

Glasgow Public Involvement in Cancer

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1 Executive Summary

- 1.1 The health inequality gap in cancer survival rates between affluent and deprived communities in Scotland is widening yet limited attempts have been made to understand the views and opinions of the people living in deprived communities on cancer.
- 1.2 It has been identified that deprived communities view cancer in a more negative and fatalistic way than affluent communities.
- 1.3 A rapid appraisal approach was adopted to explore the perceptions of cancer and health promotion in three deprived Glasgow communities in more depth.
- 1.4 Over 170 men and women aged between 16- 85 living in Govan, the Gorbals and Shettleston were consulted in addition to 19 key informants involved in local public health initiatives.
- 1.5 A commonly held initial view was that cancer was associated with death. However, upon deeper investigation more sophisticated understandings of cancer survival rates were evidenced.
- 1.6 Few, if any, of the lay participants appeared to be aware of local health improvement initiatives.
- 1.7 Contrary to most key informant views, many participants displayed a sophisticated understanding of the multiple factors that can lead to cancer and want public health professionals to acknowledge this range of factors and not solely focus on lifestyle advice.
- 1.8 The link between the adoption of health improvement behaviours and reducing cancer risk was commonly questioned, with clear reservations about the link between smoking and cancer in particular.
- 1.9 Health improvement messages relating to cancer are not received in a universal manner. Family and personal experience of cancer is crucial in how participants viewed cancer and health education messages. Messages can also be filtered by social status such as gender and age.

1.10 Residents in these areas, despite being traditionally viewed as 'hard-to-reach', were found to be willing to engage in consultations around health when involvement is localised

2. BACKGROUND

Three decades of social epidemiology have established the gap in health status between affluent and deprived groups of people as one of the most challenging public health issues of our time (Adler, Boyce, Chesney et al, 1994; Antonovsky, 1967; Marmot, Kogenivas and Elston, 1987; Wilkinson and Marmot, 1998; Wardle, McCaffery, Nadel and Atkin 2004). This gap is particularly apparent in the cancer rates of people living in affluent and deprived areas in Scotland, where the likelihood of developing cancer and the risk of dying from cancer is consistently and significantly higher for people living in the latter.

In response to this situation, current Scottish health policy (SEHD, 2000; 2005) contends that the reduction of health inequalities is designated as 'cross-cutting priorities'. The first objective within 'Health and Community Care' in the Scottish Executive's recently published spending review (SE, 2004) is "to reduce the health gap between people living in the most affluent and most deprived communities".

Scotland experiences higher incidence and mortality rates from cancer compared to other western European countries (SEHD, 2001). This 'Scottish Effect' is particularly evident in Glasgow (Hanlon, Walsh and Whyte, 2006). Whilst Glasgow has become a much more affluent city with increased employment and rising income levels in recent years, health status and inequalities in health lag behind significantly. This has been named the 'Glasgow Effect'; an excess of mortality beyond that which can be explained by current indexes of deprivation so the health status is worse than that of other comparable cities such as Liverpool (Hanlon et al, 2006). Despite a continued improvement in the survival rates for most cancers in recent years, incidence and mortality rates of cancer in Glasgow's most deprived communities are significantly worse than in the rest of the country as depicted in Figure 1.

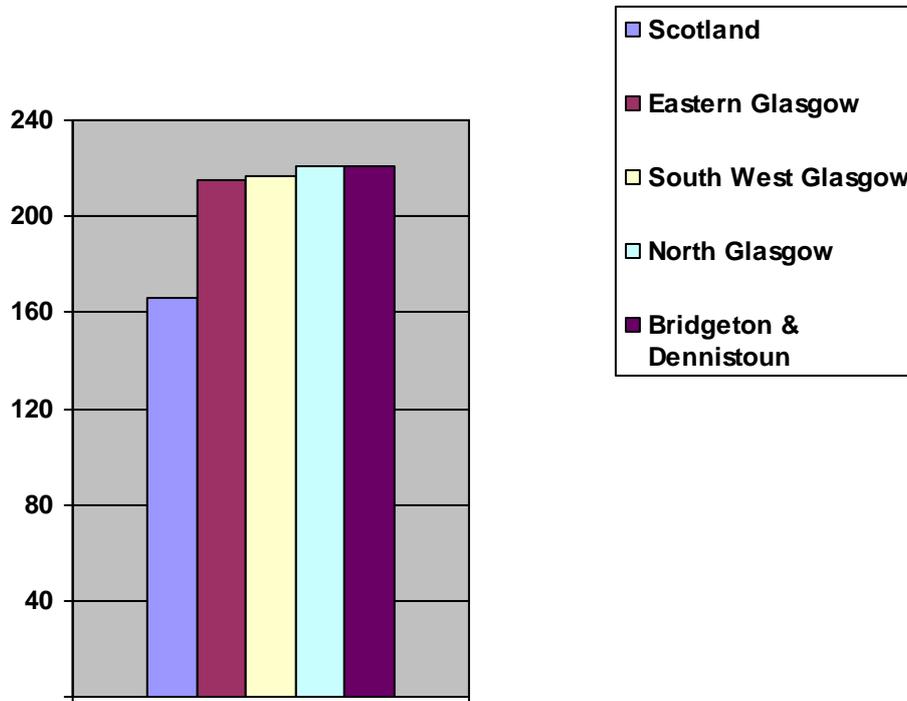


Figure 1: Average annual age-stage standardised death rates from Cancer (per 100,000) in Scotland and selected communities in Glasgow, 2000-2002. (Hanlon, Walsh and Whyte: 2006:300)

Lung, pancreas, oesophagus and head and neck cancers which are strongly linked to health behaviours such as smoking, food choice, physical activity and alcohol consumption have shown little improvement. These are recognised as behaviours that people in lower socio-economic groups are more likely to engage in (Jarvis and Wardle, 1998; Lantz and House, 1998). *Cancer in Scotland: action for change* (2000) outlined the Government’s strategy for preventing cancer, stating that the best way to tackle cancer is to change peoples’ lifestyle through health promotion and cancer prevention strategies.

What is not clear is whether current health promotion schemes are effective in improving the health of those who might benefit most. Recent research illustrates that whilst health improvements are being made across Scotland, the differences between deprived areas and the population as a whole are increasing because greater inroads are being made in affluent areas (*Social Focus on Deprived Areas*, 2005). The report suggests that this may be a consequence of health improvement messages and interventions being adopted in different ways by different socioeconomic groups. For example, the affluent and educated are more prone to modify their diets, give up smoking, and take up healthy physical activities than the less affluent and poorly educated (Vetter, 2005). Indeed, it has been suggested that

health promotion interventions frequently increase, rather than decrease, socioeconomic inequalities in health (Acheson, 1998).

In their WHO report *Closing the Health Inequalities Gap* (2005) Crombie and his colleagues suggest providing the means to tackle inequalities has often been overlooked as a result of the inevitable tension between that and the other prime goal of public health policies: to increase average life expectancy. Policies to increase average life expectancy direct resources towards the causes of mortality in all social groups, and tend towards tackling the health problems most amenable to improvement and achieving the greatest overall improvement in health from the available resources. In contrast, policies targeted at reducing inequalities on health, target resources at disadvantaged groups such as deprived populations. Crombie's argument could be applied to cancer prevention strategies where resources target affluent populations, who are those most likely to change their behaviours (Wardle et al, 2004). If resources were instead aimed towards those most at risk of cancer, the changes are not likely to be as significant and the health gains for the overall population reduced despite benefiting those most at risk.

Reducing rates of smoking, alcohol consumption and changing diets within any population is notoriously difficult. Changing these behaviours in deprived areas is particularly challenging because of the poor physical and social environment (Lantz and House, 1998). Why 'the poor behave poorly' (Lynch, Kaplan and Salonen, 1997), has been a matter of much debate in recent years. The focus has been on the down-stream agency explanations versus up-stream structural explanations. Down-stream agency explanations focus on the voluntary nature of choices with people as active agents choosing to start smoking, eat unhealthily and not to exercise. Many health promotion strategies focus on encouraging 'healthy choices' through education. Yet health improvement initiatives have at times fallen into the trap of blaming the victim by not sufficiently taking into account the importance of life circumstances; the social, economical and political factors that shape lifestyles (Ashton and Seymour, 1988). Lifestyle, diet and smoking have been presented not only as primary but as the sole causes of ill health and cancer (Watterson, 2002). Latterly, however, up-stream structural explanations, which emphasise the impact of social and economical factors on encouraging the adoption of certain health behaviours as responses to difficult and stressful conditions, have become widely acknowledged (Watterson, 2002; Wardle et al, 2000).

More stressful life circumstances are associated with higher levels of smoking, less healthy eating and less physical activity (Wardle et al, 2000, Cartwright , Wardle, Steggle et al 2003). Thus, the root causes of inequalities in health are a complex interaction between personal, social, economic and environmental factors (Gordon, 1999; Marmot and Wilkinson, 1999). This knowledge has led to the expression 'it all matters', coined by Professor Phil Hanlon. Hanlon and his colleagues state that "*health in populations emerge from a complex interplay between the physical environment, social environment, individual response and behaviour, genetic endowment and the provision of services interacting with economic and other influences*" (Hanlon et al, 2006).

Some clues to the way in which the social environment and individual response interact may be held in the value placed on, and the beliefs about, behaviours considered healthy in different socio-economic groups. Goldstein (1992) proposes that lower socioeconomic status is associated with lower participation in the commitment to health improvement through behaviour, what he calls 'the health movement', partly because of differences in values and beliefs about health behaviours. The evidence for different health beliefs and values in different socioeconomic groups is mixed, yet several studies have shown that the value placed on primary prevention behaviours such as healthy eating, an exercise regime and secondary prevention behaviours such as attendance at cancer screening are higher in higher socio-economic groups (Wardle et al, 2004; Steptoe and Wardle, 1999; Clark et al, 1995).

The interaction between beliefs, social norms and prevention behaviours may also be deduced from the attendance rates at cancer screening clinics. Participating in cancer screening arguably suggests a belief that the early discovery of cancer will be beneficial to the individual. If an individual believes that treatment will not prolong or preserve life, however, attendance at screening may not be a rational action. People with lower socioeconomic status have been shown to be less knowledgeable about cancer (Wardle et al 2001) and studies of public perceptions of cancer have identified that the majority of people belonging to lower socio-economic groups hold fatalistic beliefs about cancer (Murray and McMillan, 1993; Price, 1993). For cancers such as bowel and lung people expressed the view that there was nothing individuals could do to reduce their risk and once diagnosed the disease was fatal (Price, 1993a; 1993b).

A recent review of cancer fatalism exploring the belief that death is inevitable when cancer is present, identified this belief as a barrier to participation in cancer screening, detection and treatment (Powe and Finnie, 2003). Wardle et al (2004) also propose that cancer screening rates are lower in deprived areas because people living there hold more fearful and fatalistic beliefs about cancer.

Research by the Cancer Care Research Centre (Kearney et al, 2005) supports this. Gaining an understanding of the views of the Scottish public was a key part of the information gathering phase of the three-year programme of research, *Understanding Patient and Carer Experiences of Cancer*. This project aimed to establish baseline information on public perspectives of cancer. The findings showed clear differences in the perceptions, beliefs, preferences and views held in areas of affluence compared with areas of social deprivation. In contrast to people living in affluent areas, people living in socially deprived areas appeared to show a lack of basic knowledge about cancer risks, symptoms and prevention. They also appeared to hold more fearful and fatalistic beliefs about cancer. Whilst the benefits of screening were perhaps over-estimated in affluent communities, a number of people in deprived communities saw no benefit to the early detection of cancer, as death was inevitable 'once it's in you'. Information about cancer was derived from family and friends and media. A marked distrust in health improvement messages given by the Government and health professionals was also evident.

The relationship between health and socioeconomic position is complex, and as yet, not fully understood. More research is therefore needed to improve understanding of the routes through which deprivation leads to particular cancer beliefs and responses to health promotion activities and messages. Assumptions are often made that the barriers to the take up of health promotion, including cancer prevention, messages in people living in deprived areas lie in personal factors such as lack of motivation, fatalism or short-termism, or lack of personal resources such as money, time, equipment, or knowledge (McIntyre, 2000). Investment in health improvement activities, such as cancer prevention, has been prolific in recent years yet these activities seem to have had little effect in the populations most at risk in that the gap between rich and poor is widening (SEHD, 2005). Despite this and the current public involvement in health policy set out by the Scottish Executive, little research has been carried out in Scotland to understand cancer attitudes, beliefs, and the social context of cancer in lower socio-economic groups.

The aim of this public consultation, then, was to assess the views of people living in deprived areas of Greater Glasgow concerning cancer, health and local health improvement activities. Cancer has a high profile both in health improvement terms and in the media, yet little is known about the impact of health improvement activities, media attention and the direct or indirect experience of cancer on the views of the public living in deprived areas. It is important that health interventions are both evidence-based and designed in partnership with members of the communities targeted to increase their effectiveness. Thus, gaining a better understanding of how people in deprived areas perceive cancer, health and health promotion activities is crucial in the development and directing of future health improvement initiatives.

3. METHODS

3.1 Design

A rapid appraisal approach was adopted to develop a better understanding of the issues involved in the reception, filtering and actions taken in relation to cancer information and health improvement activities. Rapid appraisal is a mixed methods approach incorporating qualitative and quantitative research methods to gather information supplemented by documentary data.

Rapid appraisals are based on the premise that a representative picture of the views, needs and/or priorities of a local population can be derived from a small number of key informants (Ong and Humphries, 1994). In addition to actual members of the population of interest, informants may be those with some knowledge of their needs, such as health care and community professionals. In this way, rapid appraisals identify and value the knowledge within a community and tap into it by bringing together the views of key informants with key roles within the community, local members considered representative of the community and epidemiological information. The inherent triangulation of sources of data and methods of data collection provides opportunities for crosschecking and validating findings throughout (Koelen et al, 2001; Rhodes et al, 1999). One of the greatest strengths of rapid appraisal is its cyclical and iterative process, including opportunities to reflect and disseminate findings to members of the community, thus increasing validity (Koelen et al, 2001). Choices of data collection methods can also be adapted whilst still in the field to suit the community in question and in this consultation more visual methods were adopted with young people to overcome obstacles to involvement that traditional qualitative methods can pose with this age group (Morrow, 2001).

Participatory approaches such as rapid appraisals can also be an empowering process to engage community members (Heaver, 1992).

3. 2. Process and aims

Rapid appraisals took place in three areas of Greater Glasgow: Shettleston, Govan and the Gorbals, selected because of their status as areas of multiple deprivation. The methods employed included in-depth individual interviews with key informants (KI), focus groups with residents, and open stalls and exit questionnaires in key community sites. We also incorporated some participatory methods in the data collection better suited to young people. Secondary data was utilised to provide a context through compiling demographic and epidemiological community profiles of the three areas.

The data collection focused on the following key issues;

- To gain an understanding of what people living in three deprived areas in and around Glasgow think about cancer and health improvement activities in their local areas
- To contextualise these views with the perceptions of the health care and community professionals providing cancer and health improvement initiatives in these areas
- To evaluate the usefulness of a public involvement strategy to contribute to shaping further health promotion work in these and similar communities

3.3. Participants

Purposive sampling was used to reach a cross section of members of the public living in the three areas. Particular effort was taken to capture the voices that are harder to hear in health research such as those of men and young people. This was guided by information gained from an initial round of key informant interviews that included professionals with a high degree of local knowledge. Key informants included health professionals and community workers. For reasons of clarity, members of the public residing in the areas and taking part in the focus groups and open stalls will be referred to as participants and key informants responding in a professional role will be referred to as key informants (KI).

There were a total of 173 participants and 19 key informants. Demographic data was provided by the 173 participants by questionnaire.

Area	Key Informants	Open Stalls		Focus Groups		Area total
		Male	Female	Male	Female	
Govan	5	9	13	21	22	70
Shettleston	6	11	15	6	17	55
Gorbals	8	14	17	4	24	67
Total	19	79		94		192

Table 1: Project participants and key informants

3.4. Data Collection

Data collection took place between December 2005 and May 2006 and involved collection of multiple data sets as detailed below. Data collection followed a structured framework (Kearney et al 2005) as depicted in Figure 2.

3.4.1. Community Profiles

Two types of information were gathered to provide a profile for each of the target areas. First, information was obtained to provide a general profile of the area including; life expectancy, education level, socio-economic status, occupation and health status. The information was generated from a variety of sources including: census data published by the local Council, and health and well-being profile constituency data published by NHS Health Scotland. Comparative information for the country was also extracted from the Scotland Census 2001. Secondly the Information Services Division (ISD) Scotland, NHS National Services Scotland provided their most up to date cancer specific data based on the general postcode of the target areas. Cancer data for each population included:

Incidence: Numbers of new cancers diagnosed by sex, and crude rates by sex, for the combined period 1999-2001 (for all cancers combined, and for the ten most common cancers in Scotland).

Mortality: Numbers of cancer deaths by sex, and crude rates by sex, for the combined period 1999-2001 (for all cancers combined, and for the ten most common cancers in Scotland).

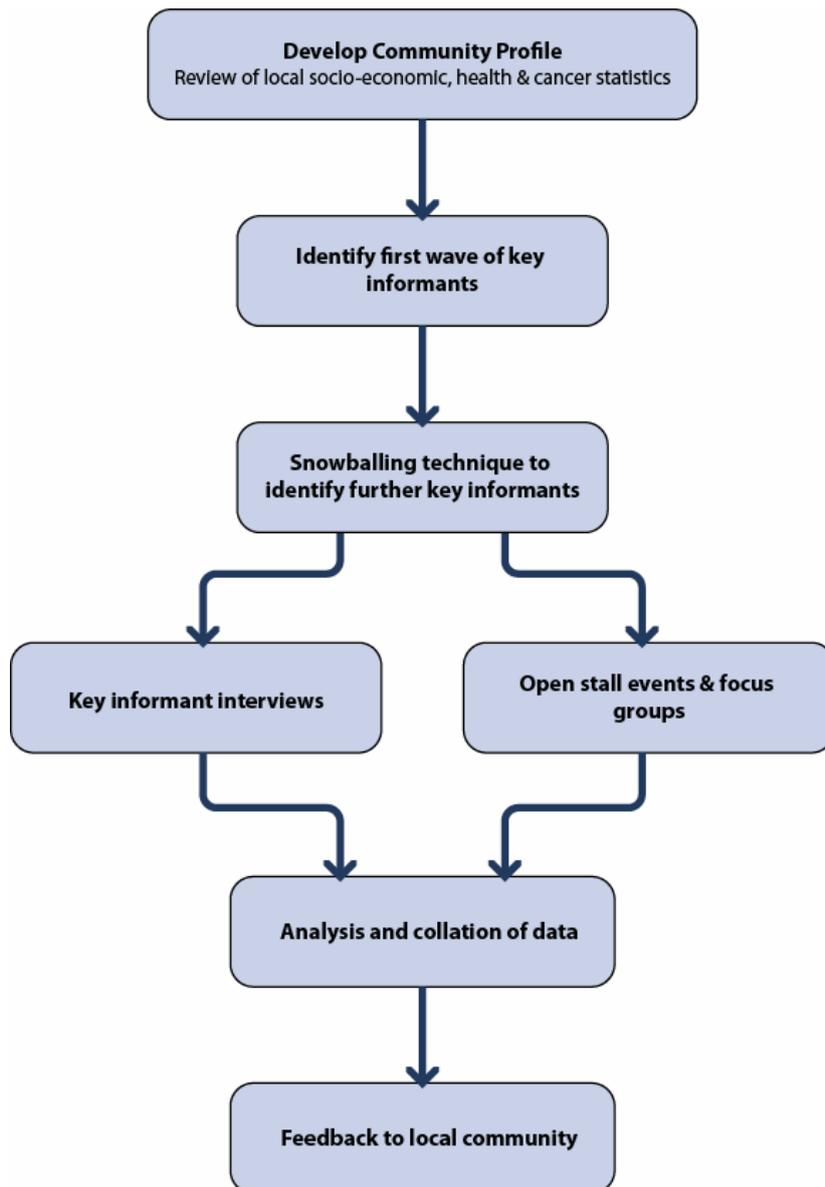


Figure 2: Rapid Appraisal process

Treatment: Numbers (and percent) of registrations by sex during the combined period 1999-2001, who within 6 months of diagnosis received (a) surgery; (b) radiotherapy; and (c) chemotherapy (for all cancers combined).

Cancer-related hospital admission for the postcode area: Acute hospital discharges (episodes) with any mention of a malignant neoplasm diagnosis by sex 1999-2002.

3.4.2. Key informant interviews

Up to eight key informants were interviewed in each community to identify salient health and social issues. Purposive sampling ensured professional insights were included by selecting individuals with knowledge of health and social issues. Key informants contacted in each area included: public health professionals; local health professionals (GP, district nurse, Macmillan nurse) and local social care/community workers. A 'snowballing' technique was adopted to allow each key informant, as well as participating members of the local communities, to nominate other people living or working in the community considered knowledgeable about local issues.

Key informants were contacted by letter, email or telephone. Those who agreed to participate were interviewed by telephone or in person, depending on their preference.

The aim of the interviews was to provide a context for the data elicited in the focus groups and open events. Informants were asked to provide answers to the following four questions:

- What are the main health needs in the area?
- What knowledge and perceptions do you find people have about cancer?
- What examples are there of local health promotion initiatives? How effective are they?
- What steps do people take to improve their health?

Probes were used to explore answers further. Key informants were also asked to identify other potential key informants. The interviews lasted between 30 and 45 minutes on average and they were recorded or detailed notes were taken as a record. In total 19 informants were interviewed.

3.4.3. Open stalls

In order to capture the views of the public, semi-structured questionnaire data was collected at open stalls in each area. The stalls took place in a shopping centre and two supermarkets. Leaflets advertising the open stalls were distributed and posters positioned in a range of places local people frequented such as shops, pubs and health centres. Key informants for each location were asked to identify the 'hub' of each community where a wide range of community members could be found. Consent to hold the stalls was sought from the manager of each location. Two researchers were present at each stall for a three hour period covering lunchtime to enable as many people as possible to participate. In one community, the research team also moved locations to a local pub as there were very few men in the supermarket. Individuals who approached the researchers were asked the following questions:

- What does cancer mean to you?
- What causes cancer?
- What can people do to prevent cancer?
- Where would you go to get information about cancer?
- What local projects or activities do you know of that help people improve their health? How would you rate them?
- What are the most important things you can do to improve your health?
- What makes it difficult to improve your health?

Detailed notes were taken of the participants' responses. A member of staff from Cancerbackup was present to provide information and support if needed. Cancerbackup literature was also freely available at the stall and cards with a free telephone number were given to each person who participated. In total, 79 people attended the open stalls in Govan (22), Shettleston (26) and the Gorbals (31). The gender composition across all areas was 34 men and 45 women.

3.4.4. Focus groups

Focus groups were chosen as a data collection method as they are considered to be excellent tools for gaining insight into complex behaviours such as perceptions of cancer risk. Deemed particularly useful for exploring group norms and implicit cultural beliefs, focus groups can also be used to examine not only *what* people think but *why* they think that way (Kitzinger, 1996:36). Focus groups can also facilitate the discussion of sensitive topics allowing less inhibited members of the group to initiate topics for others to contribute to.

Mainly recruited from local community groups across the locations, the focus groups consisted of an average of 4-8 people. In total, 11 focus groups were held across the locations. In total, there were 94 participants in the focus groups. A breakdown of the participants at the focus groups is presented in Table 3.

For young people, the rather formal nature of traditional focus groups was found to be inappropriate so visual participatory methods were utilised. These allowed young people to explore health and cancer related issues through body mapping (drawing the ideas about cancer risk and causality either outside or within the body), community mapping to show resources and risk factors for health and H diagrams (Pretty, Guijt, Thompson and Scoones, 1995), to allow positive and negative features of their lives to be recorded and changes suggested. Such methods are well suited to young people as they have been found to reduce shyness and power relations in talking to adults by focusing on their own frames of reference and experiences (Boyden and Ennew, 1997).

Location	Male	Female
Shettleston	6	17
Govan	21	22
Gorbals	4	24
Total	31	73

Table 3: Focus group participants (N=94)

The focus groups were asked the same questions outlined in the open stalls section above (3.4.3), allowing the exploration of these issues from the perspectives of the different groups. Group discussions were facilitated by a member of the research team. All participants agreed to the tape-recording of their discussions and were given information about Cancerbackup's free telephone service and the opportunity to gain information and/or support from a member of Cancerbackup staff present on each occasion.

3.4.5. Exit Questionnaire

To record the number of participants involved and identify whether or not they had been affected by cancer, all participants were asked to complete an exit questionnaire (Appendix 1) with the following information:

- Age
- Gender
- Main occupation
- Post code area
- Whether they are currently or have previously been treated for cancer
- Whether they have a close friend, partner or relative who is/has been treated for cancer

4. ETHICAL ISSUES

Throughout the Public Involvement process we adopted ethical procedures from the Market Research code of conduct (MRS, 1998). The MRS includes principles that relate specifically to eliciting the views of members of the public so is applicable to this consultation process as it involves members of the public, rather than research specifically involving people affected by cancer,

The basic principles employed are:

- Participants will be honestly and comprehensively informed about the research in which they were taking part
- The rights of participants will be paramount
- Participants will be openly asked to give their consent to take part and to any subsequent attributable use of their comments (and any other material arising from the group/interview)
- Undertakings made to participants will be honoured
- The research will respect the interests of clients

- Participants will be treated with respect at all times
- Throughout data collection and analysis, processes and procedures will be used to ensure the quality and reliability of the information.

It was not anticipated that members of the public would become distressed during this process, however cancer and cancer care is a potentially sensitive issue, therefore it was important to provide support if required. In addition to members of the research team, who were on hand to support attendees, a formal arrangement was negotiated with Cancerbackup who provided information and support as needed to each person involved in the consultation.

5. DATA ANALYSIS

Data from components of the rapid appraisals were analysed i), separately ii), as a whole rapid appraisal for each community and iii), with complete synthesis of the three rapid appraisals. Each researcher took the lead on data collection and analysis in an assigned community (WG in Gorbals, NRD in Shettleston and PS in Govan). Findings from the three appraisals were then compared and contrasted by the three researchers both in isolation and in discussion, thus building up a picture of the common themes across areas. All data collected including field notes, detailed notes from the key informant interviews and the transcripts from the focus group discussions were subject to thematic analysis aided by the NVivo computer package. The data collection was designed to adapt to the further exploration of key emergent themes.

Analysis was undertaken by one researcher and checked by another. The cross-checking and identification of themes across the three communities was overseen by all three researchers within the team. The emerging themes were regularly reviewed and discussed by members of the team involved in the analysis. This approach ensured consistency of analysis. In the Govan area, data collection compensated for the difficulties in accessing young people's views by making a concerted effort to collect such information. The analysis of this data collected through visual methods involved identifying themes that either reflected or offered new interpretations of health and cancer awareness and barriers and facilitators to the achievement of health, than those proposed by adults involved in the consultation.

6. FINDINGS

Five main themes emerged for the findings drawn from the open stalls (OS), focus groups (FG) and key informant interviews (KI). These are presented below and are reported in more detail in the remainder of this section;

1. When asked to express beliefs about cancer, participants' initial responses were "death and despair". Further investigation in focus group discussion, however, displayed knowledge of advances in medical knowledge and treatments.
2. People living in socio-economically disadvantaged areas did display understandings of cancer risks and prevention incorporating both the influence of personal health behaviour and environmental and/or cultural factors. Although participants were aware of health promotion information relating to cancer they were often critical of it. The link between the adoption of health improvement behaviours and reducing cancer risk was commonly questioned, with clear reservations about the link between smoking and cancer in particular.
3. A commonly held view was that people did not think about cancer until it affected them, their friends or family personally. However, nearly all participants had experience of cancer in their families or of close friends or partners. The nature of this cancer experience was likely to shape their cancer beliefs. For example, if the person they knew had eaten well, exercised or not smoked and had died, participants may conclude that that these health behaviours might not protect them from cancer. If the person had died, this was also likely to affect beliefs about the inevitable outcome of cancer.
4. Participants were not aware of health improvement facilities in or outside their area other than primary or secondary care centres. Nor were most people aware of cancer or general health internet sites or telephone-lines. Although some were aware of these facilities, they could not name them. Consequently, when asked where they would go for information about cancer, the majority would cite their GP or local hospital as their primary source of information.
5. Health improvement messages relating to cancer are not received in a universal manner. As well as personal experience, messages can be filtered by social status such as gender and age. In this consultation, the views of men and young people showed noticeable differences from opinions expressed by other participants.

These themes are explored in more depth below.

6.1. Meaning of Cancer

When asked what cancer meant, participants would respond that cancer was primarily associated with an almost inevitable death. However, this position was often just the starting point for an exploration of the meaning of cancer. Such responses were more commonly collected through the open stalls, where the short-response form of the semi-structured questionnaire was more likely to produce concise, non-discursive responses. We coded the categories of response to the question 'What does cancer mean to you?' at the open stalls; "death and despair" and "more positive prognosis". Initially we termed the latter category "more *realistic* prognosis" as they were often supported by personal experience of cancer in the family or social network. However we were soon led to reflect on whether the "death and despair" approach was not also based on personal experience. This was expressed by a GP working in Govan, who told us,

"It is entirely appropriate to see cancer as a death sentence when the main tumour seen is lung cancer with a survival rate of 5 percent."

Although we did not specifically ask about the types of cancer people had experience of, the exit questionnaires at the focus groups and the open stall questionnaires *do* indicate that the majority of participants had a close relative or friend who had been affected by cancer. This appeared to be a key filter through which people interpreted other information such as health improvement advice and developments in medical intervention; whether it had resonated with their own experience. For example, in a Shettleston focus group, a middle-aged woman explains that despite her knowledge of different types of cancer and improved survival rates after treatment that *"everyone I know that has had cancer has died. Sorry but I don't know any survivors of cancer. (Responding to another focus group member) I know you are saying that your ex-partner is a survivor but I don't know him so that doesn't count."* Other examples of the death and despair belief include *"The end of the world, very scary"* (Gorbals OS), *"You hear somebody's got cancer, you just say they're gonna die"* (Gorbals FG) and *"the minute they say cancer, you think that's the end"* (Shettleston FG).

Such views could further inform attitudes towards screening, early detection and treatment with such actions and treatments being seen as pointless; *"Why prolong the trouble?"* (Older male, Shettleston FG).

More positive assessments were also likely to be filtered through the prism of personal experience. In the open stalls, the more positive beliefs included;

“Death was my initial reaction before diagnoses of my mother’s cancer” (Older female, Govan FG)

“I’ve had it, at the beginning I thought I was going to die no matter what. Makes you look at life different” (Middle aged male, Govan OS).

However, this is not to understate the perceived contradiction between knowledge received from health promotion sources and that amassed through personal experience, from which dissonance and questioning could be a consequence. In the following quotation, a middle aged man expresses this ambiguity between what he gathered from health improvement sources and what he has experienced. On one level he knows that early detection of cancer can lead to a more positive outcome, but this contrasts with his personal experience;

“Twenty years ago you would not have got the public information given out about testicular cancer and how to check for testicular cancer. Over the decades I’ve seen improvement so I know when I hear cancer I don’t think that it’s full stop, you know the end of life. But I’ve lost a good friend and colleague of mine who died of cancer, so I suppose it is a kind of fear of the unknown or it’s always because it’s ended in loss of life” (Govan, FG)

This leads to another key characteristic in the lay understandings of cancer; its *mysterious* character in comparison with other diseases. This mysterious component is constructed through multiple factors according to the participants; it can be present and spread with no noticeable symptoms. It is also seen, as will be discussed in more depth below, to be *resistant* to health improvement measures in that living a healthy lifestyle is no guarantee of avoiding cancer. Unlike in heart disease, the relationship between behaviour and possible diagnosis is less clear cut. Given the contradiction between health education and experience, let alone the contradictions and uncertainties within scientific knowledge (received through the media) cancer is constructed as an outcome that defies rational action. The causes of cancer comprise a complex and inherently confusing mixture of hereditary, environmental and behavioural factors. Complexity is also added by a widespread recognition of the variety of different forms of cancers. Some of these are considered responsive to treatment by the participants;

“It’s better than it used to be as there are lots of treatments now e.g. testicular and prostate cancer can be treated.” (Gorbals OS)

“For instance, testicular cancer, there’s a high percentage of recovery from that, to say lung cancer or brain cancer. I would think that was serious, you need your brain, you need your lungs. My friend, she got cancer, it came back twice but she’s got through it.” (Gorbals FG)

6.2. Cancer risk and causes

The “death sentence” was the thematic starting point for exploring meanings of cancer and also for beginning explorations of the *causes* of cancer. Beliefs about causes highlighted understandings of risk and prevention. A remarkably common understanding was of cancer being present in all our bodies and something “*triggering it off*”. This illustrates how participants had an understanding of the origins of cancer and how subsequent events can increase the chances of a diagnosis that was similar in form, if not necessarily content, to scientific understandings. Where it did deviate from health improvement advice was in the *questioning* of the efficacy of behavioural influences on cancer outcomes. It was not that most participants denied the influence but often felt it could be over-played by health promoters. Again the dissonance between such professional advice and their own experience was key. In the following section we explore how the combination of multiple factors – genetic, events (such as falls and bumps), environment and behaviour – are incorporated into lay perceptions of cancer causation and differential risk. Another significant theme challenged the foundation of health improvement advice more directly, claiming that no one knows what causes cancer.

Fatalism, genetics and luck

After the KI interviews we expected to encounter fatalistic attitudes towards cancer. It turned out that understandings of risk were more sophisticated than the key informants suggested. A few people did express fatalistic beliefs but these were a minority.

“No, there’s nothing you can do, if it’s there, it’s there” (Shettleston OS).

“It’s chance. People do all the correct things and get it” (Govan OS).

“I don’t think you can actually prevent cancer, that you can lower the chances of getting cancer, if it’s meant to be” (Gorbals FG).

If there was a degree of fatalism in people's understandings then it was often within a hereditary understanding of risk. Participants made sense of genetic predisposition to be part of the picture of influences leading to cancer (*"you're born with it", "it's inside you"*) but it was complicated by additional environmental or behavioural components to that picture. Generally genetic factors are more accurately described in participants' beliefs as a predisposition or necessary condition for the development of cancer rather than a sufficient condition in all cases. Most people did believe there was a behavioural component to risk prevention, but equally cancer could be "triggered" (rather than "caused") by events such as a fall, stress or exposure to environmental risks.

"Everybody's got cancer in their body but certain things spark it off- smoking, drinking, different things" (Govan, OS)

"You take an illness and it just triggers it off. Something like a bang or a fall just triggers it off" (Gorbals FG)

A further complication was the understanding that people could develop and die from cancer without being diagnosed with it. This was a slightly different understanding to that of cancer being triggered, in that the cancer did not advance far enough to cause a diagnosis before some other factor intervened to cause death- such as, in the following example, being hit by a car.

"I mean there might be a lot of people carrying it, it's hereditary, but something else happens, you know you get knocked down by a car you know. So it (cancer) does not appear on your death certificate. Whereas what was happening inside of you, you know. I know there are percentages that show it's hereditary, generations of a family have you know, fallen foul of cancer." (Middle aged male, Govan, FG)

Behavioural factors

Most people contacted said they felt there was something that could be done particularly about a healthy diet and smoking yet they would also question these messages. This questioning came from some key informants too. One KI, involved in promoting healthy eating, expressed her own scant knowledge of the science around eating and cancer risk. Whereas she was confident enough in the scientific knowledge to recommend healthy eating lifestyle messages, she felt unable to explain the process by which diet increased or decreased cancer risk. Another KI reflected on her own dietary practices and her diet high in anti-oxidants that comprised her cancer risk- reducing behaviour. She admitted that her approach to this was in part ritualistic, based on faith in the science rather than a confident understanding of it, of how anti-oxidants actually reduce the risk of cancers and which ones.

Community participants did not deny that they could play a part in reducing their cancer risk but that there were limits on what an individual could do. Perhaps not surprisingly, participants commonly referred to people who had smoked and consumed alcohol all their lives and still lived long lives, set against examples of abstemious lives affected by cancer as evidence of the limits of lifestyle information. People were less able to identify where these limits lay, which educational advice to adhere to and which environmental factors or events were insurmountable. Whilst smoking was cited most frequently as a risk for cancer (47 of 79 responses in open stalls), it was nearly always accompanied with a caveat:

“Smoking, but my Aunty didn’t smoke and she got bowel cancer” (Gorbals OS)

“Drink, smoking, but I don’t know if it’s true, as I got cancer and I had not smoked for 15 years. I don’t know how I got it.” (Shettleston, OS)

“They blame it on smoking and drinking, you know, but they cannae blame it on them, when there’s people who haven’t smoked, haven’ t took a drink and they’ve caught it” (Gorbals, FG)

The weight given to smoking as a risk over other factors by health professionals was a cause of annoyance to some participants:

“Touch wood, I’m not smoking very often, but when you go to the hospital, that’s the first thing they ask you - are you a smoker? And I just think, they put everything down to smoking” (Gorbals FG)

Participants' understanding of the different risks for different cancers also led to a questioning of the primacy to behavioural factors in reducing risk:

“Things like lung cancer may be linked to smoking, but leading a healthier lifestyle-how would that prevent something like breast cancer, ovarian cancer? It seems a bit weird.” (Gorbals FG)

This was in contrast to what the key informants told us they felt we would find about people's understanding about the link between smoking and cancer, that it would be accepted as related to lung cancer. However, one key informant offered us guidance on how to interpret such priorities given to different forms of knowledge:

“Everyone has an Uncle Lenny who drank whisky every day and lived to 80. Their own experience is more persuasive than health education or scientific messages” (KI, Govan)

The KIs, however, did not perceive a developed awareness of links between diet, alcohol or drug abuse and cancer within the communities they worked. Key Informants themselves emphasised links between poverty often invoking Maslow's hierarchy of need which places health behaviours and risk reduction as higher up on the hierarchy than many of the issues that confront members of the three communities daily, such as the challenges of living on a low income. This was not entirely congruent with our focus group data which showed that people did engage with health improvement advice but that crucially they engaged *critically* with it. The role of poverty and socio-economic factors emerged more prominently with reference to the barriers to health improvement that are discussed in a later section. When one group was asked what caused cancer they told us;

“Dreadful diets, lack of exercise, smoking” (Govan FG)

However from field notes from another group, this time comprised of older women, we received a much more sophisticated exploration of the causes of cancer that explored the limits of individual behavioural factors in the face of different types of information they tried to integrate into a broad health belief;

Facilitator: What causes cancer?

Participant: Lifestyle factors included diet, smoking, alcohol and stress. People used to eat more fresh food in the past, nowadays it more expensive to eat healthy food. There are lots of additives in food grown intensively to produce large quantities.

Additives must have an effect on the body. From time to time, there are also stories in the media linking cancer with particular food too. A current example was juice, where two types of additive are thought to combine to cause a cancer inducing chemical. Smoking and alcohol are seen to be unhealthy but there were stories of relatives who had smoked and drunk regularly and lived (in one example) to 92 years of age...A number of women agreed that stress could cause cancer. Life today is stressful. This also led to the point that mental attitudes can affect one's health too. (Govan, FG)

It is important to note the form this discussion takes as it characterises much of the data we collected about the relationship between cancer risk and personal choices and behaviour. Lifestyle factors are cited but it also cites factors, that despite the adoption of these, conspire to increase cancer risk; additives, industrial processes and the way in which we live life today. This theme is significant as it says no matter what an individual does, there are many factors beyond individual control that can undermine positive individual choices and increase the risk of cancer.

KIs also expected a main factor in people's less healthy lifestyles would be the economic barriers to healthy so-called 'choices'. Whilst financial hardship certainly existed and affected choices made in relation to health such as purchasing food, people still thought about and valued health. Lack of money, time and childcare were often seen as significant barriers to health improvement, but crucially not things that stopped them from thinking about health improvement.

When participants did implicate individual attitudes as barriers to changing individual health behaviour, many were likely to break away from their own personal experience in an attempt to understand the wider culture they found around them. Socio-economic circumstances would be part of this, as these speakers in a focus group of unemployed trainees revealed, but they appear to talk about other people and not themselves;

P1 *"Yes it is down to diets and whatever, there's a lot of people who live in poverty in Glasgow and they cannae afford to change their diet because it is expensive. I know that my mother has got younger kids and changing all their diets would cost a fortune."*

P2 *"I never understood why a lot of folk that say they don't have much money smoke, but in the main I thought well maybe it gein them a wee kick just to make them feel better through the day and all that and I think poverty is related to that. People getting into bad lifestyles, it gives them a bit of gratification for a wee while, at the end of the day it's doing them harm"*

So the "up-stream factors" of the KIs' beliefs about health that locate health beliefs within wider cultures defined by socio-economic circumstances are also reflected in community members' beliefs. They too have absorbed this perspective but they appear to be able to objectify the relationship between lifestyles and health so that it does not implicate them in the stigma of being poor.

Instead, participants tended to personalise their own barriers to being healthy citing their own individual failings such as their "will power", "laziness" and difficulties breaking old habits.

Cultural and environmental issues

Community participants also cited environmental factors such as traffic pollution, radiation and occupational hazards, such as chemicals or asbestos that they or people they knew may have come into contact with. These risks often appeared as part of an argument to de-centralise causality based on individual choices. On the whole, environment was seen as beyond individual control and was therefore seen as limiting the potential effectiveness of behavioural change.

There was not a clear separation of the environment from other processes in society and, to a degree, modern life itself was seen as creating and contributing to cancer incidences. Some people asked whether cancer was a "modern disease" or something that did not affect developing countries as severely. This in part was recognition that cancer is a disease of affluence, but other remarks put a different slant on it. At a Gorbals open stall an older woman told us that cancer rates started to rise, she felt, when "*people started going to the moon*". As a herald for the start of the contemporary age, perhaps the moon landings were a marker for this woman for when the pace of life quickened and began to change in character. Many of the environmental issues also reflected Glasgow's industrial past, the growth in car use and air travel, factors that the participants themselves felt they little power to control.

The data from the young persons' group is reported in more detail below but some of the environmental factors warrant mention here. For young people, cultural and environmental factors and individual choices were also closely connected. This was a reflection of their lack of power to control influences in their environment. In order to explore the influence of factors beyond individual behaviour, the young people were asked to draw bodies and to locate factors they had control over inside the body and factors they had no control over outside the body. This was complemented by the drawing of a health map that showed health resources and threats in their community. Notably, alcohol was a factor that appeared both inside and outside the body, showing how it was both an environmental and a behavioural risk factor. It is important to note that the young people did not distinctly separate cancer risks from general health risks and well being as plainly as adults. Alcohol itself was seen as a threat to personal safety as well as health. They also drew sun-bed salons on their maps, identifying the risk of skin cancer that stems from them. These two examples underline the importance of consumer choices in individuals' lives. For young people the additional pressure to conform that is exemplified amongst their peers compounds their difficulties. Thus sun-beds, once in a community as a consumer option and having become popular among a peer-group, become difficult to resist despite known evidence of related cancer incidence. Choices are not made in isolation but in contexts where health competes with other forms of valorisation, such as social contact. Healthy choices might also be in short supply compared to riskier ones.

The quotes below, in response to the question about what causes cancer, show the importance of context;

"Culture and their environs- it's normal to spend your social time in a bar, in a smoky atmosphere or sitting watching TV. It's difficult breaking that cycle" (Shettleston, OS)

"Friends and family who think it is silly (to change behaviour) wanting to smoke with a drink" (Govan OS)

The uncertainty of evidence

Sometimes the overwhelming amount of information about cancer risk and the rapid pace at which new information emerged actually led people to lose faith in the messages they received. A belief that no-one really understands the origins of cancer would be reinforced by the variety of information available rather than this variety being interpreted as evidence of complexity in causation. Similarly, the fact that there was not yet “a cure for cancer” would support this doubting position;

“Everything (causes cancer). Does anyone know? If we know, why can’t we stop it?”
(Shettleston OS)

6.3. Risk as mediated by social position

Thus far the findings have been presented to illustrate the similarities displayed in people’s risk perception. However, some groups showed marked differences in their assessment of risks. This leads to a key finding: that health promotion advice, whilst widely cited, is not consumed in the same way. It has already been illustrated that differences in experiences of cancer could act as a filter for interpreting information about cancer. It also appears that social position, such as age and gender, can also act as a filter.

This was particularly salient in the differences identified in the views of men and young people. Men felt they had a much better understanding of the risk factors associated with heart disease and its prevention than cancer risk factors and prevention. Young people expressed their health concerns primarily in relation to emotional well-being and happiness rather than either cancer or heart disease. The male group showed evidence of attempting to understand health risks and taking positive steps to reduce their risk of disease. They did not respond to all risks equally, however, but instead made assessments with the aid of health improvement information as to what steps they should be taking to reduce relevant risks. With the support of existing medical advice, they therefore saw the risk of heart disease as the greatest threat to their health and framed all health improvement behaviours through this lens.

“Now interestingly when I talk to my doctor about my health we talk about my cholesterol, we talk about heart disease and the impact smoking would have on that, we never discuss the issue that smoking could also give me cancer... I think that some of it might have to do with the way it has been marketed at me. You know, the West of Scotland, unhealthy life, smoking, drinking, eating fatty foods and I’m in the heart attack category, you know, I’m 40 to 50, I’m overweight, smoke and you know that’s all about health promotion messages being targeted at me and some of that being taken in. Whereas, you know, I struggle...strangely enough today I saw an advert for cancer, but it was oral cancer, but other than that I struggle to think of any piece of health promotion literature in relation to cancer. You know, I can think of stuff about coronary heart disease, I can think of stuff about drug misuse, em, a couple of other bit ofprostate cancer is about the only one. That’s about the only one (Govan FG).

Young people also appeared to filter health improvement messages through personal experience. This appeared to be happening in a different way from men who perceive certain messages as being ‘marketed’ at them. Young people are aware of a range of health promotion messages relating to cancer and they could recite them accurately in focus groups (perhaps seeing health promotion information as belonging to the same category of information as that given in classrooms). When asked to draw a health map of their local community however, young people did not significantly identify carcinogenic elements of their environment (a shop selling cigarettes to young people was one amongst a number of general health related factors). The health map was a means of allowing young people to identify their own concerns relating to health. It was striking that the map was dominated by negative health influences with the small number of positive health related factors carrying caveats. A park - *“enough space to keep fit”* - was qualified with *“fighting”*, *“Broken bottles and needles”* and *“sectarianism”*. This suggests that concerns related to sociability and well-being figure highly in young people’s health beliefs and perhaps are more relevant than cancer related advice. Sociability and well-being are immediate effects of living in certain environments whereas cancer related aspects may operate outside a meaningful timeframe for young people.

This was supported by evidence collected on an H- diagram where young people were asked to identify good and bad aspects and changes they would like to make regarding their health. In listing positive aspects a range of factors emerged not all relating rigidly to physical health but to a sense of well-being grounded within the social lives of young people. They were; *People saying good things about you; caring for people; not fighting*, (and interesting in that they were contested by the youth leader facilitating the group); *sweets; candy; and chocolate* (foods whose healthy status would be contested by health promotion specialists).

6.4. Sources of information

Few, if any, participants were well-informed of local health improvement projects despite the areas having a good number of them. Most would say they did not know of any health improvement projects and would refer to GP services or a local facility such as a Healthy Living Centre or Keeping Well in Govan. The latter represented an exception in that a project linked to it supporting healthy eating was often referenced. What was most striking was that if people wanted information about cancer they would go to a primary or secondary health care source. Some participants told us they would use the internet, but it was not common for people to be able to identify a specific website.

6.5. Meaning and Value of Health

During the fieldwork we did not take for granted the idea that health was universally valued. When we asked participants about health we did however find evidence that participants appeared to subscribe to the WHO definition of health as a holistic concept incorporating quality of life, energy and an ability to participate fully in various activities (WHO, 1992). In terms of longevity, older participants in particular expressed a desire to be around to see children and grandchildren grow up. However, some men and younger people admitted to seeing things connected with health as “boring” and reflected that they switched off when hearing the words “health” or “exercise”;

“It’s not rocket science – stop doing all the things that are bad for you. But it could make you boring” (Shettleston OS)

“Just don’t call it exercise, exercise is a bad word to people” (Govan OS)

7. DISCUSSION

The objective of this consultation was to gain a better understanding of how people living in deprived areas perceive cancer, health and health promotion activities in order to aid the planning of future health improvement strategies aimed at narrowing the health inequality gap.

The majority of the 173 participants were affected by cancer either personally or through friends and family. Not surprisingly, but interestingly contrary to KI views, it was found that cancer was an important issue and thought about often. The epidemiological fact (SEHD 2001) that cancer mortality is greater in socio-economically disadvantaged communities is perceived experientially to produce a default “death and despair” attitude towards cancer. Previous research, including recent work by the CCRC (Kearney et al, 2005), has also suggested that the population of deprived communities display a lack of knowledge about cancer risks in addition to fatalism. However, by consulting more people, using a range of methodologies and focusing within less affluent areas on the issues of perceptions of health, cancer and health promotion, this consultation adds to previous literature (Murray and McMillan, 1993; Price, 1993, Wardle et al, 2004) by casting some doubt on these notions.

Rather than displaying a lack of knowledge, participants in this consultation adopted a critical stance to available evidence and the narrow focus of many health promotion messages. They proved capable of producing complex understandings of cancer causality and risk that gave efficacy to the external influences beyond their control but also incorporated genetic and behavioural aspects of risk.

The importance of family and friends and personal experience of cancer in shaping understandings of risk and health improvement is not discussed in much of the previous literature on public perceptions of cancer (Murray and McMillan, 1993; Price, 1993a; 1993b; Powe and Finnie, 2003; Wardle et al, 2004), yet it was clearly evident in the data collected. Health promotion messages were thus not received in a universally similar way. Although broader cultural influences were evident, participants would draw on their own local and individual experiences of the disease. When this experience conflicted with the focus on behavioural factors in health promotion messages, this appeared to lead to a distrust of these messages. This suggests that to be effective health education needs to reach within an individual's personal circumstances to be accepted.

Previous literature on lower socio-economic groups' perceptions of cancer shows a link between cancer and death and that these groups look for external causes of cancer to a greater extent than more affluent groups. This is described as a *fatalistic* approach (Murray and McMillan, 1993; Price, 1993; Wardle et al, 2004). Our data also illustrates that the participants clearly emphasise factors beyond individuals' control as being responsible for high cancer rates. Yet we argue that this does not justify describing these perceptions as *fatalistic* for the following three reasons.

Firstly, the term suggests passivity. Participants were engaging critically with a range of evidence and displayed an in some ways sophisticated understanding of this evidence. In many ways they were in tune with current evidence that all causes of cancer are not known. An emphasis on behavioural risk factors was seen to contradict lay understandings of scientific knowledge, interpretations of genetic inheritance and cultural and environmental influences. Scientific knowledge was seen to change rapidly and risk advice was seen as provisional. Gaps in current knowledge about cancer (including the absence of a cure for cancer) also justified a critical stance. Cancer was seen as mysterious and unknown rather than controllable and understood by science. Both community participants and key informants would cite the culture in the three areas as unhealthy and high in cancer risk factors, yet environmental factors in cancer causation were absent from health promotion messages according to community participants.

Secondly, it may also be that health improvement advice that links disease conditions such as cancer to lifestyle choices has the capacity to stigmatise individuals making such choices. The adoption of "up-stream" explanations which give weight to the constraints of socio-economic disadvantage to justify individual choices was a strategy common in the accounts of community health professionals and other local workers. However community residents could also adopt these explanations though at a distance (referring to others, not themselves) suggesting a need to maintain their autonomy as decision makers and that linking poverty and ill health creates a double stigma (of being economically poor *and* of making poor health choices despite evidence and advice).

Thirdly, as one of the KI's pointed out and as shown by the community profiles in the relevant communities, the most common forms of cancer in these areas are lung and to a lesser extent cancers of the head and neck, and these forms of cancers often result in death. Therefore rather than a fatalistic standpoint it may sadly be a partly *realistic* one.

This, in some ways sophisticated understanding of cancer risk, was also evident in the way in which people discussed health. The value of health was seen in the holistic terms of the WHO definition as "a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" rather than in a narrow physical sense (WHO 1992). Social factors such as being there for the grandchildren were commonly mentioned. Young people in particular gave priority to well-being within their peer group and rated sociability above cancer in their decisions. The sites of their peer group interaction were seen as on balance containing more risks to, than opportunity for, health.

Previous work conducted by the CCRC found significant differences in the perceptions of cancer between affluent and deprived communities and mistrust of cancer prevention advice relating to lifestyle factors (Kearney et al 2005). This consultation provides a more in-depth understanding of the reasons why behavioural factors may be discounted. The critical stance taken by many of the participants in the current consultation and the way in which they viewed health promotion messages through the lens of their family experience highlights the importance of reframing health promotion messages. Rather than lacking knowledge of cancer risks, the people who participated in this consultation appeared to want health care professionals to acknowledge that cancer can be caused by other factors than lifestyles alone. An individually tailored approach based on their own circumstances also appears desirable.

Hence, this research into public perceptions of cancer and health improvement in three deprived Glasgow communities has added three important aspects to previous literature on public perceptions of cancer, health and health promotion. People living in these deprived communities have a relatively sophisticated understanding of the cancer risks, engage critically with the evidence and viewed and valued their health from a social family perspective. Taking these factors into consideration in the development and directing of future health improvement initiatives in socio-economically deprived areas in Scotland may make them more effective.

8. REFLECTIONS ON UTILISING RAPID APPRAISAL

The mixed-method approach of Rapid Appraisal proved to be invaluable for extending the range and depth of the data in that open stalls captured the views of those who would not be inclined to take part in a focus group and more participative methods allowed young people a voice. The focus groups and KI discussions allowed for more complex understandings to emerge than were recorded in the open stall contacts.

Yet on a continuum of participation, such as that set out by Arnstein (1969), this type of engagement could be characterised as 'consultation', rather than full participation or ownership of the process. Members of the communities identified took no part in planning the study or presenting the findings, and had no involvement in analysing the findings. However this was a reflection of our approach rather than the process of rapid appraisal.

The study was subject to tight deadlines and as such, hit a tension between rapidity of assessment and the intensity of community involvement. The process of rapid appraisal may be viewed as less time-consuming than other methods but project coordination was logistically difficult and time consuming. The organisation of multi-site focus groups, open stalls and key informant interviews within a tight timeline required good organisational skills and communication within the team, and the ability to develop good relationships with key stakeholders early on.

9. CONCLUSION

From these findings it will be important for professionals working within the remit of public health and for those planning future cancer health improvement strategies in socio-economically deprived communities to consider the following conclusions. These are not intended to be prescriptive but outline the nature of approaches that may be better suited to the needs and perceptions of people living in less affluent communities based on our findings contributing to addressing cancer-related health inequalities:

- Incorporating public involvement in the design of health-improvement strategies should be achieved through displaying sensitivity to peoples' desire for personal autonomy and decision-making. Disseminating health advice without overtly challenging lay interpretations of evidence, that may be well-founded in personal experience, is crucial and may help maintain a sense of agency.

- Health promotion that is focused only on changing individual behaviour can, even when sensitively communicated, take on a character of blaming. Introducing factors beyond an individual's control, alongside the lifestyle information currently covered by health promotion materials, when talking about risk reduction may provide a more balanced and acceptable approach.
- Given the importance of personal experience in the reception and interpretation of health education and improvement information, opportunities should be sought to “narrowcast” to individuals and networks rather than broadcast to an abstracted population. This could assist in the personalising of advice to individual experiences and increase credibility to non experts. Resource constraints may mean opportunities for individualising cancer prevention information are limited so this approach could be primarily employed in verbal information exchanges between healthcare professionals and members of the public.
- Work with young people could usefully target barriers to well-being and safe peer association alongside cancer related health promoting strategies, as health is understood in this context by this age group. Having a cancer strategy that is isolated from other concerns of young people, such as their social and lifestyle opportunities, will compete with more immediate priorities for young people and consequently messages may be lost. By incorporating cancer risk awareness with issues that young people do engage with, we can encourage an understanding of cancer risk within considerations of other forms of health and well-being.
- The importance given to cultural and environmental influences by community participants is an opportunity for action. Consumer culture, like health improvement advice, is premised on the idea of individuals having choice. However rather than seeing it as a source of extended choice, participants view contemporary culture as leading to the growth of unhealthy influences beyond their control. There was a clear desire for information about the extent of these influences and how they may undermine daily health related decisions. The processes of food production and pollutants in the environment were clear concerns. Health service or community led information and crucially, discussion and advocacy about such concerns could facilitate and be an appropriate context for wider discussions about cancer risk and individual change.

This public consultation process demonstrates that people in deprived areas in Scotland engage more reflectively and critically with health improvement initiatives than previously acknowledged in the literature. A more sophisticated strategy is thus needed to address the concerns of people living in deprived areas about risk factors unrelated to lifestyle. We have found that health promotion advice is engaged with critically and actively interpreted through the lens of lived experience. Health promotion that is unidirectional will be unable to account for dissonance between health promotion recommendations and lay experience. We do not wish to be uncritical of lay experience but for health promotion advice to be adopted it must connect with experience meaningfully and without contradiction. This will be a challenge for future health improvement initiatives in areas of deprivation, particularly given the resource implications. Yet past approaches have not succeeded at narrowing the inequalities gap and we clearly need to do better in the future. The implications of this consultation process should help in designing approaches more sensitive to, and acceptable in, some of the least healthy and least affluent communities in Scotland.

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Appendix 1

Exit questionnaire

1. Your age and gender (please tick)

	Male	Female
Under 16		
17- 25		
25-44		
45-64		
65 +		

2. We would like to know where you live, could you please tell us the first 4 characters of your postcode- this means we will know where you live without being able to identify you

Please write here _____

3. Please tell us about what you do for a living

Full time carer

Full-time education

Retired

Unemployed

Disability or incapacity benefit

Work part time (and write job title)

.....

Work full-time (and write job title)

4. Have you or anyone close to you had experience of cancer

No

Yes (who?).....

Appendix 2

COMMUNITY PROFILES FOR THE THREE CONSULTATION AREAS

Introduction

The aim of this appendix is to summarise the community health profiles for three areas in Glasgow: Shettleston (G32 7), Govan (G51 3) and Gorbals (G5 0, G5 8, G5 9). A number of public health indicators, including cancer data, have been used to describe the three areas' health profiles.

Data

The majority of the public health indicators were obtained from the 2001 Census and health profiles¹ that Health Scotland produced for 66 communities in Scotland in July 2004.

The population data was obtained from the General Register Office for Scotland².

The cancer information was provided by the Scottish Cancer Register, ISD Scotland. This information was extracted in November 2005 for cases diagnosed in years 1999-2002 combined. Cancer hospital admissions for the same period were obtained from SMR01 (Scottish Morbidity Records) maintained by ISD Scotland.

Public Health profile

The health profile indicators are shown in Table 1.

Shettleston

- Shettleston community has a population of 7,313 residents. Looking at the age profile, of the three communities Shettleston has the highest proportion of the young and the elderly (20.6% of people aged 0-15 and 16.4% aged 65+). Correspondingly, the proportion of people in the working age group (16-64) is lower in Shettleston than in the Govan and Gorbals.
- Life expectancy in the Shettleston community is 66.3 years for males and 73.7 years for females.

¹ Community health profiles. Health Scotland
http://www.scotpho.org.uk/web/site/home/Comparativehealth/Profiles/profiles_intro.asp

² <http://www.gro-scotland.gov.uk/>

- According to the 2001 Census, 0.9% of Shettleston residents belong to an ethnic minority group.
- The percentage of unemployed claimants in the working age group is 5.8%.
- It is estimated that nearly 51% of Shettleston residents are smokers.
- The alcohol-related hospital admission rate (age-standardised) is 1,897 per 100,000 population.
- Based on the morbidity and mortality figures, the Shettleston community has a poorer health profile than Govan and Gorbals, with the highest rates of hospital admissions for heart diseases (1,232 per 100,000 population) and cancer deaths (2,294.3 per 100,000 population).

Govan

- Approximately 4,566 people reside in the community, with 66.5% in the working age group. The percentage of residents aged 65+ is slightly lower than the other communities considered.
- The life expectancy in Govan community is 66.7 years for males and 74.2 years for females.
- 2.3% of Govan residents belong to an ethnic minority group.
- This community has the highest proportion of unemployed claimants in the working age group.
- Govan has the poorest behaviour profile with an estimated high percentage (58.1%) of smokers and an alcohol-related hospital admission rate of 2,880 per 100,000 population.
- Around 249 per 100,000 population were admitted at the hospital with a health related condition between 1999-2002. This is lower than the rates observed in Shettleston, despite the higher level of behavioural risk factors.

Gorbals

- This is the biggest community with a population of 8,903 residents, with 68.9% of working age. The proportion of residents aged 0-15 years is lower than the other two communities.
- The life expectancy in Gorbals is 65 (G5 0) and 62.5 (G5 8, G5 9) years for males and 73.5 (G5 0) and 74.6 (G5 8, G5 9) years for females.
- The percentage of minority ethnic groups (3.8%) is higher than the other communities considered.

- The percentage of unemployed claimants from the age working group is 7.3%.
- It is estimated that 53.8% of people living in the community smoke. The alcohol-related hospital admission rate is 2436.4 per 100,000 population in G5 0 and 3839.1 per 100,000 population in G5 8 and G5 9.
- The heart disease hospital admission rate is 851.8 per 100,000 population in G5 0 and 859.2 per 100,000 population in G5 8 and G5 9.
- Gorbals present the highest number of deaths caused by cancer for both males and females.

Cancer Profiles

The cancer information is presented in Table 2 and Table 3.

Shettleston

- The incidence rate for all newly diagnosed cancer between 1999-2002 was 698 in males and 621 in females
- The mortality rate for all cancer between 1999-2002 was 498 in males and 374 in females
- The most common newly diagnosed cancers for males were lung, colorectal and prostate cancers. For females they were lung, breast and colorectal cancers.
- In Shettleston there were 1242 acute hospital discharges with any mention of a malignant neoplasm diagnosis, 583 males and 659 females. The most common hospital in-patient or day case visits were for cancers of the breast, colorectal and lung. Note that the cohort of patients attending hospital may differ considerably from the number of newly diagnosed cases, because the hospital figures will partly reflect the pattern of care needed for different cancers, and the fatality of different cancers.

Govan

- The incidence rate for all newly diagnosed cancer between 1999-2002 was 602 in males and 698 in females. In contrast with Shettleston, cancer is more commonly diagnosed in women than men in Govan. This is difficult to interpret due to the small numbers involved and the prevalence of different cancers.
- The mortality rate for all cancer is 363 in males and 349 in females.

- The most common newly diagnosed cancers for males were lung, head and neck and non-Hodgkin's lymphoma. For females they were breast, lung and colorectal cancer.
- In Govan there were 493 acute hospital discharges (episodes) with any mention of a malignant neoplasm diagnosis, 256 males and 237 females. The most common hospital in-patient or day case visits were for cancers of lung, colorectal and bladder.

Gorbals

- Gorbals has the highest cancer incidence rate for males and the lowest cancer incidence rate for females out the three communities. From 1999-2002, the rate was 725.2 and 535.7 respectively.
- The mortality rate for all cancer between 1999-2002 was 636.6 in males and 445.6 in females, the highest rate of the three study communities.
- The most common newly diagnosed cancers for males were lung, head and neck and colorectal cancers. For females they were breast, lung and colorectal cancer.
- In Gorbals there were 1036 acute hospital discharges (episodes) with any mention of a malignant neoplasm diagnosis, 606 males and 430 females. The most common hospital in-patient or day case visits were for cancer of lung, breast and bladder.

Table 1 Socio-economic profile

		Shettleston		Govan		Gorbals	
		Number	Measure	Number	Measure	Number	Measure
Demographics	Population	7,313		4,566		8,903	
	0-15	1,508	20.6%	920	20.1%	1,260	14.2%
	16-64	4,606	63.0%	3,037	66.5%	6,131	68.9%
	65+	1,199	16.4%	609	13.3%	1,512	17.0%
	Life expectancy- males		66.3		66.7		65 (G5 0) 62.5 (G5 8, G5 9)
	Life expectancy- females		73.7		74.2		73.5 (G5 0) 74.6 (G5 8, G5 9)
	Minority ethnic groups	67	0.9%	104	2.3%	338	3.8%
Economy	Unemployed claimants ²	255	5.8%	260	8.8%	430	7.3%
Behaviour	Estimated smokers ²	2,691	50.9%	1,957	58.1%	3,780	53.8%
	Alcohol related/attributional hospital admissions ¹	165	1,897.3	147	2880.2	305	2436.4 (G5 0) 3839.1 (G5 8, G5 9)
Physical Environment	Households within 5' drive-time of GP	-	100	-	100	-	100
	Households within 30' drive-time of Hospital	-	100	-	100	-	100
Morbidity and Mortality	Hospital admission- heart disease ¹	130	1,231.9	68	1,076.7	119	851.8 (G5 0) 859.2 (G5 8, G5 9)

1 Age-standardised rate per 100,000 population

2 Percentage based on 16-64 population

Table 2 Cancer Incidence and Mortality between 1999-2002. Numbers and crude rate per 100,000 person-years at risk

Cancer site / type (ICD-10)		Incidence (new cases)				Mortality			
		Males		Females		Males		Females	
		N	Rate	N	Rate	N	Rate	N	Rate
Shettleston	All cancer types (C00-C97, exc C44)	94	698.0	98	620.9	67	497.5	59	373.8
	Trachea, bronchus & lung (C33-C34)	28	207.9	25	158.4	23	170.8	21	133.0
	Breast (C50)	0	-	22	139.4	0	-	9	57.0
	Colorectal (C18-C20)	13	96.5	13	82.4	<5	-	5	31.7
	Prostate (C61)	8	59.4	-	-	6	44.6	-	-
	Head and neck (C00-C14, C30-C32)	7	52.0	<5	-	0	-	<5	-
	Stomach (C16)	6	44.6	6	38.0	5	37.1	<5	-
	Oesophagus (C15)	<5	-	<5	-	7	52.0	0	-
	Non-Hodgkin's lymphoma (C82-C85)	<5	-	<5	-	<5	-	<5	-
	Bladder (C67)	<5	-	<5	-	<5	-	0	-
Malignant melanoma of the skin (C43)	<5	-	<5	-	0	-	0	-	
Govan	All cancer types (C00-C97, exc C44)	53	601.7	66	698.0	32	363.3	33	349.0
	Trachea, bronchus & lung (C33-C34)	21	238.4	12	126.9	14	158.9	8	84.6
	Breast (C50)	0	-	19	200.9	0	-	<5	-
	Colorectal (C18-C20)	<5	-	<5	-	<5	-	<5	-
	Prostate (C61)	<5	-	-	-	<5	-	-	-
	Head and neck (C00-C14, C30-C32)	7	79.5	<5	-	<5	-	0	-
	Stomach (C16)	<5	-	<5	-	0	-	<5	-
	Oesophagus (C15)	<5	-	<5	-	<5	-	<5	-
	Non-Hodgkin's lymphoma (C82-C85)	<5	-	<5	-	<5	-	<5	-
	Bladder (C67)	0	-	0	-	<5	-	<5	-
Malignant melanoma of the skin (C43)	<5	-	<5	-	0	-	0	-	

Gorbals	All cancer types (C00-C97, exc C44)	131	725.2	94	535.7	115	636.6	73	445.6
	Trachea, bronchus & lung (C33-C34)	42	232.5	23	131.1	50	276.8	32	195.3
	Breast (C50)	0	-	26	158.7	0	-	13	79.3
	Colorectal (C18-C20)	14	85.6	7	58.4	8	48.9	<5	-
	Prostate (C61)	13	79.5	-	-	8	48.9	-	-
	Head and neck (C00-C14, C30-C32)	16	97.8	<5	-	8	44.3	<5	-
	Stomach (C16)	<5	-	<5	-	<5	-	<5	-
	Oesophagus (C15)	5	30.6	<5	-	6	36.7	0	-
	Non-Hodgkin's lymphoma (C82-C85)	<5	-	<5	-	0	-	0	-
	Bladder (C67)	8	48.9	<5	-	7	42.8	<5	-
Malignant melanoma of the skin (C43)	<5	-	<5	-	<5	-	0	-	

Notes:

1. All malignant neoplasms exclude non-melanoma skin cancer (ICD-10 C44).
2. All malignant neoplasms (incidence) exclude ICD-10 C97, which is not used by the Scottish Cancer Registry.
3. Crude rate is calculated per 100,000 person-years at risk
4. Numbers are not shown and crude rates have not been calculated when the number of cases recorded falls below 5 to preserve confidentiality
5. Due to small numbers, it has not been possible to calculate directly age-standardised rates
6. Due to small numbers, rates are liable to fluctuate substantially from year to year

Table 3 Acute hospital discharges with any mention of a malignant neoplasm diagnosis by sex from 1999-2002

		Shettleston	Govan	Gorbals
All cancer types (C00-C97, exc C44)	Male	583	256	606
	Female	659	237	430
	Total	1242	493	1036
Trachea, bronchus & lung (C33-C34)	Male	110	42	137
	Female	97	50	81
	Total	207	92	218
Breast (C50)	Male	0	0	0
	Female	251	35	147
	Total	251	35	147
Colorectal (C18-C20)	Male	111	42	72
	Female	97	33	18
	Total	208	75	90
Prostate (C61)	Male	28	16	30
	Female	-	-	-
	Total	28	16	30
Head and neck (C00-C14, C30-C32)	Male	40	29	79
	Female	8	3	8
	Total	48	32	87
Stomach (C16)	Male	61	10	15
	Female	7	9	5
	Total	68	19	20
Oesophagus (C15)	Male	42	15	39
	Female	6	7	5
	Total	48	22	44
Non-Hodgkin's lymphoma (C82-C85)	Male	47	8	9
	Female	32	15	24
	Total	79	23	33
Bladder (C67)	Male	31	56	84
	Female	18	9	41
	Total	49	65	125
Malignant melanoma of the skin (C43)	Male	2	1	2
	Female	1	2	1
	Total	3	3	3

Source: SMR01