

Basic Protocol for the Investigation of Alleged or Suspected Cancer Clusters March 2004

1. The Primary Care Trust (PCT) should establish good ongoing contacts with the local media.
2. The local Director of Public Health (DPH) should visit and talk to the residents to listen to their views and to see if they can allay the concerns that they have raised.
3. The local DPH should contact the local authority and other appropriate agencies to obtain more information concerning the potential hazard identified by the concerned residents. Any information obtained should be shared with the concerned residents.
4. If the residents still feel that their concerns have not been adequately answered, the local DPH should obtain the demographic and clinical details of the alleged cancer cases, taking care to record the period of time that the people have lived in the area.
 - Demographic details should include: name, date of birth, NHS number, address and postcode.
 - Clinical details should include: cancer site and histology, hospital(s) of diagnosis and treatment, HRT usage, PSA testing, smoking and drinking habits, previous occupation, screening history.These details should be sent to the WMCIU in order to verify the cancer cases. If the cancers are not registered, the WMCIU will follow up the cases with the local hospital and/or GP.
5. The WMCIU will provide incidence/mortality/survival data for the ward/PCT etc compared to region as a whole for the appropriate cancer site(s), sex(es) and age band(s). The WMCIU will also provide observed and expected ratios as appropriate together with information on the variation of cancer incidence, mortality and survival with deprivation status, and on screening activity in the area.

NB. Note that basic incidence, mortality and survival data at ward and PCT level are available to all PCTs via the WMCIU's electronic Cancer Information Service.
6. If the residents still feel that their concerns have not been adequately answered, the West Midlands Health GIS service can be used to identify wards with similar characteristics (cancer incidence, population density, deprivation status) in order to generate comparable incidence, mortality and survival data. The West Midlands Health GIS service can also plot individual cancer cases to examine whether similar clusters occur in absence of the alleged potential hazard.
7. If residents still feel that their concerns have not been adequately answered, the local DPH should contact the Health Protection Agency and/or the Small Area Health Statistics Unit (SAHSU) for further expert assistance.
8. At all times it should be the PCT that deals with the residents and the media not the WMCIU so that the WMCIU can remain an impartial advisor.