THE PATIENT VIEW
This is a working paper prepared by Mrs T Bevan from Cardiff, a member of the Cancer Services Expert Group (CSEG). The information has been drawn from comments and views made by patient focus groups established through the Community Health Council network in Wales and from published material. The recommendations in this report have been agreed by CSEG.

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1. INTRODUCTION

Methodology

1.1 Perspectives, attitudes and observations from those who have experienced direct treatment for cancer, as patients or as carers, provided an important input into CSEG’s deliberations.

1.2 Evidence was sought through the network of Community Health Councils in Wales. Patient Focus Groups of 10-12 people were established under the aegis of Councils to discuss key issues, and members were invited to commend or criticise services as they had experienced them.

1.3 Groups reflected a wide geographical spread and represented urban and rural communities. Reports were received from:

- Anglesey - Ynys Môn
- Brecknock and Radnor
- Ceredigion
- Montgomery
- Pembrokeshire
- The Vale of Glamorgan

Unfortunately, the Mid Glamorgan group failed to meet. The complete reports of the focus groups are available from the Project Office.

1.4 The Tenovus Cancer Information Centre were also invited to submit data, with particular reference to the Freephone Cancer Helpline established in 1992.

1.5 Much of the evidence from the focus groups is anecdotal but on analysis there does appear to be ‘common view’ on certain issues.

1.6 The groups were invited to comment on the following points:

- the initial visit to the GP
- referral procedures to the specialist
- speed of action - diagnosis and treatment
- information and communication
- travelling times
- counselling and after care
- discharge referral

2. SUMMARY OF THE FINDINGS

2.1 Breast Test Wales screening programme, including referral and counselling was universally praised.

2.2 Comments and experiences on GPs varied:

- Concern was expressed by many on the GPs knowledge of the right specialist for a particular cancer.
- GPs requiring more training in order to spot danger signs.
- Concern about the fairness of gaining access to hospitals from funded and non funded GP practices.
- A wait of months was not unusual : ‘were the referral letters urgent enough......’
- The real problem for many people was obtaining information about where was the ‘best place’ for treatment and why.

2.3 Members of all groups agreed they would travel any distance for diagnostic and surgical treatment if they knew they were going to ‘the best place’, acknowledged for expertise and excellence.

- A journey of 30 minutes was deemed acceptable to GP/Hospital, but journeys of over an hour were to be avoided for those undergoing debilitating treatment. ‘It is a myth that everyone has the use of a car’. Chemotherapy treatment could well be given at a more local level.
- Case notes not being sent to the relevant hospital caused delays, often disappointment and further appointments.
• It is worth noting that many Anglesey patients, receiving treatment at Clatterbridge, a journey of at least an hour and a half, praised the charity which organised a minibus to take patients from ‘door to door’.
• There seems general praise too for the ambulance service but there were incidents of long journeys, shared with other patients and of feeling ill and discomfort from therapy treatment. Others raised the issue of expense. One stated that over a year they had spent £5,000 on travelling expenses.

2.4 The majority expressed genuine concern at the lack of information and the need to review methods of communication with patients:
• There were many examples of a lack of privacy and insensitivity by the medical profession when conveying ‘bad news’ and a poor diagnosis.
• After initial diagnosis patients are vulnerable. They need time to come to terms with the condition and to be able to reflect before being able to ask ‘intelligent questions’ and making decisions.
• There were several instances in different parts of Wales of patients being told their diagnosis and prognosis in open wards and corridors.
• There were few complaints about clinical treatment, but a general view persists that patients are unhappy with the way in which treatment is given. Oncology staff needed to adopt a hands on, caring/counseling attitude rather than delivering a high-tech analysis of procedures.
• Many participants expressed the view that medical and nursing staff involved in cancer services should receive training in ‘communication’, i.e. how to convey life threatening diagnosis to a patient and what the treatment involves.
• There is often a lack of information given on the side effects of certain aspects of treatment such as chemotherapy and radiotherapy.
• There is a very definite lack of information about support groups, where to get help, social benefit and counseling.
• There is general dissatisfaction with the arrangements of care after hospital discharge, and particularly with the lack of information about entitlement to various services.
• Suggestions were made on the urgent need for ‘Information Packs’ for patients explaining procedures, support groups, voluntary bodies, etc. This would be a way in which the vulnerable are not left unsupported or having to fight for benefits they are entitled to. Carers and patients often felt very isolated. Information packs could well be standardised and made available to everyone.
• There were examples of communication problems between specialists and GPs on discharge from hospitals, e.g. delays in relaying information, urgency, etc.
• None had been given the choice of a second opinion. Patients it is said are too tolerant and put the medical profession ‘on a pedestal’.

The findings from national studies of the information needs of people with cancer have been replicated at the local level\(^1\)\(^-\)\(^3\). While some studies have evaluated particular ways of giving information\(^4\)\(^-\)\(^8\), further research is needed to evaluate cost-effectiveness and outcomes in terms of quality of life, patient expectations and resource usage\(^9\)\(^,\)\(^10\).

2.5 These views are reflected in the evidence provided by the Tenovus Freephone Helpline Service established in 1992. It is staffed by qualified nurses, counsellors, social workers and a welfare rights officer. An overview of the work of the Tenovus Cancer Information Centre is available from the Project Office.

In 1995, 10,000 calls were received. The reasons for the calls were as follows:
• Cancer information - prevention, diagnosis, treatment, prognosis
• Social support (financial advice)
• Resources available (how to care)
• Counseling
• Health professionals seeking information

The vast majority of calls (98%) are seeking translation and interpretation of information given by health professionals. It highlights the need to be more ‘patient friendly’ when giving information.

The counselling service is increasingly used. Currently the use tends to be as a last resort, in reaction to a crisis, and at a time of psychological distress. The pro-active role of counselling appears not to be recognised by the health care professionals.

2.6 The findings identified by the patient focus groups in Wales were similar to the research findings from a project carried out by the National Cancer Alliance on cancer patient views in England\(^11\).
3. **RECOMMENDATIONS**

1. Mechanisms should be in place to ensure that results and case notes are sent to the relevant hospital in advance of appointments to avoid delays, disappointment and further appointments\(^{(a,b,c)}\).

2. Transport should be arranged for any length of distance for diagnostic and surgical treatment, taking into account the individual patient’s needs. A journey of 30 minutes would be acceptable to the general practitioner or hospital. Journeys of over an hour should be avoided for patients undergoing debilitating treatment\(^{(a,b,c)}\).

3. Specialists and the location of specialist cancer site specific multidisciplinary teams should be identified\(^{(a,b,c)}\).

4. The communication of a patient’s diagnosis and prognosis should be carried out in strict confidence away from open wards and corridors. Medical and nursing staff should receive training in communication\(^{(a,b,c)}\).

5. Communication should be improved between specialists and general practitioners following a patient’s discharge from hospital\(^{(a,b,c)}\).

6. Methods of communication with patients should be reviewed. Information packs should be given to patients on discharge from hospital, providing information on for example, support groups, after care and entitlements\(^{(a,b,c)}\).

| Evidence base: | a. The National Cancer Alliance  
|               | b. Task Group Patient Focus Groups  
|               | c. Published papers |

4. **REFERENCES/BIBLIOGRAPHY**


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