

Putting breast cancer on the map

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• Background

'Putting Breast Cancer on the Map' grew out of the work the Women's Environmental Network (WEN) has done on polluting chemicals in the UK over the last ten years. The project developed out of a need identified by women to participate in positive action to bring about change in the minds of the government and medical establishments, as well as society at large, about the way in which breast cancer is viewed, treated and politicised in the UK.

The primary basis for this research has been the rising incidence of breast cancer in the UK, where the estimated lifetime risk for all women is now 1 in 11. Levels of incidence have increased every year this century¹. The disease was comparatively rare 200 years ago but today it is the commonest cause of female cancer death and the top overall cause of death for women aged under 50². In world terms, breast cancer incidence has increased by 33% between 1987 and 1997 (Lancet 1997). But of equal significance in terms of the design and focus of this research is the growing concern that the contributing cause of the disease may lie in the state of the physical environment we inhabit (Read 1995; Steingraber 1997).

Research carried out in Israel (Westin and Richter 1990) and studies of Long Island, USA (cited in Read, 1995; Steingraber 1998), Cape Cod, USA (Silent Spring Institute) and Lincolnshire, UK (Watterson 1998; Rattanamongkolgul et al., 1998; Dispatch 1994) have highlighted the necessity to consider the state of our lived environment to

be a significant risk factor for breast cancer. Research into genetic and heritable determinants of breast cancer has proliferated since the discovery of the marker genes BRCA1 and BRCA2³ in 1994, despite the fact that inherited breast cancer accounts for only 8-10% of all cases (Kelsey and Bernstein 1996).

In 1995 WEN submitted a petition called the National Action Plan for Breast Cancer to the Department of Health. The 80,000 signatures on the petition highlighted the need for better care and treatment of women with breast cancer. The petition particularly called for more emphasis on prevention to stop the epidemic of breast cancer for present and future generations. Petitions are an intrinsic part of campaigning and a useful tool in terms of developing networks, raising awareness and getting the issue 'out there'. However during the lifetime of the petition, it became clear that there was a distinct lack of places to refer women to when they contacted WEN with concerns about possible links between breast cancer and their environment. Women wanted to do more to publicise the breast cancer issue than sign their name to a piece of paper. They wanted to be active in campaigning at both a local and a national level to raise awareness about breast cancer and the urgent need for prevention. This need for participation developed into the project network that we continue to play a part in to this day.

WEN identified the need for a focal point for reporting and collecting women's concerns about their health and environment. A project was devised around a means of collecting this

¹ Breast Cancer Campaign (BCC) 1997; Cancer Research Campaign, (CRC) 6.2, 1996; Zeneca 1998.

² BCC 1997. CRC, 1997, 1996.

³ BRCA1/BRCA2 are human mutated genes that indicate a predisposition to breast cancer, with a 75-85% lifetime risk for people carrying these genes to develop the disease.

information via a questionnaire and a map drawing exercise. Project workshops were organised to facilitate the mapping process and as a method of engaging and supporting women to express these concerns about breast cancer and the environment in a group setting. In 1997 we submitted a successful bid to the National Lottery Charities Board who granted us £135,000 for a two-year project.

- **Project design**

The project focused on new ways of collecting information in a participatory, non-threatening and empowering way, using the network that had already begun to form. Traditional epidemiological methods of research do not usually involve the individuals or communities affected by a particular pollution source other than as study subjects and are characterised by a top-down approach. This effectively excludes local communities from participating in processes by which knowledge about health and the environment is collected. Involvement in policy or decisions reached and input into plans for change or improvement is therefore limited. There is little or no room for personal experience and concerns to be voiced by community members. A different method of collecting information was needed in order to involve women and their communities directly in the study by asking them to be their own experts. We contacted women's studies programmes for information on women's research methods. This proved useful in terms of reaffirming the value of qualitative research methods as a means of collecting women's perceptions. One of the most useful packs of information utilised was one on Participatory Appraisal from the Institute of Development Studies (IDS) at the University of Sussex. It illustrates how participatory mapping methods have been used to explore issues as diverse as women's time usage, land usage, sexual health and body image.

The project asked participants to be the researchers, as they already possessed all the skills, knowledge, experience, enthusiasm and local knowledge necessary to compile maps. They also had a vested interest in themselves, their communities and their environments to do this and this was what was missing with traditional methods of research. As one woman wrote:

"I am very concerned that breast cancer seems to be quite prevalent where I live but I can't really say or put my finger on any one thing, there seems to be so many and it becomes bewildering at times".

By involving women actively in the research process, the project sought to build on women's concerns and reach out to women all over the country to make the kinds of connections that might help identify avenues for change.

Mapping

The idea of drawing maps came from the women who were involved in collecting signatures for the petition. They were concerned about high incidence of breast cancer and what they perceived as 'clusters' either in their work or living environment. Although a number of academic and independent studies have investigated certain identified clusters, few definitive answers have been found. The definition of a cluster, as stated by the National Cancer Institute, is the occurrence of a greater than expected number of cases of a particular disease within a group of people, a geographic area, or a period of time.

Yet most clusters are initially identified by concerned residents who may live in what they define as a high incidence area or cluster. When investigated however invariably their concerns are dismissed but they are still left to worry that certain elements of their environment were overlooked. For example in the West Midlands, research around a particular landfill yielded no significant increase in ill health or breast cancer incidence. The local women knew this was because the area under study was governed by two different health authorities so the 'cluster' became half its actual size under each authority.

Maps have been used throughout history as a means of giving visual representation when discussing issues of importance, giving directions and locating landmarks. They are a very easy way of conveying information about how we relate to our environment and people tend to relate to them more easily than the

spoken word. Anyone can draw a map, you do not have to be literate or even speak a common language. They are also a good and safe way for people to convey different aspects of their lives that they may not readily admit to in words.

The background research began by looking for other examples of maps drawn by other individuals and communities. There were some very good examples of Parish maps from organisations such as Common Ground⁴ and examples from America where people were reclaiming maps as a means of identifying their bio-regions. There was also some interesting work being undertaken by some trade unions and labour activists looking at risk mapping of work environments as a useful means of indicating health risks in the work place. However these offered very little guidance in terms of women mapping health effects.

Compiling maps seemed to be an ideal way of collecting information that reflected past and present experiences of possible environmental pollution. The idea of map drawing was difficult to get across to participants in theory which made the workshops an intrinsic and crucial part of the project. The idea was that maps needed to come from the participants themselves and they needed to be individual. Purposefully no specific example was given in the project information pack as it was felt that participants might 'copy' the example and so the ideas would not come from them but be dictated by WEN. Maps were a way in which women could identify these 'clusters' while maintaining confidentiality about themselves and other individuals locally. They also served as a way for women to recall things that had happened in the past and think through possible connections, as the following comments show:

"The mapping exercise was quite useful because it made me think of incidents nearby that had happened in the past. "

"With hindsight I remember 42 years ago complaining of the smell of ICF⁵ when I lived at Norton on Tees (near Stockport). Air pollution was appalling in Billingham where my husband worked. My next four children were born, 2 months, 1 month, 6 weeks and 1 month premature - I developed breast cancer 31 years ago".

"When we first moved to the countryside I used to lose my voice when they sprayed the crops. All the family suffered from a feeling of grittiness in the eyes, some light headedness, headaches, tightness in the chest etc., when crops were sprayed".

Questionnaire

It was not enough to get visual representation from individuals about their experience. We needed to collect more personal written information in a questionnaire format. The project design was therefore two pronged with the more visual representation on the maps being submitted along with the written documentation in the questionnaires.

"After filling in this section [of the questionnaire] I have suddenly become aware of the possible harm from the materials I used (in and around home) when unemployed. Previously I had not been concerned about them and thought the proximity of the Sellafield and Chernobyl cloud the likely causes (or contributory factor) of my ill health. It has made me even more concerned about the future health of my children (both still at university) especially my daughter."

Information pack design

One of Wen's primary aims is to inform people about issues which link environment and health particularly in relation to women. We reviewed the health requests WEN had received, particularly those connected with breast cancer, in the last few years. Common threads emerged and these were used as a basis for the type of information which went into the pack. As one woman commented:

⁴ Common Ground is an organisation working with communities on Parish maps and helps to encourage people to value their own surroundings.

⁵ Imperial Chemicals Industries – one of the world's largest coatings, speciality chemicals and materials companies.

“Your information pack gives some interesting and useful sources of further information, for example details of pollution incidents from nearby factories and if I had more time that is something I would like to pursue”.

Distribution and publicity

The information pack needed to be publicised all over the UK. The best way to do this was through our existing network and local individuals. A mail-out to organisations and individuals was completed with a letter, a sample article, and a poster, asking them to publicise the pack and the project via their network, organisation, newsletter, minutes of meetings, local women’s centre, library etc. This was followed up with a phone call to elicit support, strengthen bonds and discuss ideas about promotion and possible workshops. The requests came flooding in. Individual areas were not targeted at this stage, only existing networks.

One of our best allies for promotion of this project has been the Public Sector Trade Union, UNISON⁶. This is largely due to the fact that Unison was campaigning for Lindane, a pesticide linked to breast cancer, to be banned and the fact that they have a very large female membership. The project was promoted by the National Women’s Committee in 1998 thus adding to its publicity among Unison’s members. Several other national women’s organisations such as the Women’s Institute, and the Women’s National Commission, the Inner Wheel⁷, and Breast Cancer Care were instrumental in publicising the project amongst their members on a national scale.

A press release was distributed to all the national papers, radio stations, regional media, magazines and publications from other NGOs and organisations. Media coverage was good with the biggest response coming from an article in *The Guardian*. One women’s magazine proved to be invaluable in getting the word out there. Utilising local media was an obvious way of promoting a local campaign. Participants were supported in contacting their local media as a means of

raising awareness locally and facilitating the formation of a network. While it may be quite difficult to attract the attention of the national media to a particular issue, it is easier to tackle the local media for coverage of a particular local event or campaign. This was an essential part of the press strategy for promoting the project locally.

Workshop publicity

Workshops were devised around the pack. A list of aims and objectives was compiled and the workshop developed to cover each of the aims and fulfil each of the objectives. The areas in which we held workshops basically chose themselves within about a month or two of distributing the pack, as participants rang with questions or to ask us if we would do a workshop locally. Particular regions were chosen according to criteria such as: local demand for workshop, written requests for information packs, local key contact, availability of venue, willingness for different groups to be involved etc..

Once areas were identified, at least one local person was sought to organise a venue, do some publicity and to speak to the media about local environmental issues. This local ‘key’ contact was supported by the resources of the WEN office and by the project’s staff to provide a point of contact for the developing network. Issues of confidentiality were observed by checking with people as to whether it was acceptable to pass on their details to the key person. Letters were sent out to anyone in the area who had sent for a pack and then any organisation local to the workshop. This was done about two to three weeks before the workshop date and in some cases a full month. WEN members were also mailed. A large number of workshops were facilitated by Unison through their Regional Women’s Officers who co-ordinated the event and publicity.

The key person was asked which day and time was best and the timing of the workshops were varied in order to discover if any one time was better than another. This didn’t prove the case. All local press were faxed and then phoned and asked to publicise the workshop and the project using the local contact as a source of more information. Participants who had

⁶ UNISON – Public sector trade union with over 1.4 million members in the UK.

⁷ One of the largest women’s organisations in the world.

returned a questionnaire or request were contacted with details of workshop. On the evaluation sheet at the back of the questionnaire, participants were asked if they wished to be more involved in the project and in what way. This was used to assess if people wished to become a local contact point or work on the project with as little or as much participation as they could give.

Workshops

The workshops began with a pilot session, which was planned for members of the steering group of the project, the WEN Board and local women we had identified as having expressed particular interest in being involved. The feedback from this workshop was incorporated and used to modify proceedings in preparation for the next workshop. After the initial two to three workshops, the format was changed around dramatically, as it was found there was not enough time at the end of workshops to do justice to the map drawing exercise. It soon became clear that although current concerns and exposures were relevant, so too were participants past experiences going back to birth, given that contaminants and health problems may arise from as far back as twenty years or more. In some cases, pre birth exposures could have led to breast cancer or other health effects evident today. Participants were encouraged to map their life from the cradle to present day.

The geographical area covered by the workshops was extensive. We had workshops in England, Scotland and Wales but not Ireland. We were unable to cover a few areas where we had been invited, such as the Isle of Man. In some places, we were helped by volunteers, who became workshop facilitators. The attendance at our workshops varied greatly. A poor attendance in Bristol could have been because it was held on Bonfire Night (but the only time available to the women who organised the event in Bristol). We know some of the women involved in setting up workshops, and for some it was the first time they had organised anything like this, were disappointed with the turn-out. We had some discussion about what might hold people back from coming. Not being ready to talk about the issues may have been a major factor. On the other hand, we saw from the evaluation

forms that many participants heard about the project from a wide range of sources including women's magazines, local press, local authority meetings, friends, through their union, through specialist journals etc. This indicates the project had an appeal to a very wide range of people and therefore attendance was not necessarily linked to content.

Attendance was certainly related to the amount of work that went into the organisation and one telling example is the Leeds workshop: 30 women attended after the local council had sent out around 1,000 invitations. Attendance was also linked to special conditions: in Boston, Lincolnshire, a good coverage in the local press brought in 20 people over the course of 4 hours. There is, of course, a great local concern about breast cancer in Lincolnshire, which has a higher than average incidence rate. When we went to more remote places, such as Launceston in Cornwall and Wales, the women who came were very gratified that a national organisation had made the effort to travel there.

Although we would liked to have done more workshops and to have met more women, we did get a wide cross-section of women attending the workshops, women with breast cancer, environmental activists, trade unionists, women from women's groups and health workers. For example in Cardiff, staff from the Cancer Registry attended the workshop leading to a good discussion among women who had experience of breast cancer and the group. In Hull a current and an ex-employee of the Ministry for Agriculture Fisheries and Food (MAFF) contributed alongside breast care nurses and activists from Friends of the Earth (FOE). We met our objective of getting together people looking at different parts of the breast cancer jigsaw and have started to form a unique network in England and Wales.

Observations by workshop participants

Positive comments indicated that the workshop was interesting, thoughtful and that it had raised awareness. Participants also stated that the mapping had been made easier through their involvement in the workshop. Criticism related to the complexity of issues. For example one person felt there had been a

lack of prior information; a few felt they had not had long enough to absorb the information; others wanted different kinds of information e.g. breast cancer information. On the other hand, some participants felt more information would have been overwhelming.

Specific suggestions were made for improvements in the workshops and future inclusions in our work:

- ensuring disabled access was *always* available;
- providing more positive advice on protecting our breasts and what we can do as individuals. For example breast-feeding was mentioned, as women need to know this has a protective effect for women who have babies at a young age;
- providing more information about breast cancer itself and about the environment;
- information about breast cancer in men and perhaps more targeting of men;
- scientific information more accessible; and,
- more focus on action and follow-up.

From the analysis of the workshops we can conclude that the most successful part was the content as people felt this to be thought provoking and informative. The most disappointing part of the workshop was the length; people felt they wanted more time. This was particularly true when the workshop had to be reduced to two hours due to constraints of time or availability of venue. From the comments we saw that some people wanted the time to discuss further action and follow up.

Observations and reflections of the facilitators

The time when we were organising, presenting and following-up on the workshops was a very intensive one for the team. At times we got quite fed up with the limitations of a privatised 'public' transport system especially when travelling to some of the more remote locations. Yet this was an exciting and very important experience. There was a positive two-way interaction between ourselves and the participants in the workshops, improving *our* understanding of many issues; we gathered information that we were able to feed *back* into the workshops.

The central focus on interactive mapping in the workshops was a powerful tool for drawing out both historical and/or environmental information. We were able to create group pictures of local concerns, where participants were able to spark off each other's ideas and recollections. Using 'fun' tools like fuzzy felts and bright coloured pens helped to demystify the whole mapping process. The environmental factors identified in the workshops were echoed in the respondents' maps. Flip charts were used to generate discussion about local sources of pollution and this information was used to compile a 'fuzzy felt' map of the locality to illustrate how participants could begin to imagine their maps.

This information creates an interesting picture: pesticide use was highlighted universally, even though many women did not live in a rural area. Traffic pollution was a common worry. Heavy industry, in these de-industrialised times was not a large factor. The new commonly perceived industrial hazards seemed to be computing and photocopying. We also got some information which was relevant to the location, for example radon in Kettering or the dye works in Leicester. Through the mapping exercise, we created personal and individual histories which participants were able to share with each other. Sometimes we were able to experience the landscape we visited before jumping back on the train to London.

The free-ranging discussion and mapping in the workshop allowed us to broach, if not address in depth, various political issues such as the interaction between poor social and economic conditions and a poor environment. In some instances (e.g. in North Wales) we also talked about the difficulties of getting council and health authorities to even *listen* to our concerns. Most importantly we felt that we had given women who had breast cancer the chance to ask the question 'why me?' and to explore some of the possible answers. This was therapeutic but far more importantly it was empowering with a big 'E'.

• Next steps

The bringing together of the various strands of the process produced a dynamic and 'living' picture of breast cancer incidence in the UK and possible factors which affected it. When the completed maps and questionnaires were returned to WEN, each one was given a unique reference number. The information from the questionnaire was entered onto a database at the office and analysed. In order to get the maps onto the computer a picture was taken of each one using a scanner and this allowed it to be viewed on the screen and used in the report. With the co-operation of The London School of Hygiene and Tropical Medicine, a Geographic Information System (GIS) was set up to pinpoint and locate participants and local sources of environmental pollution identified. The idea was to link each questionnaire with the geographical point on the map which represents where participants had lived or are currently living.

From an analysis of the first 545 questionnaires received, 320 maps and contributions from 26 workshops, the project participants identified a large number of breast cancer clusters and a significant number of 'hotspots' for breast cancer. The term 'cluster' was defined as 3 or more cases of breast cancer occurrence in the same location, e.g. street or place of work, in the same time period. In addition, participants were very concerned about the high incidence of breast cancer in the UK, and the increase in health problems which have been linked to environmental pollutants such as asthma and hay fever. This was expressed especially in connection with air pollution from traffic and industry.

As a result of this project WEN has put forward a number of recommendations calling on the Government to commit a large part of annual health spending to a comprehensive programme for primary prevention of breast cancer. WEN also calls for a further analysis of Health Authority data on breast cancer incidence and prevalence by locality. We want prevention of breast cancer to be very high on the agenda.

WEN recommends making women and children's health the prime indicator of the state of the environment and acknowledging women's experience and knowledge about

issues to do with their health. This could be utilised as a valid and valuable resource base from which to initiate official research programmes.

Including women as active participants in shaping this project 'Putting breast cancer on the map' has raised awareness, empowered and affirmed women's own knowledge. Women all over the UK have mobilised themselves to take forward the issue of breast cancer and environmental pollution. They are beginning to ask more questions, feel the strength of the network and develop the scope of the project beyond breast cancer to the larger issues of environmental impacts on both our health and that of future generations.

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NOTES

The above extract is from the *Putting Breast Cancer on the Map* Report. For a copy of the project report (priced £16 including post and packaging), the information pack (send an A4 sae with 66p stamp) or the Project Executive Summary (send an A4 sae with 39p stamp), please contact: Health Project, Women's Environmental Network (WEN), P.O. Box 30626, London, E1 1TZ, UK. Tel: +44 (0) 20 7481 9004; Fax: +44 (0) 20 7481 9144. Website: www.gn.apc.org/wen.

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