staff need to become more involved by working collaboratively with governments, other health professionals and health consumer organisations to promote the role of pharmacy. This recommendation will not come as a surprise to health professionals, as it is often discussed, yet with respect to community pharmacy's current structure, is extremely difficult to achieve. However, initiatives can be introduced at the grass-roots level with community pharmacy staff providing consumer education, for example, on generic medications. Emphasis on how they differ from original brands and why there is a directive from the Australian Government to move towards generic medication is critical. Community pharmacy staff should also focus on developing a relationship with consumers, as this will support the opportunity to provide further education. For example, a relationship would facilitate medication counselling, which is needed for optimising the quality use of medicines. There also needs to be greater awareness of the aspects that facilitate the operation of community pharmacy as a whole, including the PBS system and medication pricing. Whilst there is information available on government websites regarding the PBS

system,^[45] community pharmacy staff can refer consumers to this information, or even better, explain it in a way that is relevant to the customer. In order for this to work, pharmacists need to ensure that staff have expert knowledge on pharmacy practice and the system it works within, and if not, to implement training in this area.

Community pharmacy staff should always offer to check if consumers are familiar or comfortable with using their medication, thereby promoting a medication management role. Consumer education on the pharmacy's role should also incorporate the co-responsibility of the consumer, who ideally should be medicines wise. For example, consumers should also ask questions to confirm medication safety, such as 'is this medication safe to use with what I currently take?' This is particularly important if the consumer wants to initiate a new medication and they are unknown to the community pharmacy staff. Ultimately, this education would improve consumer understanding of, and how they value, the pharmacist's role and emphasise the importance of medication safety.

Conclusion

This study has shown that, from the consumer's perspective, community pharmacy has a long way to go before they are more effectively utilised. It is evident that consumers with chronic health conditions have limited knowledge of pharmacists as the medicine experts within an overall health system. Whilst pharmacies are increasing their provision of clinical services for a range of chronic health conditions, they are still viewed by consumers through the narrow lens of medication supply. With pharmacies relatively accessible to communities, increased public awareness of the scope of practice of community pharmacy and the system it works within is needed to facilitate optimal use of this health care destination.

Declarations

Conflict of interest

None.

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Authors' contributions

Study conception and design: AW, FK, MK, JW, EK; acquisition of data: SM, AS, FK; analysis: SM, AS, FK; secondary analysis: SM, AS, FK, MK; drafting or revising the article or both: SM, AS, FK, MK, AW, JW. Final approval of the version to be published: all authors.

All Authors state that they had complete access to the study data that support the publication.

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Appendix 4.7 – Chronic conditions, financial burden, and pharmaceutical pricing: Insights from Australian consumers

This is the pre-print (pre-refereeing) version of the following manuscript:

Whitty JA, Sav A, Kelly F, King MA, McMillan SS, Kendall E, Wheeler AJ. Chronic conditions, financial burden and pharmaceutical pricing: insights from Australian consumers. The final, definitive version of this paper has been published in *Australian Health Review* DOI:org.10.1071/AH13190 by CSIRO Publishing. All rights reserved. © [Whitty JA, et al 2014.]

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Chronic conditions, financial burden, and pharmaceutical pricing: insights from

Australian consumers

Abstract

Objectives: To explore the perceptions of Australian consumers and carers about the financial burden associated with medicines used for the treatment of chronic conditions.

Design: Semi-structured interviews with thematic analysis of data using the constant comparison method.

Setting: Four diverse regions in Australia, across three States (Queensland, New South Wales and Western Australia).

Participants: Australian consumers ($n=97$), who either identify as having a chronic condition(s) ($n=70$), or care for someone with a chronic condition(s) ($n=8$), or both ($n=19$). Participants included individuals identifying with an Aboriginal or Torres Strait Islander ($n=23$) or Culturally and Linguistically Diverse ($n=19$) background.

Main outcome measures: Qualitative exploration and description of financial burden associated with medicines used to manage chronic conditions.

Results: Participants described substantial costs associated with medicines use, along with aggravating factors including the duration and number of medicines used, loss of employment, lack of pricing consistency between pharmacies, and the cost of dose administration aids. Consequences included impacts on medicine adherence, displacement of luxury items, and potentially a reduced financial incentive to work. Understanding and beliefs

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related to the pharmaceutical pricing policy varied and a range of proactive strategies to manage financial burden were described by some participants.

Conclusions: The financial burden associated with medicines used for the management of chronic conditions by Australian consumers is substantial. It is compounded by the ongoing need for multiple medicines, along with indirect effects associated with chronic conditions, such as the impact on employment.

Keywords: Financial burden, pharmaceuticals, chronic conditions, Australia, Consumer experience

Introduction

A substantial proportion of the burden experienced by people with chronic conditions and their carers is directly related to the multiple, potentially complex, and often lifelong treatment and monitoring regimes that are required to manage their conditions. Financial burden is a key component of the burden arising from multiple and ongoing treatments.^{1, 2} However, we know little about the subjective perception of financial burden and its consequences for consumers and their families, particularly as it applies to the current Australian context.

Medicines are a common form of treatment in chronic conditions. Australians spend more than AU\$18 billion per year on medicine, over half (AU\$10.7 billion in 2012) of this is for prescription medicine subsidised under Australia's national Pharmaceutical Benefits Scheme (PBS).^{3, 4} Australia's National Medicines Policy states that *"cost should not constitute a substantial barrier to people's access to medicines they need,"*⁵ and the PBS, which operates within the National Medicines Policy, aims to *"provide reliable and affordable access to a wide range of necessary medicines."*⁶ Nevertheless, consumers bear the full cost of medicines that are not included on the PBS, and are also required to make a substantial co-payment for each supply of a PBS pharmaceutical. Indeed, consumer co-payments in Australia are substantially greater than in New Zealand (NZ) or the United Kingdom (UK, Table 1). A comparison across seven countries found median out-of-pocket prescription costs in Australia to be second only to those in the United States.⁷ Australian consumers with chronic illness are, therefore, likely to be at particular risk of financial burden associated with medicines use.⁷

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Table 1: Consumer co-payment for Australian PBS subsidised medicines, compared to subsidised medicines at a national level in New Zealand and England, UK

| | Australia PBS^{a,e} (at 1 March 2013) | New Zealand Pharmaceutical Schedule^{b,e} (at 1 January 2013) | England, UK^{c,d,e} National Health Service (at 1 April 2013) |
|--|--|--|--|
| <i>Co-payment per item</i> | <ul style="list-style-type: none"> • General consumers: Maximum AU\$36.10 (may be charged less) • Concession card holders (predominantly adults ≥65yrs, low income): Maximum AU\$5.90 | <ul style="list-style-type: none"> • Fixed NZ\$5.00 • Children under 6 years: Free | <ul style="list-style-type: none"> • General consumers: Fixed GB£7.85 per item • Children <16yr, Adult >60yrs, pregnant women or new mother (within a year of birth), specified medical conditions or physical disabilities, war pension, low income: Free • Contraceptives: Free |
| <i>Additional charges</i> | <ul style="list-style-type: none"> • Therapeutic or brand premium fee may apply in addition to the co-payment, representing the difference between the consumer's medicine/brand and the cheapest medicine/brand in a reference-priced therapeutic group | <ul style="list-style-type: none"> • A brand premium may apply in some cases if the brand supplied is partially subsidised (when a different brand is under contract) | <ul style="list-style-type: none"> • Not applicable |
| <i>Safety Net</i> | <ul style="list-style-type: none"> • Annual threshold General consumer: AU\$1390.60 (38.5 items at maximum co-payment); co-payment at concession rate after reach threshold • Annual threshold Concession card holder: AU\$354.00 (60 items); free after reach threshold | <ul style="list-style-type: none"> • Annual threshold: NZ\$100 (20 items); free after reach threshold | <ul style="list-style-type: none"> • Prospective prescription prepayment certificate: GB £29.10 for 3 months (cost saving if need ≥ 4 items in 3 months) GB £104.00 for 12 months (cost saving if need ≥ 14 items in 12 months) |
| <i>Special access for disadvantaged groups</i> | <ul style="list-style-type: none"> • Eligible Aboriginal or Torres Strait Islander people with chronic conditions and Australians living in remote areas can receive medicines under special access schemes | <ul style="list-style-type: none"> • Not applicable | <ul style="list-style-type: none"> • Not applicable |

without a co-payment
(‘Closing the Gap’)

^a Australia – source PBS,⁶ special access schemes.^{8,9}

^b NZ – <http://www.health.govt.nz/our-work/primary-health-care/primary-health-care-services-and-projects/pharmaceutical-co-payments>; accessed 26th July 2013

^c England - source <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx>; accessed 26th July 2013. Specified medical conditions include a range of conditions (but not all) requiring ongoing prescriptions e.g. diabetes mellitus, epilepsy, cancer.

^d Medicines in Scotland, Northern Ireland and Wales are free,

<http://www.politics.co.uk/reference/nhs-prescription-charges>; accessed 22nd August 2013

^e AU\$1 ≈ NZ \$1.14 ≈ GB£0.60 at July 2013

The financial burden related to medicines use, including co-payments, is associated with reduced adherence and other cost-coping strategies.^{2, 7, 10-15} An estimated 9% of Australians delay or do not fill prescriptions because of cost,^{15, 16} a percentage that increases to 11-22% for those with a chronic health condition.^{7, 16-18} This finding is not surprising given that people with chronic conditions often fall into the most socioeconomically disadvantaged sectors of the population, the group for which there is arguably the greatest health gap.

Pharmaceutical pricing reforms such as price disclosure have been implemented with the intention of reducing the cost of medicines to the Australian Government and maximising the health outcomes achieved for the community. However, some commentators have argued these reforms do not go far enough to achieve value,¹⁹⁻²¹ particularly for generic medicines. It has been estimated that consumers not entitled to concession on the full co-payment could save up to AU\$20 per month for some commonly prescribed medicines if prices for pharmaceuticals on the PBS were to be benchmarked against the prices paid in New Zealand and by Australian public hospitals.⁴ Thus, the current pharmaceutical pricing policies, whilst supporting the availability of innovator medicines, are potentially contributing to the financial

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burden for Australian consumers taking prevalent, generic medicines for chronic conditions.

This has led to a recent campaign urging consumers to “Stand up for Cheaper Medicines.”²²

In this study, we seek to contribute to the debate around financial burden and pharmaceutical pricing reform by reflecting the voices of Australian consumers who identify as either having, or caring for someone with, a chronic condition(s). The aim of this study is to explore the perceptions of Australian consumers and carers of the financial burden associated with the use of medicines for the treatment of chronic conditions.

Methods

Semi-structured in-depth interviews were undertaken during May-October 2012 with 97 consumers who self-identified as having one or more chronic condition(s), as an unpaid carer of someone with a chronic condition(s), or both. Ethical approval was obtained from a University Human Research Ethics Committee (PHM/12/11/HREC). Participants were purposefully recruited from Logan-Beautesert and the Mount Isa/North West region (Queensland), Northern Rivers (New South Wales) and the greater Perth area (Western Australia), using advertisements at pharmacies, medical centres, other health clinics, community groups and via consumer health organisations in these regions. To ensure diversity, Aboriginal or Torres Strait Islander people and individuals from multicultural backgrounds were targeted alongside those not identifying with these groups.

The methods have been described in detail elsewhere.²³ Interviews were conducted face-to-face ($n=49$) or via telephone ($n=46$) and were transcribed verbatim. Questions related to the experiences of participants in managing chronic conditions, their use of medicines, the cost

and financial burden associated with their use, if any, and their experiences of health professionals and community pharmacy. Data from these interviews relating to financial burden associated with medicines use were identified and analysed thematically using the constant comparison method, with the support of the qualitative software package QSR NVIVO® (Version 9; QSR International PTY LTD).

Results

Most participants were consumers with chronic conditions (denoted C in quotes; $n=70$, 72.2%), or carers (CA; $n=8$, 8.2%), but some identified as both a consumer and carer (CC; 19, 19.6%). The majority of participants were female ($n=65$, 67.0%), with mean age 57.2 years (SD 13.0; range 16-83 years). Forty-one participants identified as being from an Aboriginal or Torres Strait Islander ($n=23$, 23.7%) or multicultural ($n=19$, 19.6%) background. Participants self-reported a range of chronic health conditions including diabetes, mental health, cardiovascular, respiratory and musculoskeletal conditions.

The financial burden associated with medicines featured prominently in the interviews. Participants described the financial burden associated with medicines as having a substantial impact on them and their families. Many spoke of financial burden being the “*biggest impact*” of their medical conditions [C015], with one participant reporting household medicine costs of up to AU\$700 per month [C1005]. Selected participant quotes illustrating themes related to financial burden are provided in Figures 2-4.

Participants reported a range of factors that aggravated financial burden (Figure 2). They emphasised the additive nature of medicine costs over time and across the multiple medicines

often required to manage chronic conditions. For example, one participant stated *“You’ve got the medications and they can be quite costly when it’s cumulative and you’re dealing with more than one”* [C1015]. The long-term nature of this burden was aggravated by having to cease employment prematurely due to ill health. Apart from the impact that might be anticipated to result from employment loss on other domains of life, it clearly increased the financial strain associated with the management of chronic conditions.

Some aspects of community pharmacy services also aggravated financial burden. Specifically, participants described their frustration about the different prices charged for the same medicine at different pharmacies, which was considered by some to be inappropriate. Dose administration aids (such as WebsterPaks®), added to financial burden, but were also seen by some participants as essential aids for medicine management.

Participants outlined a range of consequences of financial burden (Figure 3). Several referred to intentional non-adherence, choosing the medicines they felt they needed most, when they perceived they could not afford to obtain all their medicines. Similarly, some avoided starting new medicines, particularly when they were not subsidised on the PBS. Medicine costs displaced luxury items, including alcoholic drinks and cigarettes that may not be in the interest of an individual’s health, but that nevertheless provided choice and pleasure for consumers. Whilst chronic conditions may have resulted in cessation of employment, some participants also spoke of a realisation that medicines may become more affordable in their circumstances if they gave up employment. They would then become eligible for a low income concession card, indicating the concession system may incentivise some individuals not to maintain their working arrangements. Participants described using proactive strategies

to minimise the cost of their medicines, including stockpiling of medicines to reduce the co-payment after reaching the PBS Safety Net and selecting doctors who provided free medicine samples.

Figure 2: Participant quotes illustrating factors aggravating financial burden associated with medicines

| | |
|---|---|
| 1. Duration | <i>"\$10.50 a week for many years is too much"</i> [C(multicultural)1133] |
| 2. Polypharmacy | <i>"I take a slew of medication if I have to get them all at once it's \$60."</i> [C(Aboriginal or Torres Strait Islander)1159] <i>"Before I was a pensioner... I was paying \$34 a script and I was getting six scripts a month"</i> [CC(multicultural)1130] |
| 3. Cease employment | <i>"I think it is quite a financial drain. I mean now I've given up work... And you're spending out on medications... twenty five bucks a week or something like that, which doesn't sound much but...you don't have an income that's quite a financial burden."</i> [C1052] |
| 4. Lack of consistency of cost between pharmacies | <i>"It's cheaper than the one down by the doctors. She's [pharmacist] sometimes \$7 dearer..."</i> [C1002] <i>"I think they're totalling overcharging it and since a lot of the medication these days is paid by the public purse, you should be able to get the medication at any chemist, same price."</i> [C1035] |
| 5. Dose administration aids | <i>"Also with Webster-pak every time it cost us, so it is additional cost, and we cannot compromise this because if you look at his Webster-pak how many medicine in each, I really cannot do that. It's too much work."</i> [C(multicultural)1038] |

Figure 3: Participant quotes illustrating the consequences of financial burden associated with medicines

| |
|---|
| <p>1. Reduced adherence</p> <p><i>"Sometimes I just didn't get it because I can't afford it. I get the ones I felt were the best to deal with my health issues."</i> [C(Aboriginal or Torres Strait Islander)1159]</p> <p><i>"They say could you try this and you go to the chemist and its 40 bucks and then you think no I'll go without it"</i> [C1022]</p> |
| <p>2. Cost displaces luxury</p> <p><i>"... if you like to drink, or you like chocolate... And I think... what about the eighty dollars a month for the chemist bill and how much for your health insurance and so much for running your car and so on ... that eats up anything you've got left."</i> [C1022]</p> <p><i>"I've given up smoking, I've replaced it with pharmaceuticals (laughter)... half the money that I was saving from giving up smoking I think is now pharmaceuticals."</i> [CA1013]</p> |
| <p>3. Not worth working</p> <p><i>"I got told that I earn too much and I work too many hours... I just wanted the [concession] card to be able to help with the cost. And I said to them [social security], "So if I quit work and I live on the system, I can get it?"</i> [C1121]</p> |
| <p>4. Stockpiling</p> <p><i>"One month to go in the year I just ... stocked up on six months insulin at five dollars, so saved a bit that way... I thought oh Medicare would pick up on it and I'll just say that I forgot I got the insulin, cause you can at my age forget."</i> [C002]</p> |

Participants displayed a broad understanding of the health system as it relates to pharmaceutical pricing (Figure 4). One participant expressed distrust of the process by which medicines were costed, citing an example relating to a combination medicine which cost more than the two constituents sold separately, leading him to conclude that a pharmaceutical company was *"ripping the government off,"* and *"if the medication doesn't help you at least it*

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helps the pharmacist.” [C1035]. This participant saved money by obtaining the two medicine constituents separately. One participant expressed a sense of unfairness, indicating people with chronic conditions were not responsible for causing their illness, and yet they have to pay full costs for a medicine that “*works so well*” to manage their condition because it is not funded by the PBS [C1121].

Despite the clear burden associated with the ongoing use of multiple medicines, participants acknowledged the benefits of PBS medicine subsidies (Figure 4). They highlighted the financial relief experienced as a result of being eligible for a health concession card and having reached the Safety Net threshold. Several participants acknowledged the substantial reduction in costs received as a result of PBS subsidy. Furthermore, many Aboriginal or Torres Strait Islander participants emphasised there was no cost associated with medicines for them, except when their prescription didn’t qualify for the Closing the Gap arrangements.

Figure 4: Participant quotes illustrating understanding of the health system as it related to pharmaceutical pricing and beliefs associated with pharmaceutical pricing

| |
|---|
| <p>Understanding of the health system as it related to pharmaceutical pricing</p> <p>1. Not on PBS</p> <p><i>“if that could be put on the PBS it would make a tremendous difference financially to people dealing with multiple chronic conditions...a lot of my medications aren’t on the PBS and I think that needs to be looked into for people who do have complex issues” [C1015]</i></p> <p>2. Relief of costs</p> <p><i>“I... need a health care card to help cover the cost of the medication to bring them from being \$36, which is cheap in comparison with what the drug costs, down to \$5.80...” [C1121]</i></p> <p>Beliefs around pharmaceutical pricing</p> <p>1. Distrust</p> <p><i>“... I’m concerned about the money that comes out of the public purse. There’s only so much [money] allocated and it’s being ripped off for no good reason by the pharmaceutical company.” [C1035]</i></p> <p>2. Unfair</p> <p><i>“When I was working and I was paying over twelve thousand dollars tax a year, and I pay the Medicare levy every year... So if you add all those up, it’s not fair that I pay the full price for those medicines, it has to be subsidised somehow.” [C(multicultural)1129]</i></p> <p><i>“Yes, I am a diabetic, I didn’t do anything to cause it and yet you’re making me pay, ‘cause forever I paid a hundred and sixty dollars a vial for my (insulin), because it wasn’t covered, but it just works so well. You can’t not have something that’s going to work for you.” [C1121]</i></p> |
|---|

Discussion

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Australian consumers in this study attributed substantial financial burden to ongoing treatment for chronic conditions. The impact of medicine costs on consumers is clearly compounded by the ongoing need for multiple medicines or several members of the family being affected, along with the indirect effects associated with the impact of the illness itself, such as impact on employment. Although this finding is consistent with our limited understanding of financial burden, there is a surprising dearth of research into the financial burden borne by consumers and its impact on health, consumer medicine taking behaviour, and quality of life. This study has shown the important link between the financial burden of medicine and adherence to treatment regimes, but also to the poor use and storage of medicines.

The opinions of our participants raise a number of considerations relevant to medicines policy in Australia. Medicine costs are clearly a substantial burden for those with chronic conditions; however, we do not have good information on the size of the problem. The reported prevalence of not obtaining medicines due to cost has ranged widely in previous studies from 9-22%.^{7, 15-18} Research has yet to fully explore the priorities on which consumers base their decision to not obtain recommended medicines, or the impact of medicine cost on other treatments or domains of life. However, if there is poor adherence to medicines designed to reduce risk factors and manage chronic conditions, then disease progression may be managed sub-optimally, resulting in greater long-term costs for both the individual and the government. Before we can rigorously explore the consequences of financial burden for consumers in Australia and the strategies that might appropriately alleviate such burden, we need to undertake representative population-based research to assess the extent of burden related to medicine use, as well as other treatments.

Although the absolute out of pocket cost for pharmaceuticals may be a key driver of financial burden, other factors related to price also contributed. For instance, the varying prices charged at different pharmacies for medicines that are below the co-payment threshold or not included on the PBS potentially increased the burden on participants due to the need to shop around for a lower price. Some countries such as the UK and New Zealand (where a fixed co-payment applies, Table 1) regulate the price for prescription medicines at the point of dispensing. Our findings suggest that the consistency of co-payment amounts may impact on consumers. This area would be worthy of further exploration, particularly given that the co-payment scheme is designed to improve consumer experience and reduce financial burden. Our findings also indicate that dose administration aids can increase the cost borne by consumers, even though they play an important role in promoting adherence and good medicine management. The cost borne by consumers for these aids may also vary between pharmacies, thus adding further to the financial burden associated with medicines.

Health professionals who assist consumers to manage their medicines need to be aware of the potential for financial burden associated with medicines use and its impact on adherence. Strategies to reduce costs for consumers, such as selecting the lowest cost medicine that is appropriate for the indication and the use of generic medicines should be considered. Many participants were aware they paid less money for their medicines as a result of the PBS, including the concession and Safety Net entitlements implemented to reduce the financial impact of multiple and continued medicine use. Of particular note, many Aboriginal or Torres Strait Islander participants indicated they had no financial burden associated with their medicines when they were covered under the Closing the Gap arrangement. Thus, this study

provides an example of how a policy to reduce financial burden for a population with greater health disparity has been perceived by people in that population as highly beneficial.

However, whilst observations from this study provide some reassurance around the effectiveness of the concession and Safety Net systems, they did not completely relieve the financial burden associated with medicine use. Furthermore, not all the consumers and carers were familiar with the PBS Safety Net, indicating an important role for health professionals to raise consumer awareness. In contrast, some consumers were able to maximise their benefits under the Safety Net system through the process of stockpiling. The PBS Safety Net 20 day rule, in which the Safety Net does not apply to many medicines if re-dispensed within 20 days of the previous month's supply, was initiated in 2006 in an attempt to discourage stockpiling.²⁴ Some consumers also minimised costs by obtaining free medicine samples. Although the judicious use of free samples may have a place when closely supervised, this may come at an increased cost in terms of risks around the safe and quality use of medicines. The prescription and supply system in place in most developed countries has been established to reduce safety risks (such as expiry, accidental overdose, and incorrect storage). It also promotes quality issues, including regular monitoring and follow-up with health professionals, advice and counselling about medicines, and continuity and communication of total medicine regime and records between health providers. There is a need for health professionals to educate and assist consumers with chronic conditions to ensure they can navigate the health system to maximum benefit and receive financial entitlements for which they are eligible.

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This study explored financial burden for Australian consumers, drawing on the experiences and perceptions of a diverse group of participants with chronic conditions, or those who care for someone with a chronic condition. Our study deliberately targeted consumers who were most likely to be affected by financial burden, in that almost half of our sample identified with a minority group. Further research needs to confirm and build on these findings in extended samples, and quantify the financial burden of medicines and its impact on adherence and quality of life. Our study has enabled the voice and experiences of Australian consumers and carers with chronic conditions to contribute to policy debate on pharmaceutical pricing regulation in Australia.

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Competing interests

Jennifer Whitty is contracted by the Department of Health and Ageing to undertake external evaluations of submissions to the Pharmaceutical Benefits Advisory Committee for listing of pharmaceuticals on the PBS. This article contains the opinions of the authors and does not in any way reflect the views of the Department of Health and Ageing, the Pharmaceutical Benefits Advisory Committee, the Australian Government or The Pharmacy Guild of Australia.

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Appendix 5

Stage 2 Nominal Groups

Appendix 5.1 – Nominal group methodology

This is the pre-print (pre-refereeing) version of the following paper:

McMillan SS, Kelly F, Sav A, Kendall E, King MA, Whitty JA, Wheeler AJ. The paper we needed at the beginning: how to analyse results from the nominal group technique. The final, definitive version of this paper has been published in *Health Services and Outcomes Research Methodology* DOI:10.1007/s10742-014-0121-1 by Springer US. All rights reserved. © [McMillan SS, et al 2014.]

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The paper we needed at the beginning: how to analyse results from the nominal group technique

Abstract

The nominal group technique (NGT) is a method to elicit healthcare priorities. Yet, there is variability on how to conduct the NGT, and limited guidance on how to analyse a diverse sample of multiple groups. This paper addresses some of this ambiguity, and explores whether different approaches to analysis provide the same outcome/s. Conceptual papers and empirical studies were identified via PubMed and informed an adapted version of the NGT. Twenty-six nominal groups were conducted, which provided in-depth knowledge on how to best conduct this method. Pilot group data was used to compare different analysis methods and to explore how this impacted on reported outcomes. Data analyses for large data-sets are complex; thematic analysis is needed to be able to conduct across group comparisons of participant priorities. Consideration should be given not just to the strength, i.e. sum of votes, or relative importance of the priority, but to the voting frequency, i.e. the popularity of the idea amongst participants; our case study demonstrated that this can affect priority rankings for those ideas with the same score. As a case study, this paper provides practical information on analysis for complex data sets. Researchers need to consider more than one analysis process to ensure that the results truly reflect participant priorities. A priority that has a high score may not necessarily reflect its popularity within the group; the voting frequency may also need to be considered.

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1 Introduction

The importance of healthcare user's views and priorities is now increasingly recognised, particularly as consumers are more likely to use a service that meets their specific needs. Given the growing emphasis on addressing the rising rates of chronic conditions and providing patient-centred care, policy makers are more likely to seek consumers' healthcare expectations and priorities.

However, opinion varies as to the best method(s) to elicit consumer priorities (Ryan et al. 2001). The methods used include consumer surveys, focus groups, citizen juries, discrete choice experiments and Delphi-like methods, all of which have strengths and weaknesses (Ryan et al. 2001). For example, focus groups can generate more ideas than a single interview, but dominant personalities can influence the discussion (Gallagher et al. 1993), and ideas are not prioritised. Citizen juries allow participants to become informed about a particular topic, but are expensive and time-consuming (Ryan et al. 2001). The Delphi technique provides participant anonymity, but there is a risk of response bias (Ryan et al. 2001). Discrete choice methods can identify attributes of a service that are important to consumers, as well as their relative importance (Naik-Panvelkar et al. 2013), yet are complex in terms of design, and dependent on poorly defined processes for selecting attributes (Hilgsmann et al. 2013).

One method, the Nominal Group Technique (NGT), can explore healthcare priorities (Hutchings and Raine 2006), whilst addressing some of the above limitations. The NGT was developed by Delbecq and Van de Ven (1971) over four decades ago, as a process for '*identifying strategic problems and developing appropriate and innovative programs to solve them.*' The NGT facilitates the generation of ideas in relation to problems, solutions, or both, which are then discussed and ranked in order of priority by individual participants (Gallagher et al. 1993). It also allows comparisons of priorities between different groups, such as health consumers and healthcare professionals, which can then identify divergence in views (Cantrill et al. 1996). The NGT facilitates equal participation and allows all opinions to be respectfully considered (Carney et al. 1996), thereby minimising dominant personalities and focus on one particular viewpoint. Furthermore, the NGT is more likely to reach a clear outcome, providing a sense of

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achievement for participants (Harvey and Holmes 2012). Importantly, the NGT requires less time and resources than another consensus method, the Delphi technique (Delbecq et al. 1975).

The NGT has been applied in numerous studies to identify current opinions, or achieve consensus on a healthcare topic. These applications include preferences and views on end-of-life care (Denning et al. 2012), patient-centred healthcare professionalism (Hutchings et al. 2010), priority treatment outcomes (Sanderson et al. 2012), concerns (Miller et al. 2000), or challenges (Dewar et al. 2003) regarding specific chronic conditions, the evaluation of healthcare experiences (Potter et al. 2003) and unmet healthcare needs (Drennan et al. 2007), and to establish guidelines or research priorities (Vella et al. 2000). Participants have included consumers with various chronic conditions, carers, and varied healthcare professionals, such as nurses (Hutchings et al. 2012), doctors (Vella et al. 2000) and pharmacists (Hutchings et al. 2010).

Although there is considerable consensus on how to conduct certain aspects of the NGT, there is still some variability in its application. As most studies have involved small numbers, i.e. between one and five groups (Bissell et al. 2000; Denning et al. 2012; Gastelurrutia et al. 2009; Hiligsmann et al. 2013; Miller et al. 2000; Sanderson et al. 2012; Tully and Cantrill 2002; Vella et al. 2000), there is limited information on how to conduct and analyse a study with larger data sets. Our study helps to bridge this gap by exploring data analysis methods for 26 nominal groups (15 consumer and carer groups, 11 healthcare professional groups; participant range 2-14 per group). The focus of our study was the potential role of community pharmacy in the management of chronic disease. The large number of groups was conducted to ensure diversity with respect to participant demographics, i.e. location, cultural diversity and the chronic condition/s experienced. However, given that limited guidance existed about how to conduct data analyses across such a large number of groups, we were faced with questions about how to collapse and compare the findings. We also questioned whether different approaches to analysis would provide the same outcome/s.

The aim of this paper is to provide an overview of the NGT method as it has been applied in healthcare, and to illustrate some nuances of the NGT approach using a case study. Our intent is to provide

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recommendations on the analysis of multi-group NGT and address some of the ambiguity surrounding its use. The paper begins with a description of NGT literature, and our specific adaptation of this method. We then compare the different data analyses options and related outcomes using our data (pilot group 2) as a case study.

2 Method

2.1 Literature Review

A literature search for conceptual papers and empirical studies utilising the NGT was conducted using PubMed as the primary database; other articles were searched via pharmacy specific journals and reviewing the reference list of obtained articles. Included articles referred to, or involved the use of the NGT in the healthcare sector, and were written in English. The studies described here were chosen to reflect the diversity of nominal group procedures and analysis within healthcare (see Supplementary material Tables 1 & 2) (Allen et al. 2004; Bartunek and Murningham 1984; Carney et al. 1996; Claxton et al. 1980; Gallagher et al. 1993; Jones and Hunter 1995; Potter et al. 2004; Sink 1983; Bissell et al. 2000; Denning et al. 2012; Dewar et al. 2003; Gastelurrutia et al. 2009; Hiligsmann et al. 2013; Hutchings et al. 2012; Miller et al. 2000; Potter et al. 2003; Sanderson et al. 2012; Tully and Cantrill 2002; Vella et al. 2000; Aspinall et al. 2006; Kristofco et al. 2005). Despite the diversity in application, there was general consensus on four core NGT phases: *silent generation*, *round robin*, *clarification* and *ranking*. These four stages were used in the current study.

2.2 NGT process

We applied an adapted version of the NGT when exploratory research highlighted that many consumers are poorly informed users, with limited awareness of community pharmacy services (McMillan et al. 2014). Therefore, a pre-elicitation technique (Gonzales and Leroy 2011) was used; participants were sent an information guide describing current and potential pharmacy services prior to attending a group. To inform participants of the aim and the importance of the session, the two questions to be posed to the groups were also provided. Contrary to most nominal group questions which are problem focused (Bissell et al. 2000; Dewar et al. 2003; Hutchings et al. 2012; Miller et al. 2000; Tully and Cantrill 2002; Vella et

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al. 2000), the study questions intended to get participants to think about their ideal healthcare (question 1); and pharmacy service (question 2), i.e. *“imagine your pharmacy in the future and what service could they offer to help you meet you're your individual health goals.”*

The phrasing of these questions built on an appreciative inquiry approach (Gonzales and Leroy 2011), which can be used when participants find it challenging to articulate their preferences due to a lack of technical (e.g. pharmacy) knowledge.(McMillan et al. 2014) This approach directs participants to adopt a positive outlook, think beyond fixing problems and into the future, thereby promoting greater engagement and creativity (Gonzales and Leroy 2011). To further facilitate this approach, participants were asked to describe ‘the best of what is,’(Gonzales and Leroy 2011) in this case, a positive experience with a healthcare professional or service.

2.2.1 Introduction to the process

Our experience with 26 groups reinforced the need to train three facilitators to adopt distinct role/s; a primary facilitator to lead and provide directions to the group, one to take field notes, and the other to write participant ideas on a whiteboard (Carney et al. 1996). Upon consent, all groups were recorded, transcribed (Potter et al. 2004) and quality checked.

Like any other methodology where participant consent is required, providing an overview of the study and objective/s is essential, as well as re-inforcing the value of their individual contribution (Delbecq et al. 1975). The majority of papers (Claxton et al. 1980; Sink 1983; Gallagher et al. 1993; Carney et al. 1996; Dewar et al. 2003; Potter et al. 2003; Potter et al. 2004; Kristofco et al. 2005; Hiligsmann et al. 2013) briefly mentioned or described an introductory step that was useful prior to starting the nominal group. Three papers (Hiligsmann et al. 2013; Carney et al. 1996; Potter et al. 2004) described explaining the entire group process, or steps involved, in this stage. However, we found that it was less confusing to provide a brief study overview and then clarify the procedure as the group progressed through each stage. Although this is not explicitly stated by Delbecq et al. (1975) their worked example of the NGT process also provided in-depth facilitator instructions for each stage.

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In general, one (Bissell et al. 2000; Denning et al. 2012; Gastelurrutia et al. 2009; Hiligsmann et al. 2013; Miller et al. 2000; Sanderson et al. 2012; Tully and Cantrill 2002; Aspinall et al. 2006; Kristofco et al. 2005) or two questions (Dewar et al. 2003; Hutchings et al. 2012; Potter et al. 2003) are posed per group, with each question usually considered as a separate nominal group process. We found it useful to include two questions to provide broader contextual discussion and promote familiarity with the group process prior to tackling the primary question of interest. This also enabled us to determine the extent to which specific demands of pharmacy could be distinguished from the broader health system.

2.2.2 Silent Generation

Participants are given up to 5 (Dewar et al. 2003; Aspinall et al. 2006; Kristofco et al. 2005), 10 (Denning et al. 2012; Miller et al. 2000; Potter et al. 2004; Carney et al. 1996), 15 (Gallagher et al. 1993; Sink 1983), and 20 minutes (Claxton et al. 1980) to consider the question. During this time, participants are instructed to individually record, in silence, as many ideas as possible. Any discussion should be avoided (Delbecq et al. 1975); however, the literature varies slightly as to the role of the facilitator at this stage. Delbecq et al. (1975) recommended that facilitators model participant behaviour, i.e. to write down and share their own ideas. The majority of papers emphasised the need for the facilitator to simply maintain silence. Whilst undertaking our nominal groups, we realised that although the silent generation phase seemed straight forward, participants with low health knowledge, complex health conditions or poor literacy experienced considerable difficulties. Consequently, participants were advised that ideas need not be written down but could be simply thought about. Given that our target population was people with chronic condition/s, of which many had complex or multiple conditions, our facilitators chose to sit quietly and assist participants if they required help with writing (Tuffrey-Wijne et al. 2007). A variation on this model would be to work in small groups to generate ideas, making sure that each participant was able to contribute.

2.2.3 Round Robin

This phase can last from 15 (Denning et al. 2012) to 25 (Sink 1983) or 30 minutes (Potter et al. 2004), providing everyone the opportunity to contribute one idea at a time until all ideas are exhausted. Delbecq

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et al. (1975) advised facilitators to encourage people to add new ideas after listening to other comments, but only when it is their individual turn. Discussion during idea-presentation is generally not recommended (Delbecq et al. 1975). However, we found some discussion to be culturally appropriate for particular groups. For example, for Aboriginal and Torres Strait Islander people, discussion helped to create a safe space for participants. Therefore, the round robin and clarification phase were conducted simultaneously for some groups.

There is consensus in the literature that ideas should be recorded verbatim on a whiteboard or flipchart for participants to see. However, there are differences of opinion with respect to the facilitator's role at this stage. For instance, Delbecq et al. (1975) suggested that the facilitator contribute ideas in the same way as participants. We chose not to do this, fearing that it may bias participant responses.

2.2.4 Clarification

This phase ensures that participants understand the meaning of each idea, thus enabling individuals to make an informed decision when ranking their priorities. The ambiguity about this phase relates to whether ideas can be grouped or eliminated. Some papers document the grouping of duplicate (Carney et al. 1996) or similar ideas (Dewar et al. 2003; Potter et al. 2004; Jones and Hunter 1995; Hutchings et al. 2012; Sink 1983), the inclusion (Gallagher et al. 1993; Potter et al. 2004) or deletion of items or duplications (Claxton et al. 1980; Hutchings et al. 2012; Sink 1983), or both, i.e. inclusion and exclusion of items (Aspinal et al. 2006), or all three, i.e. inclusion, exclusion and grouping of items (Bissell et al. 2000). Other studies discussed the alteration of ideas (Vella et al. 2000; Allen et al. 2004), or generation of themes (Dening et al. 2012). The study by Sanderson et al. (2012) did not involve a clarification phase, but allowed participants to present a rationale for their chosen priority. Another study asked groups to pass their suggested items to other groups for feedback, which enabled participants to revise and regroup items (Bartunek and Murnighan 1984).

Since grouping similar ideas and removing duplicates can be more complicated (Sink 1983), the literature indicates that this phase should be allocated the most time, i.e. 20 to 30 minutes (Sink 1983; Gallagher et

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al. 1993). According to Delbecq et al. (1975), the facilitator's role in this stage should be to pace the group to avoid argument, and ensure that all ideas are discussed. However, we found that this phase needed to be adapted if there was participant confusion, and that amalgamating similar ideas was contingent on group consensus. Furthermore, not all ideas on the board needed to be grouped, even if they appear to be similar. Carney et al. (1996) suggested that attempts to condense ideas into broader themes should be resisted. In our study, the clarification phase was difficult, but resulted in a more succinct list of ideas for easier participant ranking. We also found that the primary facilitator needed to clarify to participants that although they may not agree with a particular idea, the purpose of this phase was only to clarify the ideas; the next stage would allow participants to vote on their preferred ideas. In our study, participants appreciated the use of one large whiteboard where one half of the board listed the round robin (original) ideas, and the other half contained the clarified ideas in a different coloured font.

2.2.5 Ranking

There are a variety of ways to conduct the ranking phase of the NGT. For example, participants could rank a number of ideas in terms of importance (Carney et al. 1996; Denning et al. 2012; Miller et al. 2000; Dewar et al. 2003; Potter et al. 2004; Sink 1983; Tully and Cantrill 2002; Gastelurrutia et al. 2009; Drennan et al. 2007), or could use a two-step process comprising secondary ranking (Gallagher et al. 1993; Hiligsmann et al. 2013; Allen et al. 2004; Bartunek and Murningham 1984; Hutchings et al. 2012; Jones and Hunter 1995; Claxton et al. 1980; Sanderson et al. 2012; Aspinal et al. 2006; Kristofco et al. 2005). The latter approach extends first ranking discussions to include either individual re-ranking (Hiligsmann et al. 2013; Claxton et al. 1980; Hutchings et al. 2012; Jones and Hunter 1995; Kristofco et al. 2005; Aspinal et al. 2006), priority ranking, i.e. 0-100 (Gallagher et al. 1993), re-ranking of a secondary questionnaire, i.e. if a questionnaire was used initially to obtain priorities (Allen et al. 2004), or public voting (Bartunek and Murningham 1984). Delbecq et al. (1975) suggested that public voting could instigate social pressure to conform to the norm, so proposed a more private voting process. Because of time constraints in our study (our groups took up to three hours for consumers), we decided that a secondary ranking process by participants was not feasible.

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Participants are asked to select and then rank their top ideas, which can range from 5 (Carney et al. 1996; Denning et al. 2012; Sanderson et al. 2012; Drennan et al. 2007; Dewar et al. 2003; Miller et al. 2000), 8 (Claxton et al. 1980) and 10 or more options (Gallagher et al. 1993; Hiligsmann et al. 2013). This phase can take up to 10 minutes (Denning et al. 2012). Although our original intent was to have participants' rank 10 items, pilot group 1 participants indicated that this process was too difficult. Pilot group 2 confirmed that ranking five items was more manageable. Some participants still expressed difficulty in choosing only five items because they thought all ideas were important. Thus, it was essential for facilitators to explain that all ideas were considered important and would be taken into consideration. Participants were first asked to individually select their top five ideas from the entire set of generated ideas. They were then asked to rank those five ideas, with five points allocated to their top priority and one point to their lowest priority. To avoid errors, we provided participants with a ranking sheet for recording their votes. These unidentifiable ranking sheets allowed participants a relatively private method of allocating their votes. The ranking process was completed individually, without group discussion.

In the initial groups, some participants allocated the same points for more than one idea, and we found that explaining the ranking process step-by-step and giving them sufficient time to vote minimised these mistakes. If further instruction was required, we provided similar advice given by Delbecq et al. (1975): *"From your chosen top five, please allocate a mark of 5 for the one most important to you"* (followed by time to vote). We then instructed them: *"From the four choices remaining, please allocate a mark of 1 for the item least important to you,"* (followed by time to vote) and so on. One facilitator quality checked the ranking sheets as they were handed in.

2.3 Data management

There was minimal reference to data management in the NGT literature. As our study involved a large number of groups, data management was particularly important to ensure a streamlined analysis process. We utilised Microsoft Office® Excel (v14) spread sheets to record the scores allocated by each participant and the ranked priorities for each group, i.e. the raw data. We calculated the sum of the scores for each

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idea, and noted whether the idea was in the top five, i.e. its ranked priority (Table 1). This allowed for immediate reporting back of the results to participants.

3.0 Analysis and Results

Data analysis was ongoing and an overview of the process used in our study is provided in Figure 1. This involved i) analysis of the raw data, ii) thematic analysis of the raw data, iii) analysis of secondary coded data, and iv) qualitative analysis. All stages will be described in further detail below.

3.1 Analysis of the raw data

Initial review of the raw data (i.e. the original participant data) from the Excel spread sheets identified any anomalies or nuances within the data. For instance, in pilot group 2, two ideas (*24-hour access* and *health information*) obtained the same score, i.e. a score of 14 (Table 1). This process is known as the summing of votes (Dening et al. 2012; Sanderson et al. 2012; Tully and Cantrill 2002) or the strength of vote score (Sink 1983). The above result was also reflected by the relative importance (Gastelurrutia et al. 2009), i.e. the proportion (%) of all scores in the top five, which was calculated using the following equation: (score achieved for the item)/(maximum possible score) x 100. Both of these ideas had the same relative importance, and subsequently, the same ranked priority list obtained by the sum of scores (Table 1). This situation raised the question as to how similarly ranked priorities should be handled. In this case, the number of votes (Sink 1983), i.e. frequency, or the number of times a particular idea was voted for (Miller et al. 2000; Dewar et al. 2003) by participants was useful; a high score does not necessarily reflect that an idea was frequently chosen by participants to be in their top five priorities. More participants, i.e. five out of six participants, voted for *health information* rather than *24-hour access*, i.e. four out of six participants, therefore making it a slightly greater priority (Table 1). Subsequently, the raw data was organised with respect to the sum (or the relative importance) and frequency of votes, meaning that if two items had an equal score, then the item with the highest frequency of votes was prioritised first. However, our 26 nominal groups generated a large number of ideas (question 1 = 203 ideas; question 2 = 276 ideas), and ranked priorities (question 1 = 83 priorities; question 2 = 130 priorities), posing a challenge in terms of how best to compare and present this large data set.

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3.2 Thematic analysis of the raw data

Researchers have thematically analysed the raw data from groups of ten or more (Dewar et al. 2003; Aspinall et al. 2006). Aspinall et al. (2006) indicated that this was done ‘to facilitate cross-group comparison of data.’ It was difficult to compare raw data across the groups in our study because of the diversity in group composition and approach to the task. Each group generated multiple ideas, and grouped those ideas differently in the clarification phase. For example, the ideas related to ‘Access’ were described in numerous ways, including: *drive-thru*, *less restricted medication access*, *24-hour pharmacy environment*, *more on duty-pharmacists* and *accessibility*. Furthermore, some ideas may not have been grouped if there was no agreement between participants during the clarification process. Alternatively, if participants felt that one idea fitted across numerous clusters, it was not grouped. Thus, to manage this diversity, a thematic framework was developed.

Thematic analysis has been conducted in many different ways in the NGT literature. Aspinall et al. (2006) described a process by which two researchers independently grouped similar ideas and then met to agree on the corresponding themes. Hutchings et al. (2012) followed a process similar to Aspinall et al. (2006), but a third researcher amalgamated the themes produced by the first two researchers. Dewar et al. described a more complex process whereby four researchers individually developed a classification framework, which was then standardised via discussions to reach consensus (2003). The standardised framework was applied to the nominal group data by two researchers, and checked by a third researcher (Dewar et al. 2003).

We adapted the more complex process (Dewar et al. 2003) further. One researcher independently reviewed the priorities for all 26 nominal groups using the raw data, and generated an initial framework which was reviewed and clarified by another researcher. Further discussion resulted in 23 agreed themes. Four researchers deliberated over the 23 themes in order to develop higher order themes and subthemes, i.e. a secondary coding framework. For quality control purposes, a workshop was held with the entire research team to review the secondary coding framework, which resulted in 12 over-arching themes. This

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final framework was applied to the raw nominal group data by four independent researchers, who then met to discuss and reach consensus for the secondary coded data, i.e. themes for all raw data. Subsequently, additional analysis of the secondary coded data was conducted to allow comparative analysis between groups.

3.3 Analysis of secondary coded data

To address the challenges of equal scores as described above, and the ambiguity surrounding the NGT data analysis process, we decided to trial two analysis processes with the secondary coded data; analysis of only the top five themes (option A), and analysis of all the themes generated by the group, i.e. beyond the top five themes (option B). These methods were chosen to be able to compare across groups rather than as one complete data-set (i.e. combining the data for all 26 groups).

3.3.1 Analysis of the top five themes only (option A)

Summing the votes allocated to each idea is the most common way to analyse and describe nominal group data (Hilgsmann et al. 2013; Dening et al. 2012; Sanderson et al. 2012; Miller et al. 2000; Dewar et al. 2003; Tully and Cantrill 2002). However, given the number of groups included in our study, variation in group size and the diversity of the themes identified during discussions, it was difficult to compare the relative importance of particular themes across groups.

For this method of analysis, the overall priority score for each theme was calculated, i.e. the top priority received five points, the second received four points etc. However, as can be seen from the pilot data (Table 2), themes can arise more than once in a group. For example, 'Access' was a higher order theme that encompassed the following two ideas that were raised in the pilot group; *24-hour access* and *environment*. As 'Access' was the third (equal to 'Consumer information or education') and fifth priority for this group, this provided an overall priority score of four (i.e. three points for third and one point for fifth priority). This resulted in the following priority list in descending order: 'Continuity and coordination of care', 'Quality of service delivery' and 'Access' as equal second priority and 'Consumer information or education' as fourth priority (Table 2).

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Next, the voting frequency for the top five themes was calculated to determine how many times a particular theme was voted for, and subsequently, how popular the idea was amongst participants. This style of analysis accommodated the fact that one participant could have voted for two different ideas which were then coded into the same higher order theme, meaning it appeared twice. For example, four participants voted for *24-hour access* and four voted for *environment*, and both were coded into the higher order theme 'Access.' Therefore, 'Access' as the secondary code was voted for eight times compared to 'Quality of service delivery' which was voted for four times (Table 2). When considering this additional information, the priority list changed again: 'Continuity and coordination of care,' 'Access,' 'Quality of service delivery,' and 'Consumer education and information.' The voting frequency was useful to differentiate between the two equal priorities seen via the sum of votes (i.e. 'Quality of service delivery' and 'Access').

3.3.2 Analysis of all the themes generated by the group (option B)

The second analysis process that we trialed focused on all the results generated by the group; beyond the original top five priorities. The total score for each theme generated by the group was calculated, i.e. the sum of votes, resulting in the following priority list: 'Continuity and coordination of care,' 'Access,' 'Quality of service delivery,' 'Consumer information or education' and 'Affordability' (Table 2). The same priority list was achieved by calculating the relative importance of the themes. As there were no similar scores or proportions, there was no need to review the number of votes.

Therefore, there was a difference in priority lists between the two analysis methods for the secondary coded data. Option B, reviewing all data resulted in another theme ('Affordability') included into the priority list. This raises the question of which secondary analysis method best represents the data? We believe that the secondary coding of all themes (option B) is better than secondary coding of the top five themes only by awarding a score of five to the top scoring theme, four to the next highest score and so on (option A). Option A reflects a practical approach, yet it only considers high scoring ideas and not when related ideas (i.e. coded under the same theme) appear elsewhere in group preferences. Option B accounts

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for when a common theme was considered a priority by any participant, even though they may prioritise specific aspects of that theme (e.g. *environment* vs. *24-hour access*). This analysis approach reflects the predominance of a theme more accurately. Although calculating the relative importance provided the same ranked list as summing the votes in option B, it can be used to demonstrate how important a theme is within a group (i.e. the total value placed on that theme by participants).

The median, inter-quartile range (IQR) (Hutchings et al. 2012; Aspinal et al. 2006), mean and standard deviation of votes (Kristofco et al. 2005) were also calculated for the pilot group data. However, this descriptive data cannot be used to compare preferences across groups and we have not presented it here.

A method to identify the overall priority list when combining data from multiple groups into one complete sample has been described elsewhere (Van Breda A.D. 2005). Van Breda (2005) considered the average scores for the raw data, the average scores for the themes and the frequency of themes (i.e. how many times a theme appeared in the top five and how often an idea was raised and coded under the same theme). Our paper will not go into detail using Van Breda's (2005) recommendations as our analysis was focused on group comparisons to reveal nuances in priorities across a diverse sample. However, when comparing our method of analysis to Van Breda's (2005) method for individual groups, the same themes were identified in the top five, although in slightly different priority orders; we conducted this quality check for three of our groups. Therefore, we suggest that Van Breda's (2005) more complex method be used as a sensitivity analysis or if analysis of combined data is an objective.

3.4 Qualitative analysis

Transcripts were also analysed to provide additional context, such as underlying rationale for individual ideas and related discussion undertaken in the clarification phase. The researchers read over the transcripts and applied the secondary coding framework, i.e. the 12 overarching themes and their subthemes, using NVivo 10®.

4.0 Discussion and recommendations

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The NGT is a useful method for eliciting priorities in healthcare. However, our study demonstrates that conclusions drawn from the NGT about priorities may change slightly depending on the method of analysis used. For researchers conducting multiple nominal groups who wish to compare *across* groups, we recommend using the secondary coding and subsequent analysis process for all themes (option B) as explained in this paper. Otherwise, if wanting to combine the entire data set into one group, then Van Breda's (2005) process is a possible alternative.

Nominal group analysis should consider themes across the entire group rather than restrict this to the top five priorities. This allows researchers to look at the importance of a theme in the context of the total possible score for the group. It also allows exploration of nuances in preferences between different aspects of the same construct (e.g. 'Access'). It is conceivable that this approach would inform policy makers on the themes / issues that are of particular importance whilst providing insight that allows targeted improvement (e.g. *24-hour access*). When analysing data, if themes have equal relative importance, the voting frequency then needs to be considered. This latter process will not affect those priorities that are clearly differentiated. Furthermore, consideration of not just the themes that were highly valued with respect to score, but those valued with respect to a higher frequency of votes, may provide a more true reflection of priorities.

Qualitative data should be used to support and contextualise the justification of priorities identified through the quantitative analysis, and also inform targeted policy change. For NGT studies involving multiple and diverse groups, secondary coding of the priorities according to higher-order themes can assist with cross-group analysis. Furthermore, our coding framework, whilst needed to conduct across group analyses, changed group priorities; there were differences between raw and secondary coded priority lists in our case example. It is therefore important that researchers develop a rigorous process with respect to thematic analysis in order to remain true to the data and therefore, participant views.

With respect to the group process, we found that this can (and needs to) be adapted according to participant needs, without comprising research integrity. For example, facilitators may need to provide

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further assistance to participants with lower literacy levels or health conditions, thus ensuring that their voices are heard. Furthermore, the creation of a safe space that is culturally appropriate needs to be supported. We also recommend having a minimum of three facilitators for group and data management purposes, and a maximum of seven participants per group. This group size makes the process easier for facilitators to manage or if participants need extra assistance.

The analysis of nominal groups is complex, and researchers need to reflect on the analysis strategies to employ in order to truly reflect participant priorities and reveal subtle nuances in these priorities that can inform effective utilisation of health resource. Only then can healthcare professionals, organisations and policy makers obtain a full understanding of the needs of health consumers.

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Ethics approval

Ethics approval was obtained from Griffith University Human Research Ethics Committee (PHM/12/11/HREC). Informed consent was obtained from all participants who were involved in the nominal groups.

Conflicts of interest

None.

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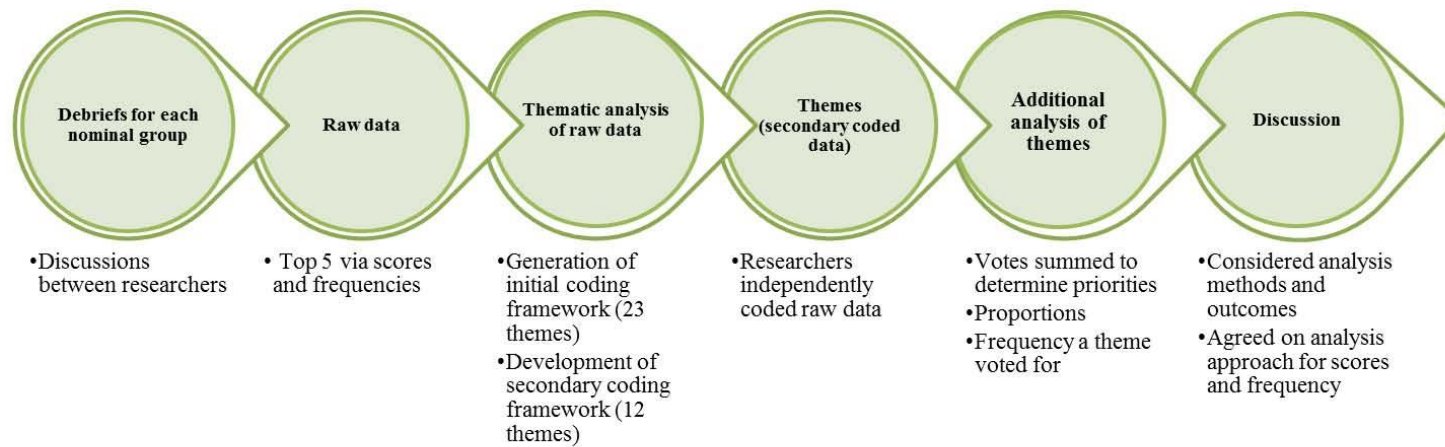


Figure 1: The study (quantitative) analysis process

Table 2: Secondary analysis of pilot group data

| | idea) | | | | | | | idea) | | & frequency) | | |
|---|-------|---|---|---|---|---|----|-------|------|-----------------|---|----|
| | 1 | 2 | 3 | 4 | 5 | 6 | | | | | | |
| Care coordination (e.g. referrals) | 5 | 5 | 5 | 4 | 5 | | 24 | #1 | 26.7 | #1 | 5 | #1 |
| Professional competence (e.g. don't give generics) | 4 | 2 | 4 | | | 5 | 15 | #2 | 16.7 | #2 | 4 | #2 |
| Health information | 2 | 4 | | 3 | 3 | 2 | 14 | #3 | 15.6 | #3 | 5 | #3 |
| 24-hour access | | | 3 | 5 | 2 | 4 | 14 | #3 | 15.6 | #3 | 4 | #4 |
| Environment (e.g. private space, friendly service, chairs) | 1 | | 1 | | 4 | 1 | 7 | #5 | 7.8 | #5 | 4 | #5 |
| Consistent medication pricing | 3 | | | | | 3 | 6 | | | | 2 | |
| Follow up (e.g. Skype, email, phone) | | 3 | 2 | | | | 5 | | | | 2 | |
| Discount cards | | | | 2 | | | 2 | | | | 1 | |
| Smoking support | | | | | 1 | | 1 | | | | 1 | |
| Records of people | | | | 1 | | | 1 | | | | 1 | |
| Complaints/compliments box | | 1 | | | | | 1 | | | | 1 | |
| Walking groups | | | | | | | 0 | | | | 0 | |

*Relative importance = [(score for the item) ÷ (maximum points for the group i.e. participant number x 15 points) x 100]

| Secondary coding: top five themes only (option A) | | | | | | Secondary coding: all themes in the group (option B) | | | | | |
|---|------------------------------|-----------------------------|--|--------------------|---|--|--|------------------|-------------------------------|--|---|
| Overarching theme (raw idea) | Sum of scores (raw) | Freq. of voting (raw) | Summing by votes ⁺ (priority score for top 5) | Ranked priority | Ranked priority (scores & freq.) | Sum of scores (for all themes) | Ranked priority (via scores for themes) | (%) [*] | Ranked priority (via %) | Freq. of voting (for all themes) | Ranked priority (scores & freq.) |
| Continuity & coordination of care (<i>Care coordination</i>) | 24 | 5 | 5 | #1 | #1 | 30 | #1 | 33.3 | #1 | 8 | #1 |
| Quality of service delivery (<i>Professional competence</i>) | 15 | 4 | 4 | #2 | #3 | 16 | #3 | 17.8 | #3 | 5 | #3 |
| Consumer information or education (<i>Health information</i>) | 14 | 5 | 3 | #4 | #4 | 14 | #4 | 15.6 | #4 | 5 | #4 |
| Access (<i>24-hour access</i>) | 14 | 4 | 3 | #2 | #2 | 21 | #2 | 23.3 | #2 | 8 | #2 |
| Access (<i>Environment</i>) | 7 | 4 | 1 | # | | - | - | - | - | | |
| Affordable (<i>Consistent medication pricing</i>) | 6 | 2 | | | | 8 | #5 | 8.9 | #5 | 3 | #5 |
| Continuity & coordination of care (<i>Follow up</i>) | 5 | 2 | | | | - | | - | | | |
| Affordable (<i>Discount cards</i>) | 2 | 1 | | | | - | | - | | | |
| Health promotion (<i>Smoking support</i>) | 1 | 1 | | | | 1 | | | | 1 | |
| Continuity & coordination of care (<i>Records of people</i>) | 1 | 1 | | | | - | | - | | | |
| Quality of service delivery (<i>Complaints/compliments box</i>) | 1 | 1 | | | | - | | - | | | |
| Health promotion (<i>Walking groups</i>) | 0 | 0 | | | | 0 | | 0 | | | |

+Summing by votes: Points allocated to each theme as per priority list via raw scores (i.e. top priority = 5 points, fifth priority = 1 point). # There is no fifth priority as access arose as a theme twice in the top 5 (i.e. joint third priority points + fifth priority points = 4).

*Relative importance = [(total score for the theme) ÷ (maximum points for the group i.e. participant number x 15 points) x 100]

Supplementary Table 1: Description of conceptual papers and studies utilizing the nominal group technique.

| Author (Yr.) | Description of conceptual paper | Additional NGT information | Recommended or actual ranking process |
|-------------------------------|--|---|---|
| Allen <i>et al</i> (2004) | Description of NGT stages; adapted NGT; case example. | Suggested: 9-12 participants. Qualitative survey sent to a target group in a different region; responses categorized into themes to generate Likert questionnaire statements; postal questionnaire to NGT participants; analysis and revised questionnaire to remove consensus statements; NGT participants given a second, individualized questionnaire with their original scores and median group scores; group discussion and individualized re-scoring; post-group analysis to determine degree of consensus. | 2 rounds: Individual ranking of initial questionnaire; individual re-scoring of second questionnaire. |
| Bartunek & Murnighan (1984) | Description of NGT stages; adapted NGT process. | Introduction to process; presentation of problem; silent generation; round robin; discussion (clarification – categorization, discussion, new ideas and discussion); reflection; straw vote and discussion; public vote (to increase acceptance). Clarification process: groups wrote suggested ideas down, passed it to other groups who wrote additional questions or comments, groups revised list via clarification. | 2 rounds: Anonymous rating with four categories (e.g. absolutely no, absolutely yes). Ratings/ comments summarized and fed back; group discussion and public voting of ratings. |
| Carney <i>et al</i> (1996) | Rationale for using NGT; description of stages; case example. | 3 separate groups (5-8 per group). | 1 round: Chose and ranked five ideas (1=most important; 5=least important) |
| Claxton <i>et al</i> (1980) | Description of NGT stages; case example, comparison with surveys and focus groups. | Round robin phase: participants can briefly explain their point to ensure clear meaning. Clarification phase: ensure participants understand responses and eliminate duplicate ideas. | 1 or 2 rounds: participants ranked top eight problems. Second round is recommended if a reasonable level of consensus is required or there is high variability. |
| Gallagher <i>et al</i> (1993) | Description of NGT stages; Comparison with focus and brainstorming groups; case example. | Separate consumer and health professional (mixed professionals) groups. | 2 rounds: Individuals ranked top 10 items; group discussion; individuals re-rank and allocate value towards each ten items (0-100; 100 being most important item). |

| | | | |
|----------------------------|---|---|--|
| Jones & Hunter (1995) | Defines consensus and consensus methods; describes NGT and Delphi techniques and associated methodological issues. | Suggested: 9-12 participants. Stated that consensus does not mean that the correct answer has been found, the NGT is a method for identifying common opinion and areas of disagreement. | 2 rounds: Individuals rank each idea; group discussion; individuals re-rank. |
| Potter <i>et al</i> (2004) | Compares NGT, focus and brainstorming groups; issues to consider; description of NGT stages including analysis; review of NGT research and application in health. | Suggested: 5-9 participants. | 2 rounds: Individuals chose top ten items (1=least important; 10=most important); value allocated (0-100; 100 being most important item) |
| Sink <i>et al</i> (1983) | Description of NGT stages; case examples. | Discussion of group consensus after individual voting and ranking. If there are difficulties in clarification, allow individuals to note down what they perceive as overlapping ideas and vote for the idea/point they feel is most representative. | 1 round: Rank ideas (1=least important; highest number=most important). Number to rank depends on number of ideas: 15 ideas = 5 votes; 20-30 = 7 votes; >30 = 9 votes. |

| Author (Yr.) | Question/s or task of study | Additional NGT information and recommendations | Ranking/ Consensus process |
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| Bissell <i>et al</i> (2000) | How would you assess whether a consultation between pharmacy staff and a consumer was in/appropriate? | 1 group: experts from practice, academic or policy areas of community pharmacy ($n=8$). Information pack included: study purpose, transcripts of advice-giving from community pharmacies (previous stage) and readings on appropriateness measurements. Discussion: inclusion or exclusion of an item decided via majority of hands. Participants sent criteria for further consideration and to comment on suitability one week after focus group. | 1 round: Individuals asked to prioritize, however felt this was impossible given the degree of inter-dependence between categories. A unanimous group decision led to assigning similar weight to each criterion. |
| Dening <i>et al</i> (2012) | To consider what their preferences for care would be if they were approaching death. | 3 groups: people with dementia ($n=5$), carers of people with dementia ($n=6$), people with dementia and their carers ($n=3$ dyads). Round robin phase involved two separate parts: Discussion (including clarification) and further generation of ideas. | 1 round: Individuals ranked top five items (1=most important; 5=least important). |

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| Dewar <i>et al</i> (2003) | What problems do you experience when dealing with your chronic pain? What would you like to see happen to better meet your needs as a person in pain? | Advertised as a needs assessment public forum with educational workshop on pain management strategies to encourage participation. 10 groups ($n=3-7$ per group). <i>NGT can be used to develop questions for more in-depth surveys.</i> | 1 round: Individuals ranked top five items. |
| Gastelurrutia <i>et al</i> (2009) | To identify facilitators for practice change in Spanish Community Pharmacies. | Part of the study involved 2 NGTs: community pharmacists ($n=7$) and strategists ($n=7$). Scores presented to participants to verify results were a true reflection of their views. | 1 round: ranking of the facilitators in terms of importance (1=low, 5=high) and applicability (1=low, 10=high). |
| Hiligsmann <i>et al</i> (2013) | To determine the most important attributes for osteoporosis drug therapy | 5 groups of people with osteoporosis or had a recent fracture requiring osteoporosis medication ($n=26$; 4-8 per group). 12 attributes randomly divided into five sets and each of the groups received a different ordering of these sets. No silent generation phase as attributes were identified in the literature, however participants could include any missing attribute in first ranking. NGT sessions conducted until rank order of the most important attributes did not change any further. <i>Clear description and explanation of any attribute is required. Avoid ranking too many attributes as this could place substantial cognitive burden on participants (e.g. rank their 5 most important attributes).</i> | 2 rounds: Individuals rank attributes (1=most important, 12=least important). Group review of scoring and individual opportunity to re-rank. |
| Hutchings <i>et al</i> (2012) | What are the positive and negative exemplars of patient-centred professionalism within community nursing? | 2 NGTs: workshop ($n=34$) and a mixed-group forum event ($n=17$). Participants: members of the public, stakeholders, community nurses (separate groups). Forum participants asked to rank the themes (that they viewed as important) from the first workshop prior to attending the forum. Forum discussion then individual re-ranking to develop a final consensus ranked list. <i>Approach can be applied to a mixed group of individuals (e.g. forum)</i> | 1 round (initial NGT): Individual ranking of exemplars (1=most important, subsequent ranks of diminishing importance). 2 rounds (mixed-group forum): Individual ranking of themes in order of importance (1=most important) prior to the forum. Re-ranking of themes at forum. |

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| Miller <i>et al</i> (2000) | What issues or concerns have you had to deal with since diagnosis? What issues or concerns have you had to deal with since you learned your family member had diabetes? | 2 groups: People with diabetes ($n=13$) and caregivers ($n=8$). The two groups were described as being in the same NGT meeting. <i>At least two groups of 6-12 people should be involved. Conduct separate groups based on gender, race and age.</i> | 1 round: Individuals ranked top five items (1=least important; 5=most important). |
| Potter <i>et al</i> (2003) | The qualities of a 'good' physiotherapist, and the physiotherapy experience. | Piloted with 5 patient volunteers. 6 groups with 3-5 current and former physiotherapy patients ($n=26$). | 1 round: voting and ranking of ideas. |
| Sanderson <i>et al</i> (2012) | What results would you want from a drug treatment when your rheumatoid arthritis is bad? | 5 groups ($n=26$ patients with rheumatoid arthritis). Single and mixed gender groups. Groups prioritised and rated outcomes from a previous study. Participants asked to firstly rate the importance of 63 outcomes (not important, important and very important). Re-rated the very important outcomes (very important and most important). The most important outcomes were discussed in a round robin followed by the last rating and ranking. | 3 rounds: individually rated the importance of the outcomes twice to identify the most important ones. Individuals then ranked top five outcomes. Survey then conducted. |
| Tully & Cantrill (2002) | How can we [as pharmacists] assess inappropriate drug therapy of individual patients that is responsive to pharmaceutical care? | 1 group: hospital pharmacists ($n=2$), community pharmacists ($n=4$), academics/researchers ($n=3$) and pharmacologist ($n=1$). Provided participants six key articles about appropriate prescribing to ensure a similar conceptual basis. Discussion with participants of the issues surrounding pharmaceutical care to develop research question. | 1 round: individuals had to consider the importance and operationalisability of the items. Consensus at >70% agreement. |
| Vella <i>et al</i> (2000) | Many questions relating to various topics e.g. should relatives be present at resuscitation attempts? Does the presence of an advanced nurse practitioner affect outcomes etc. | 1 group: 10 doctors, 2 nurses from different geographic locations and roles ($n=12$). First-round questionnaire: rate level of support for 100 topics. Likert scale (1=no support, 5=moderate support, 9=strong support). Second round questionnaire (NGT) – personalized with own ratings and distribution of ratings from 1st questionnaire. Opportunity to re-consider initial ratings. Questionnaire sent to other professionals not previously involved to assess representativeness of NGT's views. | No pressure to achieve consensus. |

Supplementary Table 2: Types of analysis for NGT

| Methodology | Description of the method | Further description of analysis | Examples | Presentation of results |
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| | <i>Summing by votes (sum of votes per item)</i> | <p>Identification of consensus (any score >70%).</p> <p>Collation of group scores to identify overall priority.</p> <p>Calculated the percentage of maximum possible score.</p> <p>Proportions/aggregated score (score x100/maximum possible score).</p> | <p>Tully and Cantrill (2002)</p> <p>Denning <i>et al</i> (2012)</p> <p>Sanderson <i>et al</i> (2011)</p> <p>Gastelurrutia <i>et al</i> (2009)</p> | <ul style="list-style-type: none"> Described number of ideas (before and after clarification) and themes. Table: themes, items, sum of votes and if consensus was reached. Bar graphs: sum of votes for each item for each group and overall (in rank order). Described number of items (before and after ranking), and top five items prioritised overall (%). Tables: aggregated scores for each item from each group (ranked by importance and then by applicability). Priority matrices: compare importance and applicability per group. |
| | <i>Summing by votes and impact of NGT on ranking</i> | Impact of NGT on ranking (at individual and group level). | Hilgsmann <i>et al</i> (2013) | <ul style="list-style-type: none"> Bar graph: number of groups where the attribute was ranked in the top five. Table: initial, final and average rankings per each attribute for all groups. Described the number of participants who changed ranking after NGT, and the average absolute change between rankings (also shown as a bar graph). |
| | <i>Summing by votes (ranking by score and/or frequency)</i> | <p>Frequency of actual scores per item shown (e.g. documented each participant vote).</p> <p>Researchers developed a standardised classification system, group responses were re-classified.</p> | <p>Miller <i>et al</i> (2000)</p> <p>Dewar <i>et al</i> (2003)</p> | <ul style="list-style-type: none"> Described number of themes generated per group. Tables: votes accorded per item (i.e. ratings by participants) and corresponding sum of votes per group. Organised in order of priority (by sum). Tables: Overall, top priorities and solutions for groups (by frequency). |
| | <i>Summing by votes, median and range</i> | Calculated number of times an item was ranked first to fifth (i.e. in top five priorities). | Aspinal <i>et al</i> (2006) | <ul style="list-style-type: none"> Tables: top themes for each group with associated score, median, range and theme; themes given the top ranking by participants (demonstrated by frequency of vote). |

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| | <i>Median and Interquartile ranges (IQR)</i> | Consensus ranked list based on the final median ranks. | Hutchings <i>et al</i> (2012) | <ul style="list-style-type: none"> • Tables: Lists the ideas generated from each group; list of final themes, median ranked thematic lists prior and after a forum event (including IQR). |
| | <i>Mean and standard deviation (SD)</i> | Also showed frequency of vote. | Kristofco <i>et al</i> (2005) | <ul style="list-style-type: none"> • Described the number of individual items, the items endorsed as the most important. • Table: mean, SD, and frequency of votes for each rating. |
| Qualitative | <i>Descriptive</i> | Listed ideas (not themes) generated by groups. | Miller <i>et al</i> (2000) | <ul style="list-style-type: none"> • Table: listed the remaining ideas that were not prioritised. • No quotes provided. |
| | | Further information on priorities. | Dewar <i>et al</i> (2003) | <ul style="list-style-type: none"> • Quotes: used to exemplify priorities. |
| | | Listed and described themes. | Bissell <i>et al</i> (2000) | <ul style="list-style-type: none"> • Described number of individual items; number of criteria (themes) initially produced then reduced following discussion. |
| | <i>Content or thematic analysis</i> | Content analysis to support and confirm content validity. | Dening <i>et al</i> (2012) | <ul style="list-style-type: none"> • Table: description of each criterion (theme) after validity. • Described emergent themes using quotes and listed the priorities for each group. |
| | | Grounded Theory coding paradigm. | Sanderson <i>et al</i> (2011) | <ul style="list-style-type: none"> • Themes and quotes used to provide insight into prioritization. |
| | | Themes with examples. | Aspinal <i>et al</i> 2006 | <ul style="list-style-type: none"> • Table: list of themes, description of theme and representative quotes. |
| | | Researchers developed a final set of common themes. | Hutchings <i>et al</i> (2012) | <ul style="list-style-type: none"> • Table: list of final themes and examples. |
| | <i>Analyst triangulation</i> | Conducted by two independent researchers. | Potter <i>et al</i> (2003) | <ul style="list-style-type: none"> • Tables: lists ideas provided by 3 or more groups; ideas provided by 1-2 groups (organized according to themes); quotes representing ideas |