

The PPI Hawker: An innovative method for public involvement in health research

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Methodology

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Abstract

Background: A universal challenge in Public Involvement (PPI) in health research is attracting a diversity of patients' perspectives and experiences. In Singapore, including the public's voice in research is in its infancy and different ways of involving the public have to be explored.

Objective: To design a PPI initiative that enables members of the public to share their ideas and opinions about health research, and then to assess its feasibility in the Singaporean community.

Study design: Building on the concept of the PPI Café we designed a PPI Hawker for Singapore. Observations and reflexive field notes were used to evaluate the PPI Hawker's feasibility, acceptability and utility.

Results: From three PPI hawkers we were able to engage 72 members of the public in discussions about a population-based research study for which the researchers wanted to better understand the public's perspective on various aspects of research design. Three quarters of those approached agreed to participate, indicating the feasibility of this method. PPI participants came from the three major ethnic groups in Singapore and were broad in age, suggesting PPI Hawkers are easily accessible. The majority of participants were willing to discuss all of the questions posed by the researchers. Both participants and researchers recognised the utility of the PPI Hawker, reflecting on people's willingness to talk about the research issues, engaging in informative conversations and posing relevant questions.

Discussion: The PPI Hawkers succeeded in engaging the public in conversations about a local population-based study. The public brought to the researchers' attention a variety of previously unheard perspectives about the research. Each event fostered connectivity between professionals and the public, generating among researchers a more positive perception of the power of public involvement.

Conclusion: PPI Hawkers provide an opportunity for meaningful co-design and co-conduct of research studies with diverse members of the public. They create a focus within a community setting for researchers to engage with the public. The resources needed (costs and preparatory time) are relatively few. Not only do PPI Hawkers have potential in Singapore, but also for the rest of Asia.

Background

Although public involvement (PPI) is becoming a common component of health research in Western countries, such as the UK, Australia and Canada (1–5), PPI is still in an early stage of development in Asian countries, including Singapore (6). It is recognised that PPI enhances the quality and relevance of the research, and its impacts are greater when implemented early in the research cycle (7–9). If Singapore wishes to remain at the forefront of Asian health research, public involvement in health research must be cultivated, with public perspectives being heard and their concerns addressed.

Often when PPI is in its infancy, a few selected public collaborators are invited to engage in a two-way conversation (10). These same individuals may contribute repeatedly during the research process and also return for future studies led by the same team. Whilst this model of involvement is strong on continuity, it generates concerns about tokenism and risks the public contributor remaining as a “thinker at the edges” (11,12). More refined PPI initiatives strive for greater inclusivity and diversity of involvement.

Recent PPI developments have focussed on ways to include disadvantaged communities in these “privileged” spaces, recognising it is often vulnerable people who have the greatest health needs (10,13,14). PPI Cafés are an example of such developments. By merging the characteristics of a “science café” and a PPI workshop PPI Cafés create an opportunity for the public to have hands-on experience of PPI by contributing to a real-life research project and also generating public opinion that can be incorporated into the project design and process. This initiative was first piloted at the 2018 Imperial Festival (15), a science festival for the public organised by researchers at Imperial College London. The public were invited to join the “baristas” (researchers, public facilitators and PPI facilitators) for a drink in a space customised to look like a café (15). Tables were dedicated to different research studies and at each table a facilitator introduced the research study, before the researcher posed the issues about which the public’s perceptions and comments were needed. As the PPI Cafés’ guests, members of the public, were invited to write their comments and placed them in a container in the centre of the table. Other PPI initiatives have made imaginative use of a variety of media to promote outreach. For example, the AudioLab used creative sessions (including spoken word, debate, panel discussion, music, dance, rap battle, hands-on ‘wet’ science activities) to engage young people with relative socioeconomic, educational and/or health disadvantage in health research (16). Another PPI initiative worked with members of a community in a deprived area to develop a tool kit which enabled the public to rearrange photographs to express their priorities for research about child health and development (17).

To date there has been little attention to the inclusion of PPI in research conducted in Asian countries. Currently in Singapore the role of the public is almost exclusively limited to taking part in research. While the benefits of public involvement and co-production are well established in the literature (7,18–30), methods for an Asian context have yet to be explored. Here we describe the PPI Hawker, an adaptation of the PPI Cafés used in Western cultures. The PPI Hawker was designed to enable the Singaporean public to share their personal perspectives of health research in an informal environment throughout the country. This article shares our experiences of developing and conducting PPI hawkers.

Methods

Towards an Asian friendly PPI Café

In Singapore cafés are not as widespread as in Western countries, but hawker centres, also known as food courts, (shown in Fig.1) are frequently used for eating and socialising. They are physically and financially more accessible to a wider sector of society than cafés. Hawker centres, described as

“Singapore in a nutshell” (31), provide a one-stop destination for everyone with a wide choice of high-quality food at inexpensive prices (meals are priced at S\$3-4 and a local drink costs about S\$1.5 (32)). Open from 7 AM to 10 PM and managed by the National Environment Agency, hawker centres are typically found near public housing estates or transport hubs, with more than 15,000 food stalls (33) serving the majority of the 5.64 M people living in the country (34). Hawker centres are so integral to Singaporean life that in March 2019, the Singaporean government nominated hawker culture for UNESCO listing of Intangible Cultural Heritage of Humanity (35).

Similar to the PPI Café, we designed the PPI Hawker to reduce the hierarchies between researchers and the public, enabling a two-way conversation, which could facilitate the sharing of knowledge and improved relevance of research studies. Through short and informal conversations, the PPI Hawker brings together members of the community (past, current and future patients and their caregivers) with researchers, reducing the boundaries between non-experts and experts. PPI Hawkers encourage recognition of complementary expertise by positioning lived experiences and personal perspectives at the same level as expert knowledge. Organising the discussion in a setting familiar to the public facilitates discussion, encouraging ideas to be explored in spontaneous conversation, building trust between lay people and researchers.

Designing and testing the feasibility of the PPI Hawker

To progress the design of the PPI Hawker, we formed a development team with a coordinator (LLP), two PPI Leads with experience of conducting PPI Cafés in the UK, a researcher from the population-based study and a Singaporean resident.

Adaptation of the PPI Café to the Singapore context required more than just change in location: the multi-ethnic community required us to consider how we would facilitate, and record discussions conducted in several languages. We decided to work in pairs organised in such a way as to maximise the local languages available for discussion (Mandarin Chinese, Cantonese, Malay and Tamil). Note taking was always in English as this is the *lingua franca* of Singapore, thus enabling access to the documentation by all facilitators and members of the research team.

From the PPI Café (Fig.3) we wished to retain the informal atmosphere, the use of members of the public as facilitators, the involvement of at least one researcher from the study team, the offer of refreshments, and working in pairs to facilitate this task. We disbanded the display of research materials, as well as preparing the drinks ourselves. We added the use of cue cards, consisting of simple prompts and a logo for each question, as shown in Fig.2. During the table discussions, participants were also able to refer to a card with an overview of the study aims and process, to reinforce the explanation given orally. One facilitator introduced and guided each conversation, using their local language skills and the second facilitator made notes of the discussion.

The development team of five piloted the first PPI Hawker pilot, but subsequently we worked as a team of four (PPI Hawker coordinator, researcher representing the study, and two public facilitators). The public facilitators were selected for their language skills (speaking English, and one or more local official languages: Mandarin, Malay and Tamil), their comfort engaging with the public and an interest in research. They were briefed on the research study objectives and the issues the researchers wanted the public to consider. Before going to the Hawker Centres the team used role play to familiarise themselves with the cue cards and how to focus discussion on those topics.

After each PPI Hawker, the facilitators reflected on the session, and documented any difficulties encountered, for example involving the public from a particular demographic or engaging the public in conversation around a particular issue.

Criteria for evaluation

Before piloting the PPI Hawker, we defined desirable outcomes and how these could be assessed:

- Feasibility was defined by the capacity to engage members of the public in discussion. Our goals were:
 - at least 50% people approached agreeing to participate,
 - to engage a minimum of 20 participants in each session, at least 10 individuals responding to each question.
- Acceptability referred to how well we engaged with a cross section of our target, the general adult population of Singapore. We sought representation from diverse ages (20-80) and all major ethnic groups (Chinese, Malay and Indian).
- Utility was the extent to which the public generated ideas were subsequently adopted by the researcher Utility was assessed by the researchers' response to the presentations and written reports of PPI Hawker discussions.

Results

Our experience of piloting the PPI Hawker

The pilot PPI Hawker was held on November 8th, 2018, in Serangoon Gardens Market and Food Centre (Fig.1). It soon became apparent that inviting participants to join our table as they queued to buy themselves refreshments from the hawker stalls was not going to work (Fig.3). Everyone approached refused to join our table, but instead invited us to join theirs. After a quick discussion, we decided to approach people already sitting and asking if we could join their table. With this amendment, 28 members of the public participated, but all declined the offer of a free drink.

Our experience with the first PPI Hawker highlighted the need to be clearer when introducing PPI and describing the overall aim of the research study being discussed. The need for this information became apparent when members of the public initially misunderstood what they were being asked to do, thinking

that we were seeking participants for the study. The public required sufficient background in order to meaningfully engage in the conversation. Therefore it was crucial to have one of the in a facilitating role to communicate information about the research project both to the public and other facilitators. Finally, it was helpful to work in pairs, with one person capturing all the insights shared by members of the public and the other focusing on the conversation. To increase the clarity and utility of the comments collected, we developed a coding system for future PPI Hawkers.

The conduct of two further PPI Hawkers

Our pilot involved mostly Chinese, so to achieve greater ethnic diversity the two subsequent PPI Hawkers were conducted in locations frequented by more Malay and Indian residents (Malay and Indian represent 13 and 9% of Singapore's population respectively, 74% being Chinese (34)). With our revised method (Fig.3), we engaged a further forty-four members of the public (24 Indian, 13 Malay and 7 Chinese), in short conversations (around 15 minutes per table) sitting at 33 tables (16 in Admiralty and 17 in Tekka Centre).

We found the presence of the public facilitators was particularly helpful with developing trust, for example with the Indian population an introduction in Tamil defused feelings of being caught in an unfamiliar situation to inclusion in a conversation in which they were central.

Alongside positive aspects of the PPI Hawker, some negative views were also noted. Around a quarter of members of the public approached wanted to be left "alone", others wished to discuss topics not related to the research study (e.g. digressing to complain about the government), but only one individual responded with some aggression, sharing their dogmatic beliefs about medicine. No offers of a drink were accepted, and occasionally a participant expressed offense when offered a free drink, as they saw it as too small a token of appreciation, because it was something that they could easily afford for themselves.

Achieving our goals

On evaluation the PPI Hawkers exceeded our predefined goals for feasibility, acceptability and utility. At each PPI Hawker more than twenty members of the public were engaged, and within each session at least ten individuals responded to each of the questions posed. The PPI Hawker concept was well received by the public; 75% of those approached at their tables agreed to engage in a conversation with us. We involved members of all three ethnic groups in Singapore and spoke to adults from a wide age range, confirming accessibility of the PPI Hawker.

Researchers' feedback

The Steering Group's response to the feedback from the public about their population-based study was encouraging, and they expressed the need to continue with the PPI Hawkers to also understand the views of populations from different neighbourhoods. The researcher involved as a facilitator commented on how "The public's opinion are very diverse, and I learnt that if you spend the time to listen to public, there

are many things that you can learn. People are generally willing to help, and their feedback will only make our research stronger!" With subsequent PPI Hawkers her appreciation of their value was strengthened by observing the hidden knowledge within different communities. She commented "An eye opener, certainly I could see the totally different perspective from those of lower socio-economic classes about research health screening".

The discussion of the feedback from participants prompted refinements to the PPI Hawker including more consistency in the terminology used. For example, while some facilitators had used the word "confidentiality" others had used "anonymity" when discussing data sharing issues. This inconsistency made the PPI feedback less useful as it was not always possible to know which term the public were responding to. As a result, we agreed facilitators should only use the terminology on the cue cards and would always explain any technical terms before engaging in discussion.

Examples of how PPI impacted on the design of the population-based study can be found in the box 1 below.

Box 1: Impact of the PPI Hawkers on the study design

After the PPI Hawker Pilot, members of the Steering Group were receptive to the public's suggestions to allay concerns about data security by sharing more information on how participant data is stored and by requesting additional consent for data sharing with commercial collaborators (Question 1), to consider how the research data could be incorporated into the individual's health records (Question 2) and to regularly update participants on the study's progress (Question 3).

After the two subsequent PPI Hawkers researchers introduced a number of changes to the research process supported by the public's comments. Researchers are seeking to establish new recruitment strategies, by formalising agreements with various employers (Question 1) and are setting up a community Advisory Group that could provide regular advice on issues that can't be discussed in the context of the PPI Hawker (Question 3). Changes also included amendments to the informed consent form, giving research participants the choice of who their data could be shared with in the future without the need to recontact them (Question 2). There were four categories to select from; (i) Universities/academic institutions, (ii) Health institutions, (iii) Government institutions and (iv) Commercial bodies. The amended consent also includes an improved explanation of incidental findings using simple terms, detailing the pros and cons, and giving participants the option to decide whether they would like to have their incidental findings communicated to them (Question 4).

The public's perspective of the PPI Hawker

From the public's feedback the opportunity to take part in the PPI Hawker conversations was appreciated. Most members of the public we spoke to were "*happy to give [us their] opinion*". Participants enjoyed "*feeling helpful*" contributing to something that would benefit their community. They felt that by meeting

in the familiar space of the hawker centres, researchers lost “*their authoritarian attitude*”. Moreover, they recognised that “*researchers don’t know [our needs and wants], we have to tell them*”. The format of the PPI Hawker as an involvement method for Singaporeans was widely supported; participants valued its concise and one-off nature, because of the pressures on their time and no wish to talk about research on a regular basis. One member of the public finished their conversation with us by thanking us for meeting the public: “*You are doing a very good thing for people [coming to ask for people’s perspectives at the hawker centre]. I have to appreciate*”.

PPI facilitator’s experience

Facilitators observed how the informal setting allowed members of the public to talk openly and freely and share personal experiences. This relaxed environment allowed us to approach audiences unfamiliar with research, where they felt able to comment freely and also ask questions on topics beyond those proposed by the researchers. Facilitators were encouraged by their experiences of the PPI Hawkers, and highlighted the feasibility and accessibility of this method of involvement in the Singaporean context.

The reflexive notes of the coordinator captured how the degree of engagement exceeded her expectations:

“I was surprised by how most people were receptive and keen to discuss the project with us. Singaporeans are often zealous in the protection of their privacy and are reluctant to share their opinions. However, those we interacted with were willing to talk at length about the issues, curious about the research, and seemed to enjoy the experience” (LLP).

One of the public facilitators recorded their observations of how the public’s initial hesitancy to be involved was quickly transformed into engagement:

“People were apprehensive when we first approached them (like we were going to sell something/ask them for something/like we were disturbing quiet, family time) but once it was clear we just wanted their OPINIONS, the conversation flowed quite effortlessly. I was surprised to see them have so much to say, so much to contribute to each of the questions asked. The public are not as oblivious or ill-informed as some may think, they may not be researchers but everything that was said made perfect sense and was of great value. We could not have predicted those responses or gotten a more honest feel for their perception of research in general or the barriers and facilitators to research if we did not sit down and talk to them in person, in a natural setting as we did today.” (Public facilitator, reflecting on sessions #2 and #3)

Discussion

Summary

In three PPI hawkers we were able to engage 72 members of the public in discussions about issues the researchers of a population-based study wanted the public's perspective. This novel approach of involving lay people on research-related matters achieved an engagement rate of 75%. Participants came from the three main ethnic groups in Singapore and were broad in age. Since the hawker centres are spaces visited by almost all Singaporeans, this PPI method facilitates engagement with a broad sector of society in different neighbourhoods. Using short one-off conversations in their mother tongue in a familiar environment the majority of participants were willing to discuss all of the questions posed by the researchers. Researchers recognised the utility of the PPI Hawker, reflecting on people's willingness to consider research issues, engaging in informative conversations and ask relevant questions. During these conversations, facilitators observed the traditional barriers between experts and non-experts being broken down, leading to mutual respect and sharing of ideas.

Advantages of the PPI Hawker

The PPI Hawkers have the potential to be used more widely for PPI in Singapore and potentially in other Asian contexts. This approach to PPI has identified two major attributes:

Firstly, the PPI Hawker reduces communication barriers, making it easier for researchers to reach the public and vice versa. The process of the public inviting researchers to join them at their own tables appeared to enable the public more control over the amount and direction of the discussion. These conversations become opportunities to share knowledge and together improve the research. Reluctance to participate in PPI (6) may be exacerbated further by the poor research knowledge, lower literacy and limited (oral skills) often seen within those sub-populations with the greatest health needs. We observed within the PPI Hawker dialogue, reciprocity, openness and respect, enabling thoughtful communication between the facilitators and the public.

Secondly the PPI Hawker reduces the barriers between experts and the public, flattening or reversing the pyramid of hierarchy (37). Conventionally lay people are reluctant to challenge perceived expertise (38,39), but the round table discussions appeared to generate mutual trust, and a willingness for the non-expert to comment, critique and challenge the research. Such exchange is often difficult to achieve in hierarchical societies like Singapore (38,40) but the PPI Hawker appears to do this by the development of a collective consciousness.

Effective and efficient use of resources

PPI is often characterised as a time and energy intensive activity, deterring researchers' engagement (6). The PPI Hawker addresses some of these concerns as it does not require the administrative burden or the expense of sending out invitations, hiring a venue or transport cost for participants. However, what it does require is time for the initial planning (a one-off activity), and then the conduct of the PPI Hawker(s) and collating of ideas. In our experience the time spent planning preparing and training for the project-specific

PPI was 10 person hours in total. Each PPI Hawker required 2 hours of facilitators time (including a 30-minutes briefing) before each. Collating comments and drafting a summary for the research team took a further 8 hours of the coordinator's time and 1 hour for each of the other facilitators' time.

Limitations and strengths of the PPI Hawker

A challenge for PPI globally is the need to hear a wide diversity of perspectives. Increasingly more groups have been empowered and are being heard, but some groups still remain at the margins. PPI Hawkers offer a helpful solution to this challenge; but PPI Hawkers are not without their limitations. For example, it is recognised that long-term involvement throughout the different stages of the research process increases the impact of PPI (7) but the PPI Hawker is a one-off encounter. Not collecting personal and demographic data also makes it difficult to characterise or target respondents. For example, we used appearance to identify the ethnic group of participants. This may be impossible if one wishes to target people of a specific age, sexuality, marital status or income group. Lastly, the PPI Hawker may not be appropriate for all types of research, including studies about sensitive topics or studies where the provision of a substantial background and explanation are needed before the public are able to comment.

We have demonstrated in this study how the PPI Café can be adapted to suit a non-western culture. Although our experience is currently confined to Singapore we anticipate that this model of involvement would be applicable to other Asian countries (Fig. 4). We are also keen to explore in the future whether the PPI Hawker could be an avenue for dissemination of research findings, an under-developed aspect of PPI (41). Research findings continue to be shared conventionally, disseminated in academic environments (e.g. conference presentations, journal papers and academic books) and far less through channels easily accessible for the public (e.g. public exhibitions, podcasts and blogs). PPI Hawkers may be an effective way to increase the public's awareness of the findings of health research that may impact on their lives. The feasibility of this needs further exploration and piloting.

Conclusion

This study has demonstrated how the PPI Hawker aligns with the ethos of public involvement in research. It has the potential to be the major model for PPI initiatives in Singapore, facilitating knowledge exchange in community spaces accessible to a wider number of people. Further feasibility studies are needed to confirm the PPI Hawkers utility when used to discuss studies in different topic areas and with different methods, but preliminary findings are encouraging.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

LLP was the coordinator of the PPI Hawkers. She designed and conducted the three PPI Hawker sessions, and she analysed the comments coming out of it. She only maintained the relationship with the PPI Facilitators and the researchers from the population-based research study throughout. HES was a major contributor in writing the manuscript. All authors read and approved the final manuscript.

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Appendices

Appendix 1: Questions for the public in the PPI Hawker Pilot

1. If you were a participant in the study...

- What would be needed for you to be reassured that your personal data is being protected?
- What types of information are acceptable to collect from people participating?
- Would it be acceptable for anonymized data to be shared with:
 - Other health care professionals in Singapore?
 - Industries in Singapore?
 - Overseas organisations?

2. Increasingly health records are being digitalized: in theory personal health records and the research study could be linked, and data shared...

- What do you think the benefits could be of such data linkage?
- What concerns might you have of researchers from this study accessing (*taking data*) your electronic health data or contributing (*providing data*) to your electronic health data?

3. If in the future this study asked its participants to return for further data collection...

- What concerns might people have about continuing involvement?
- How could these concerns be reduced?

Appendix 2: Questions for the public in PPI Hawker Sessions 2 and 3

1. If you were to be recruited for this study...

- What would be attractive in this study?
- How would you like to be recruited?
- What concerns would you have about it?
- How could these concerns be addressed?

1. Research records are anonymised, so the researchers don't know participants' names and personal information. The information researchers work with is called anonymised research data.

- How would you feel if your anonymised research data was shared with:
 - Other healthcare professionals in Singapore?
 - Other researchers in Singapore?
 - Public institutions in Singapore?

- Commercial partners in Singapore?

Then ask the same for overseas.

1. The study has a commitment with the communities it serves and would like to engage its participants further, even after their visit. Previous participants are part of the study “family”, and we want them to feel included. By building long-term partnerships with them they can advise on how to develop the study and share their expectations.

- Would you like to be engaged with the study after your visit?
- If so, how often? For how long? With whom?

4. 10 years after the study has finished, researchers find a gene in a research participant which might indicate increased risk of cancer later on in life (this is known as an incidental finding). However, treatment for this cancer still does not exist.

- Do you think the study should track back the participant and inform them of this finding?
- Would you think differently if there was some form of treatment available?
- Do you have any concern/ anxiety knowing that this could happen?
- What sort of incidental finding do you think should be reported back to participants?

Figures



Figure 1

Photograph of Serangoon Gardens Market & Food Centre. Photo Credit: Cynthia Chew (36)

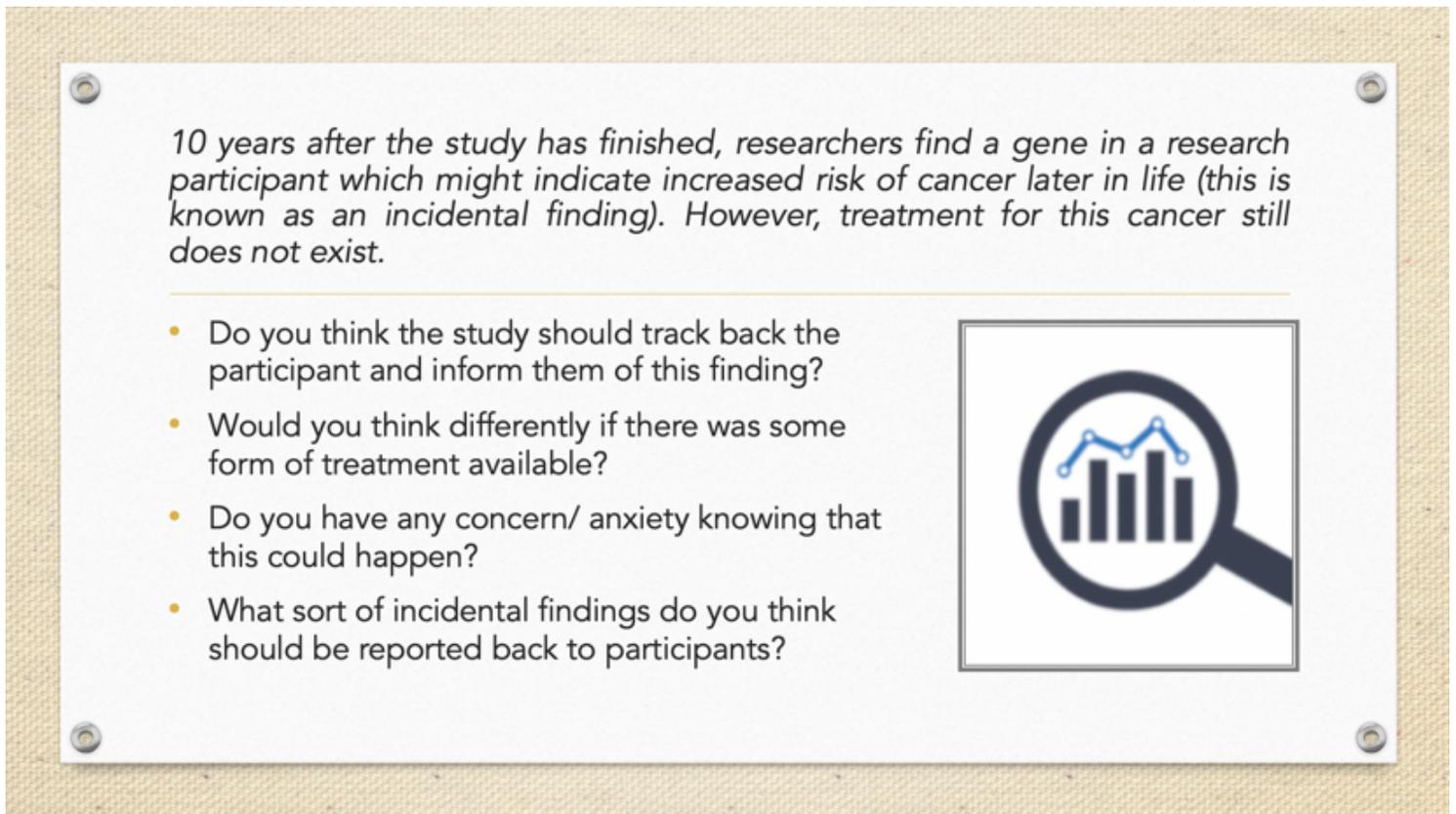


Figure 2

Example of cue card containing a question and prompts for the PPI Hawkers

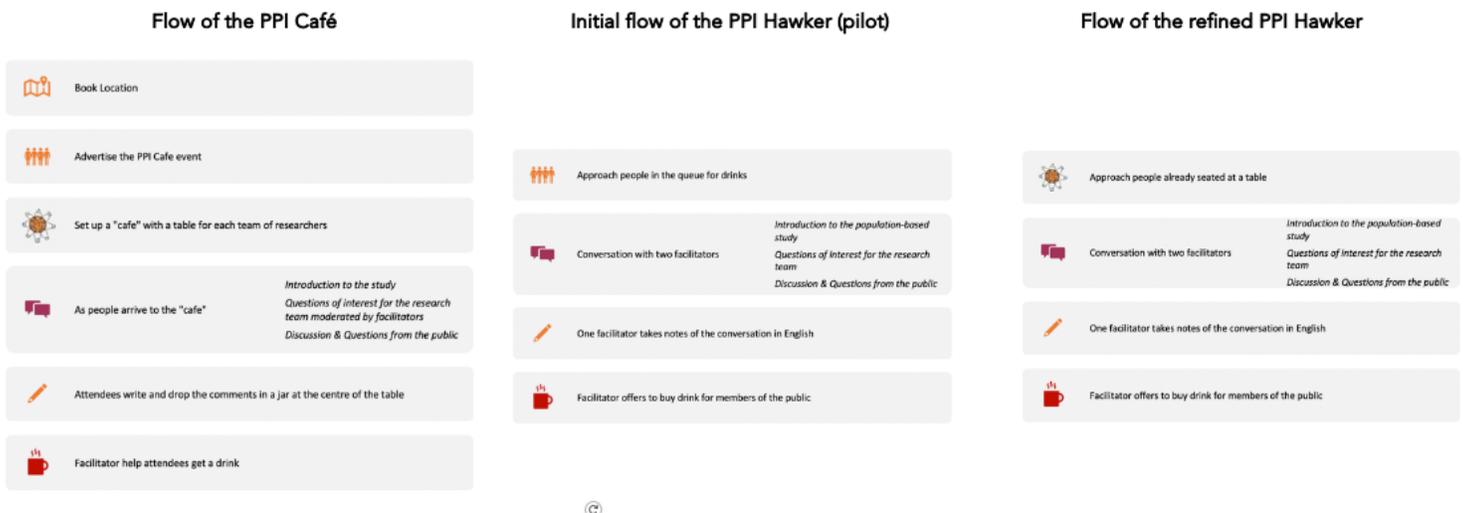


Figure 3

Design of the PPI Hawker, building on the PPI Café



Figure 4

How to organise a PPI Hawker in 5 steps