BRIEFING PAPER 2 FINDINGS SERIES

**Perceptions of Cancer** in Three Deprived Communities in Glasgow: Findings from the **Glasgow Public Involvement** in Cancer Study

- Individuals critically interpret health promotion advice in light of personal experience.
- The way in which health promotion advice is received can be filtered by the age and gender of the recipient.
- A sense of personal autonomy and decision making in relation to health behaviour is needed for successful uptake of health promotion advice.

The gap in cancer survival rates between affluent and deprived communities in Scotland is widening. This is particularly evident in Glasgow where, 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.

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Previous research into the effects of health promotion suggest that health messages are adopted differently across socioeconomic groups and that affluent and educated groups are more likely to respond to health promotion through behavioural changes that will improve their health<sup>2</sup>. Potentially, health promotion interventions may increase rather than decrease social inequalities in health unless we begin to understand how such messages are received, interpreted and acted upon across different communities. It is also important that health interventions are not only evidence-based but designed in partnership with members of the communities they target to increase their effectiveness. Thus, this consultation was designed to increase understanding of how people in poorer areas perceive cancer, health and health promotion activities with a view to assisting the development of future health improvement initiatives.

### PPROACH AND METHODS

A rapid appraisal approach was adopted to develop a better understanding of the issues involved in the reception, filtering and responses taken to cancer information. Rapid appraisal is a mixed method approach incorporating both qualitative and quantitative research methods to gather information supplemented by secondary data.

The rapid appraisals took place in three areas of Glasgow selected because of their status as areas of multiple deprivation: Shettleston, Govan and the Gorbals. In-depth interviews with key informants, focus groups with residents and open stalls and semistructured questionnaires in key community sites were used to gather data. Purposive sampling was used to reach a cross section of members of the public living in the three areas with particular effort being made to capture the voices of those 'harder to reach' in health research such as young people and men. Key informants included health professionals and community workers. In total there were 173 respondents plus 19 key informants. Community profiles were also developed and illustrate statistically the general demographic and socioeconomic character of the three areas as well as the cancer incidence and mortality data for each area.

#### **FINDINGS AND CONCLUSIONS**

The following key themes emerged in the data.

### How personal experience shapes perceptions of cancer prognosis

When asked to express beliefs about cancer, respondents' initial unelaborated responses (as collected at open stall semi-structured questionnaires) would display a 'death and despair' position: that the prognosis for those diagnosed with cancer was unequivocally bleak. However, when respondents explored their beliefs in more depth (as in focus groups) they began to display knowledge of advances in treatment that present more optimistic outcomes for cancer patients. An important element was the influence personal experience brought to people's understandings of cancer prognosis. Knowledge of either positive or negative outcomes would shape their estimation of survival rates. As one GP told us "it is entirely appropriate to see cancer as a death sentence when the main tumour seen is lung cancer, a cancer which has a survival rate of five percent." Yet, those who had survived, or knew of people who had survived cancer, reported more positive outlooks: "I've had it, at the beginning I thought I was going to die no matter what, but having had it, it makes you look at cancer and look at life differently (female in Gorbals)".

#### A critical engagement with health promotion advice relating to cancer risk reduction

The extent to which behaviour shaped cancer incidence was guestioned. Given the competing scientific claims for poverty, genetics and environmental factors in cancer risk, respondents often felt behavioural factors were overplayed by health promoters and medical professionals. Fatalistic health beliefs were expressed by a small minority of respondents. However, a more representative description is that health beliefs and risk perceptions were sophisticated combinations of received health promotion advice, scientific knowledge (received through media sources) and personal experience. Where there were contradictions or tensions between sources of advice and knowledge, personal experiences would take precedence. One behavioural factor which was questioned widely was smoking. Again it was not that the risk of smoking was denied, it was that it was felt to be overplayed. As one respondent told us: "when you go into hospital, that's the first thing they ask you, are you a smoker? Then they put everything down to smoking". This was felt to personalise the development of cancer when factors beyond individual control were also important.

### The first ports of call for cancer related health advice were primary or secondary care centres

Respondents rarely cited cancer or other health related websites, health consumer groups, telephone help lines or libraries. The most popular response for first contact if concerned about cancer would be their GP. Those who had experience of cancer in their family or social network also cited specific specialist hospital departments.

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### Gender and age can act as a filter on the reception of health promotion advice

This could operate through cancer prevention messages being given a lower priority by certain groups. The male group in our consultation felt they were targeted for heart disease related health promotion rather than cancer. Consequently, given that they felt they had a higher risk of heart disease they would be less sensitised to cancer related health promotion. One individual summed up this perspective by saying that when his doctor spoke to him about his smoking, he felt it was a conversation related to heart disease risk reduction rather than cancer risk reduction. For young people, health and wellbeing were linked to peer activity and sociability, and these issues took precedence in decisions made about health behaviours. For example, fitting in with the peer group was seen as more positive to health and wellbeing than the adoption of specific cancer risk reducing behaviours.

#### The desire for personal autonomy over health decisions and behaviour

Running centrally through these findings is the need to maintain a sense of personal autonomy. Health advice that overtly challenges lay interpretations of health, that may be well-founded in personal experience, will also challenge the basis on which individuals have control over their life and circumstances. In this vein respondents would accept deprivation-based accounts of health inequalities for others in their communities but not for themselves. Not only is poverty stigmatising and challenging to self-identities but the absence of control over life-circumstances that it implies is strongly resisted. Whereas the key informants in the study would be more likely to invoke poverty as a factor that took away personal choice, community respondents would invoke less stigmatising constraints on choice, such as the physical environment, traffic and industrial pollution, and attempt to show evidence of welljudged, rational decision making on their own behalf.

## CONCLUSIONS

These findings show how personal experience and social location influence the reception of health promotion advice. Previous studies have suggested that health beliefs in poorer communities are fatalistic<sup>3, 4</sup> but this view undermines the active work members of such communities do to understand sometimes contradictory advice and information. Scientific knowledge as communicated through media sources, often displays uncertainty about what causes and protects against cancer incidence. Health promotion advice is only one source of information used by those living in poorer communities to make decisions about health and lifestyles, there is also an awareness of non-behavioural influences which, given the moral implications of behavioural factors, are less threatening to self-perceptions and identity.

Perceptions of Cancer in Three Deprived Communities in Glasgow:

From the findings described in the full report, the following recommendations can be made:

- Public involvement in the design of health improvement strategies can be aided through displaying sensitivity to people's desire for recognition in the arenas of personal autonomy, personal agency or decision-making. Disseminating health advice without overtly challenging lay interpretations of evidence or current behaviours could help maintain a sense of agency.
- 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 thereby in increasing credibility of the message. We recognise that resource constraints may mean opportunities for individualising cancer prevention information are limited so this approach could primarily be employed in verbal information exchanges.
- Work with young people should look to optimising wellbeing in the peer group alongside cancer risk reduction. The peer group and contentment within it is an immediate priority in young people's lives, cancer risk reduction less so.
- Health promotion is premised on the idea of individuals having choice. However, rather than seeing it as extending choice, many respondents saw contemporary culture as leading to the growth of unhealthy factors beyond their control. This was twinned with a desire to be seen as autonomous, rational decision makers. There was a clear desire for information about the extent of these influences and how they undermine daily health related decisions. Discussion and advocacy on such concerns could facilitate an appropriate context for wider discussion about cancer risk reduction and individual change between health providers and promoters and those living in disadvantaged communities.

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The full report of the Glasgow Public Involvement in Cancer consultation is available on the GCPH website at http://www.gcph.co.uk/library/references.htm.

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