"You've got to breathe, you know" - asthma patients and carers' perceptions around purchase and use of asthma preventer medicines

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Conclusions: Patient barriers to adherence with asthma preventer medicines including cost are ongoing. Healthcare professionals need to encourage empathic discussion with patients about cost issues.

Implications for public health: Asthma patients and carers could benefit from greater involvement and respect within shared decision-making. Healthcare professionals should be aware that cost may be a barrier for patient adherence, and provided with information about the relative costs of guideline-recommended asthma medicines. Patients and healthcare professionals need education around the efficacy of ICS-alone treatment and the rationale behind co-payments, for initiatives around quality use of medicines to succeed.

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Key words: asthma, medicine costs, shared decision making

Asthma is a chronic condition affecting 11% of Australian adults and children.1 In addition to day-to-day symptoms, asthma carries the risk of serious flare-ups (also called attacks or exacerbations) that may be life-threatening. Guidelines therefore recommend that most patients with asthma should be prescribed regular inhaled corticosteroids (ICS), as well as a reliever medicine for as-needed use.2,3 Australian guidelines4 endorse a stepped approach to treatment, including regular ‘preventer’ treatment with low-dose ICS-alone for most adult patients and low-dose ICS or leukotriene receptor antagonist (LTRA) for children. However, in Australia, most patients are prescribed a combination of ICS/long-acting beta2-agonist (LABA) rather than ICS-alone. Of all the individuals who had any ICS dispensed in 2013, 81.4% were dispensed ICS/LABA.4

Despite higher adherence to ICS being associated with lower asthma mortality, fewer emergency department visits and hospital admissions,5,6 poor adherence is extremely common and is associated with greater risk of severe exacerbations.7 Analysis of Australian dispensing records has shown that among people aged ≥65 years who received any ICS-containing medicine in 2013 only 30% could have used it regularly (≥7 prescriptions filled annually).8 Rates were even lower for people aged 35–64 (15.8%) and 15–34 years (7.3%). A nationally-representative self-report survey of adults with asthma also confirmed poor adherence to asthma medicines.8

Multiple factors are acknowledged to affect medicine adherence in asthma, including perceived necessity of medicines, ease of use, concerns about and experience of side effects, forgetting and busy lifestyles.9,10 Out-of-pocket costs for patients are also known to affect medicine adherence and management decisions in asthma,11,12 even after adjustment for socioeconomic status.13

In Australia, all ICS-containing asthma medicines are subsidised through the Pharmaceutical Benefits Scheme (PBS), with

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the current maximum patient co-payment per dispensed prescription being $40.30 for general beneficiaries and $6.50 for concession card holders (see Box 1). The monthly out-of-pocket cost for ICS-alone can be as little as 15% of that of ICS/LABA preventers but recent qualitative research suggests that Australian GPs are not aware of the cost of different treatment options and few discuss cost of medicines with their patients.

Little is known about the patient’s perspective on asthma preventer choices and on the effect of cost on medicine choice or adherence. This study aimed, through qualitative interviews with adults with asthma and carers of children with asthma, to explore factors that influence patients’ choice and use of preventer medicines. In addition, the study explored the feasibility and acceptability to patients of financial incentives to encourage use of low-dose ICS-alone rather than ICS/LABA combination medicines in line with guideline recommendations.

**Methods**

**Study design**

Semi-structured telephone or face-to-face interviews were conducted with a purposive sample of adults with asthma and carers of children with asthma. Two investigators conducted the interviews using a purpose-designed guide (see Supplementary File 1), which was informed by expert opinion and empirical research in the fields of asthma and health economics. Broadly, interviews canvassed patients’ and carers’ understanding, choices and use of asthma medicines; factors affecting their decision to take or give their children preventer medicines; and potential acceptability of differential co-payment arrangements for different preventer medicines.

**Box 1: Australian Pharmaceutical Benefits Scheme (PBS)**

The Pharmaceutical Benefits Scheme is an Australian Government scheme that subsidises medicine costs for all Australians. A patient co-payment is usually required, paid to the pharmacist at the time of dispensing. Currently (from 1 January 2019) the maximum patient contribution per prescription dispensed is $40.30 for general beneficiaries, or $6.50 for concession cardholders. The government pays the remaining cost.

The PBS Safety Net reduces the cost of prescription medicines for individuals and families who reach the threshold of $1,550.70 per year (general) or $390.00 (concession). The safety net patient contribution is then $6.50 (general beneficiaries) or free (concession cardholders) for the remainder of the calendar year.

**Data collection and analysis**

Interviews were digitally recorded and transcribed verbatim using TapeACall Pro. Interviewees were assigned pseudonyms for reporting purposes. A code framework was developed and agreed by two authors (SD, HR). Due to the exploratory nature of the topic, a descriptive qualitative design, combining empirical and grounded theory approaches was used for analysis. Emergent themes and divergent views were identified and discussed, and differences between patients and carers, and across socioeconomic categories, were explored. Transcripts were revisited frequently during analysis to confirm the validity of themes.

**Recruitment**

Participants were recruited through the contact list of a consumer organisation (Asthma Foundation NSW, now Asthma Australia) and through a practice-based research network in a less privileged area of the Sydney metropolitan region. This ensured sampling of participants in a range of socioeconomic areas. Recruitment continued until data saturation was reached.

**Ethics**

Ethics approval was granted by the University of New South Wales Human Research Advisory Panel (#HREAP-2014-7-34). All participants provided informed consent.

**Results**

Twenty-four adults with asthma and 20 carers for a child with asthma were interviewed (one adult was also interviewed as a carer so total participants n=43). Males (n=13) comprised 54% of the adult interviewees. Participants came from major cities (n=33, 77%), inner regional (n=8, 19%), and outer regional areas (n=2, 0.5%). Just over one-quarter of participants were concession card holders. One-third of participants were recruited from Asthma NSW (14/43), with the remainder sourced via medical practices in South Western Sydney. Further demographic information is available in Table 1.

**Participants’ experiences of asthma and medicine use**

The interviews elicited information about participants’ overall experience of having asthma, or being a carer for a child with...
asthma, and their use and understanding of asthma medicines. Co-morbidities such as allergic rhinitis and allergies contributed to participants’ overall asthma experience. Participants spoke about the effect of asthma on their quality of life, usually in negative terms, affecting every facet of daily life to varying degrees. However, most perceived their asthma as “OK” provided they were taking their medicines as prescribed. The majority of participants revealed that they attended their doctor only if they were symptomatic and not for regular asthma review. By contrast a handful of carers were more proactive, with their child’s health being the priority and not something to be compromised.

Knowledge of different classes of asthma medicine varied widely, from rudimentary knowledge to being able to name preventers that other people may be using. Of those using a combination ICS/LABA (63% adults, 14% children), few seemed to know that this contained a preventer and a bronchodilator. Information seeking and confidence in discussions with healthcare providers (HCPs) appeared to differ depending on the recruitment source, with participants recruited via the consumer organisation exhibiting higher levels of engagement.

Themes around asthma preventer medicines

Three major themes were explored (see Table 2):

- Influences on decisions about preventer choice
- Barriers and enablers to preventer adherence
- Perceptions around cost of medicine.

Influences on decisions about preventer choice

Participants’ comments shed substantial light on their experience of conversations with HCPs about medicine choice and their comfort with initiating such discussions. Some participants were comfortable with discussing preventer rationale or choice with HCPs, but described it as having their questions answered rather than in-depth shared decision making. In fact, both adults and carers placed the responsibility for medicine changes firmly with the doctor, citing reasons such as lacking the requisite expertise and, frequently, that this was not their role as a patient or carer:

Well, it’s not like I went in there and said to him, “I’ve decided my son needs a preventer.” … It’s just not what I do as a parent, a parent of a patient. That’s not my job, it’s the doctor’s job, you know (Yolande, carer-IRSAD3)

When probed about factors that would affect decision making about preventer choice, if this were offered, treatment effectiveness was the key factor for most participants. This was particularly evident for carers, who additionally wanted their child to have as normal a life as possible.

So long as it works. That’s all that matters (Miriam, carer-IRSAD2)

Participants’ decision making was also influenced by recommendations from family and friends, often related to the availability of new medicines:

My nephew has asthma like my son, and if he’s having better results on a different medicine and my sister discussed that with me ... then I would ask, or recommend something with my GP. (Mai, carer-IRSAD2)

Barriers and enablers to preventer adherence

Barriers

Participants reported more barriers than enablers. Barriers included participant behaviours, medicine-related factors such as side effects and cost, and characteristics of healthcare professionals.

Participants’ responses revealed a number of behaviours such as skipping doses or delaying refills, associated with intentional and unintentional lack of adherence. Intentional non-adherence factors included concerns about the need for regular medicine use per se and the perceived stigma of using asthma medicines in front of others. Non-intentional factors included forgetting and out-of-pocket medicine costs. Some participants reported not being able to judge if the preventer was actually working and therefore whether it was required:

Then you stop taking it for a few days and then when it [asthma] comes back up and then, you know, you realise you need it. So … you know, you don’t think it’s that important and when it’s important you take it, that sort of mentality … (Eduardo-IRSAD8)

Some behaviours related specifically to children, such as their ability to co-operate and use devices correctly. Having a chronic disease was noted by one carer as adding an extra layer of responsibility onto children. Several carers expressed a dislike of giving any medicine to their child and some actively searched for alternative therapies to avoid medicine use:

We went to a Naturopath, recommended by someone whose daughter was cured of asthma, and I used to go monthly (Shivon-IRSAD3)

The barrier most often cited by participants related to perceived side effects of asthma medicines, particularly corticosteroids. For some adults weight gain from oral corticosteroids was the major concern. Instead, for carers, possible effects of ICS on growth of children were paramount. Whilst some carers saw corticosteroids as a last resort, other had weighed up the risks and benefits and decided to give the preventer to their child:

The only side effect I am aware of is the, the fact that it’s got steroids and they, you know, can cause growth [sic] or that sort of thing. But the amount of steroids in it, from what I’ve learnt, is very minor. So no, the side effects are not a factor for us giving him the preventer. (Amanda, carer-IRSAD2)

Carers were also aware from media activity of a link between LTRAs and mental health issues, including suicidal thoughts, and were concerned about the lack of long-term safety data:

I would be concerned about the safety and side effects as well, because … more than anything else … one of the Doctors at the beginning wasn’t keen on [LTRA], because it was a newer drug and there wasn’t enough historical data to look at it. I mean, we still went ahead with it, but actually it was a valid point (Donna, carer-IRSAD4)

Characteristics of HCPs, including behaviours and accessibility, represented another barrier.

Table 2: Themes and subthemes.

<table>
<thead>
<tr>
<th>Influences on decisions about preventer choice</th>
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</thead>
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<tr>
<td>Perceived responsibility for medicine changes</td>
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<tr>
<td>Perceived effectiveness of prescribed asthma medicines</td>
</tr>
<tr>
<td>Influences of family and friends</td>
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<tr>
<td>Barriers and enablers to preventer adherence</td>
</tr>
<tr>
<td>Characteristics of medicine e.g. side effects; perceived lack of effect; cost</td>
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<tr>
<td>Participant behaviours</td>
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<tr>
<td>Characteristics of healthcare professionals + communication skills</td>
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<tr>
<td>Perceptions around cost of medicines</td>
</tr>
<tr>
<td>Primacy of health</td>
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<tr>
<td>Patients’ innate characteristics and current circumstances</td>
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<tr>
<td>Societal affordability/ government responsibility</td>
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<tr>
<td>Cost of not taking medicines</td>
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<td>Prompted perceptions around cheaper preventers</td>
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Some participants perceived HCPs as poor communicators—not hearing the patient, or adequately educating them:

I was angry at the professionals that hadn’t given me the time, that hadn’t properly explained things to me…I have found the whole process tremendously trial and error, and very frustrating. (Jenny, carer-IRSAD5)

Practical issues such as the need (and cost) to visit a doctor to obtain scripts, and the availability of medicines and accessories in pharmacies were perceived to be a problem especially in rural areas:

Some chemists… keep in stock for you, and it’s usually not the local chemist, it’s usually one that you’ve got to travel a good half hour away to. (Tina, carer-IRSAD4)

### Enablers

Enablers of good adherence mentioned by participants included strategies such as a sense of accountability to their HCP, visual cues to remember to take medicine, and development of good habits, which assisted participants included strategies such as a

...and worse asthma control:

Well it just allows me to do things. It means I’m not reliant on a medical system to, you know, bring me back to life. I can just get on with things, doing what I need to do. Before preventers and relievers, people would have been just sitting on the sidelines, just on the sidelines of life. We don’t have to anymore. (Robert-IRSAD1)

### Perceptions around cost of medicines

Participants spontaneously mentioned cost issues as a barrier to preventer use during the interviews, however, it was not a focus for most participants. Most participants prioritised health over medicine cost; with the primacy of health came a resignation to the need for medicine and a willingness to pay. Moreover, several carers expressed that they would go without if it meant getting their child the treatment that he/she needed:

Look love, I’d find a way. I’d find a way. You’ve got to breathe, you know? (Connor-IRSAD5)

First is our son’s health. So I would pay, you know, all my wage into keeping my son healthy (Miriam, carer-IRSAD2)

The main medicines that were perceived to be expensive were LTRA tablets (for adults at the time (prior to the availability of generic substitutes), around $70 for a month’s supply), and ICS/LABA inhalers, by comparison with reliever inhalers. For some participants, cost contributed to intentional non-adherence and worse asthma control:

I’m a bit slack ‘cause the [ICS/LABA]’s pretty expensive and if I, if I sort of can’t afford it, I’ll go without it for a couple of months and…I notice it really, really badly (Anthony, IRSAD not known)

I have quite a long list of medications, actually, so yeah it does [impact on what I take], definitely. Sometimes I don’t take my arthritis medicine, you know? Sometimes I can’t afford all the scripts so I have to weigh up which scripts I need most at the time (Megan, IRSAD2).

Several participants reported being unaware of medicine costs until actual purchase, as costs were only raised by the pharmacist:

Several participants were eligible for reduced (concessional) co-payments expressed that medicine costs could still be a struggle, and they may need to go without medicine, lower their dose or frequency of use temporarily, or make a sacrifice in some other area. Others, noting that they had lower out-of-pocket costs for medicines, reported feeling lucky and likely to be non-adherent otherwise:

I’m entitled to a health care card. Before then, that was where it had come down to with the [ICS/LABA], with me going, “Okay, can I afford it this week?” … you wouldn’t take it for a week, because you’re looking at how many puffs are left on it (Melinda-IRSAD1)

The affordability of asthma medicines at a societal level was also a concern for many participants, with the government seen to have an important role. Several participants expressed that patients cannot help suffering from diseases such as asthma and shouldn’t have their treatment compromised because of cost:

I think it’s absolutely reasonable and the right thing to do, that chronic illnesses, things that nobody did anything wrong to get them, they should be able to access affordable medicines. (Yvonne, carer-IRSAD2)

Importantly, the cost of not taking medicines was raised by several participants, noting both direct costs (relating to the person’s health) and indirect costs (such as lost wages and decreased workforce productivity) were associated with omitting asthma medicines:

You don’t want to put your child into hospital because you wanted to save a buck, you know? (Meryl, carer-IRSAD3)

The cost if I don’t take it is higher, because when you take time off work, that costs you money, or costs me money… because if you’re always sick and stuff like that and can’t catch up with your work … (Hasham-IRSAD1)

Finally, some participants mentioned that costs may be influenced by pharmaceutical manufacturers:

I think I’m naturally suspicious of pharmaceutical companies, and so I would think, “Well, what’s the deal for this pharmaceutical company, and what’s the deal for the government here with this one?” (Jenny, carer-IRSAD5)

At the end of the interview, participants’ understanding of patient co-payments was explored and they were also presented with hypothetical scenarios concerning availability of cheaper or free preventers. The concept that what was paid to the pharmacist was a co-payment to government for part of the cost of the medicine was poorly understood overall. Several participants confused these payments with Medicare payments to healthcare professionals. The need for more education regarding co-payments
Perceptions around preventer medicine purchase and use

was expressed by a couple of participants, suggesting that this concept is not explained routinely to patients:

Well we’ve never really been told what the gap is … how much does it really cost for that medicine, and how much are we being charged? (Mai, carer-IRSAD2)

When asked whether lower co-payments for asthma medicines would affect their purchasing behaviours, participants’ responses varied depending on the priority they ascribed to their health, the importance they placed on preventer use and whether they had a healthcare card. Several participants noted that circumstances might change in this regard:

Yes, definitely ‘cause I am … we’re a one-income family. If we didn’t have a healthcare card, we would really find it quite hard, especially one of these preventers, when I found out the full cost was $70 without a $6.10, you know, healthcare card. (Michaela, adult and carer-IRSAD2)

Concerning the hypothetical scenario of a lower patient co-payment for only some medicines (ICS-alone), several participants saw this as equitable, particularly if the treatment needs of individual patients would not be taken into account; they felt that extensive justification would be needed. Moreover, the notion of free preventers was generally viewed with scepticism:

But you know, like anything for free, you often get a bit suspicious as to what’s the catch: Is it faulty? Is it going to work? What’s the story? (Tracey, carer-IRSAD4)

Discussion

The findings of this qualitative study of adults with asthma, and carers of children with asthma, provide important insights into the quality use of asthma preventer medicines in Australia and the role of cost in patient decision making. Notably, there were multifactorial influences on patients’ decisions about preventer choice, including perceived effectiveness of prescribed asthma medicines, and ease of communication with HCPs. However, participants’ responses regarding perceived responsibility for medicine changes showed they had little actual experience of shared decision-making. Participants revealed a number of barriers and enablers to preventer adherence, once a medicine had been dispensed, and they provided useful feedback regarding asthma medicine costs, as well as the likely effect on their purchasing behaviours with hypothetical changes to prescription co-payments.

Factors influencing decisions about preventer choice

This study showed that effectiveness of preventer medicines, in promoting good asthma control, was the stated priority for participants. Maintenance of health was prioritised above cost by most participants, particularly carers.

The concept of shared decision making around responsibility for medicine decisions did not resonate with many participants in this study. Shared decision making, which warrants that HCP and patient share relevant information, express treatment preferences, deliberate the options, and agree on the treatment to implement,17-19 is known to improve adherence and outcomes.17 However, although some participants reported discussing treatment options with their doctor, most did not regard themselves as primary decision makers about preventer use. These findings mirror UK research in 230 adults with asthma, where most perceived that their role was passive or semi-passive in respect of treatment decisions.20 In a qualitative study of Australian GPs’ views on the influence of cost on prescribing of asthma preventer medicines, GPs reported that they did not initiate discussions of cost with patients, and they did not mention a role for the patient in making the decision, other than one GP noting that “some patients expressed difficulty affording medicines, not just for asthma”.

Concerning barriers and enablers to preventer adherence

Most participants agreed that preventers were indeed important in maintaining good asthma control and quality of life. Despite this, they revealed that in practice they may be poorly-adherent, with cited barriers representing both intentional and unintentional behaviours.

The types of barriers reported in the current study are in line with those cited in Australian and international asthma research, including (lack of) perceived necessity of medicines, ease of use, and concerns about and experience of medication side effects.10 The balance between necessity vs. concerns is well acknowledged in the literature; patients are more likely to take a treatment if “convinced that it is necessary to maintain or improve our health now and in the future, have few concerns about negative effects, and can overcome the practical difficulties in following the regimen (e.g. forgetting, difficulties using the administration device, and affording co-payments)”21

In our study participants mentioned behaviours such as reducing their prescribed dose, or going without for a couple of months; they did not necessarily perceive this as stopping their medicine, but rather titrating depending on cost. This behaviour is similar to that cited in a literature review of patients at risk for cost-related medicine non-adherence where participants delayed or failed to fill prescriptions, cut dosages and reduced the frequency of administration.22 Some of our participants, when faced with cost pressures, prioritised which medicine(s) to reduce based on their perceived importance to their health.

Characteristics of GPs, including their ability to communicate, were of concern to participants in this study. Lack of shared decision making appeared to have been exacerbated in many cases by perceived inadequacies in HCP communication. The need for more education and adequate consultation time was also identified, but it may be difficult for HCPs to incorporate self-management topics during consultations.23 By contrast, several participants indicated their willingness to use preventers due to their implicit trust in their HCP’s knowledge and the ongoing respectful relationship with them. Opportunities for collaboration are enhanced when patients perceive relationships as trusting, empathic and positive, fostering a sense of being respected and cared for by healthcare professionals.24

Concerning perceptions around cost of medicines

There was heterogeneity between participants in this study regarding the impact of medicine cost. For a few, medicine affordability critically affected their quality of life; however most stated that they would prioritise health above medicine cost. While this may reflect social desirability bias, it is in line with results of a UK qualitative study that concluded that “the impact of prescription charges on asthma patients is uneven and unpredictable”.25 Participants in the current study also noted that financial circumstances are fluid, not fixed, and may change at any time.
Further regarding medicine costs, responses in this study suggest that, although medicine costs are factored into patients’ decision making, doctors do not routinely discuss these costs and a pharmacist is more likely to give this information to the patient at the point of purchase. Our results support previous research suggesting that doctors are not knowledgeable about the cost of medicines to patients and do not discuss costs when prescribing.14,26 This is unfortunate, as prescribers might otherwise “be able to reduce the impact of cost by, for example, prescribing generic or lower cost medicines when appropriate”26.

Understanding of co-payments

Overall, participants in this study had a very limited understanding of the concept of co-payments and it was therefore difficult to draw conclusions regarding the success of possible government changes to co-payments for asthma preventer medicines, including ICS-alone. Other authors have argued that for incentive-basedformularies (tiered co-payments) to operate as intended, consumers must be aware of cost-sharing information about prescription drugs and communicate their preferences.27

Proposed solutions

Our results suggest that to address preventer adherence issues, including cost, support is required for both HCPs and patients. Regarding HCPs, who have been identified in previous research as lacking information about medicine costs,15,28 prescribing decision support should include real-time data on the relative costs of therapeutically equivalent medicines.26,29 For asthma preventers, with multiple doses and devices available, these costs are not necessarily easy to calculate.14,26 Armed with this information, pharmacists also have an important role in providing patients and carers with information about medicine costs,15,28 prescribing appropriately in the context of patient need, and being able to reduce the impact of cost by, for example, prescribing generic or lower cost medicines when appropriate.26

Study limitations and strengths

Strengths of this study include the insights provided on how patients and carers make decisions around asthma preventer choices, with participants sampled from a broad range of socioeconomic backgrounds. It is the first study to canvass patients’ views on how different hypothetical funding models for preventer medicines might affect them. Regarding limitations, the study was conducted in one geographical area (NSW) and we were not able to recruit any male carers for interview, which may limit generalisability. Due to heterogeneity among participants regarding the importance of medicine cost, it was not possible to draw any firm conclusions about the effects of relative advantage or disadvantage on the perceptions of participants regarding costs. No objective measures of patient behaviour were available and participant responses about priorities, as in any qualitative research, could have been subject to social desirability bias.10

Practice implications

• Asthma patients and carers of children with asthma could benefit from education regarding shared decision-making, to empower them in their dealings with HCPs and choices of medicine.
• HCPs, including GPs, need to be aware of the medicine choices that are available and actively encourage patient engagement.
• This study confirmed the important effect of cost in adherence for many patients. General practitioners need to encourage empathic discussion about barriers and enablers.
• At a policy level, both HCPs and patients need to be provided with information about the relative costs of asthma medicines and the role of co-payments.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Supplementary File 1: Study Interview guide.