King's Fund

Promoting Action on Clinical Effectiveness

Patient Involvement Workshop

28 June 1996

This report provides a collection of papers and related material from the workshop discussion on 28 June. It includes:

- a brief introduction
- OHP slides used in the four presentations
- examples of topic guides for focus groups from SCPR
- brief notes from the round table discussions
- details of participants

Michael Dunning
PACE Programme
July 1996

Introduction

At the initial meeting of the PACE Project Group in Birmingham in April 1996, we discussed access to information about current perceptions of good practice. The discussion spanned a wide range of issues pertinent to the progress of local projects. As a consequence of the meeting, arrangements were put in hand for a workshop to discuss issues related to patient involvement in the development of local projects. The programme for the day was designed to provide background information which local project teams could build on when taking their work forward.

The programme for the day included presentations on :

(1). the practicalities of running focus groups;

(2). linking work on *Clinical Effectiveness* to *Local Voices* initiatives;

(3). information sought by patients; and

(4). creating information for patients.

This report covers the four sections identified above plus two others :

(5). a note based on the round table discussions; and

(6). a note of the participants at the workshop and their contact details.

Each separate section starts with a coloured page.

A summary report of the workshop discussion is being prepared for wider distribution.

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Section 1. The practicalities of running focus groups

Presentation by :

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Copies follow of

a. the slides used in Rebecca's presentation.

b. example of topic guides which are used by SCPR to guide focus group discussions.

c. a reading list on focus groups which Rebecca has provided.

The presentation raised many issues and some of the points which arose in the discussion following Rebecca's presentation were :

- create a topic guide which outlines the key areas to be covered; it is preferable not to give respondents notice of the questions
- the moderator should remain impartial in the discussion and not put forward their views
- the sample should be selected purposely to ensure diversity
- in creating the group bear in mind that patients may feel freer to talk if no clinical staff are involved; if clinical staff are moderating or observing they should be introduced as researchers
- encourage the group to discuss between themselves so that issues can be explored and debated
- give respondents the opportunity to explore both sides of an issue
- consider the possibility of setting up a panel of respondents. so that groups can be reconvened and attitudes explored over time

THE PRACTICALITIES OF RUNNING FOCUS GROUPS

King's Fund PACE Programme
Patient Involvement Workshop
Friday 28 June 1996

ISSUES COVERED

☆ ***WHAT*** focus groups are

☆ ***WHEN*** to use them

☆ ***WHO*** to include

☆ ***HOW*** to moderate them

WHAT ARE FOCUS GROUPS?

- ☆ SMALL GROUPS (6-9 PARTICIPANTS)
- ☆ CONVENED FOR RESEARCH PURPOSES
- ☆ FOCUS ON ISSUES RELATING TO A SPECIFIC TOPIC
- ☆ RUN BY A MODERATOR
- ☆ AVERAGE LENGTH IS ONE AND HALF HOURS
- ☆ USUALLY MEET ON ONE OCCASION
- ☆ DISCUSSION IS TAPE RECORDED

WHEN TO USE FOCUS GROUPS

WHEN	?
☆ SOME SENSITIVE ISSUES	☆ SOME SENSITIVE ISSUES ☆ WHERE SOCIAL NORMS PREDOMINATE
☆ ISSUE RAISING AWARENESS/MISCONCEPTIONS IDEA GENERATION	☆ DETAILED EXPLORATION OF ATTITUDES/ BEHAVIOUR
	☆ WHERE PARTICIPANTS...... know one another widely dispersed communication difficulties mobility problems busy

WHO TO INCLUDE - THE GROUP COMPOSITION

NEED TO CONSIDER

☆ DEGREE OF HOMO/HETEROGENEITY REQUIRED DEPENDING ON

- Nature of research questions
- Type of participants

☆ SIZE OF GROUP DEPENDING ON

- Knowledge/status of participants
- Age of participants
- Numbers in population
- Type of research

☆ COST / TIME CONSTRAINTS

MODERATING FOCUS GROUPS - THE MODERATOR'S ROLE

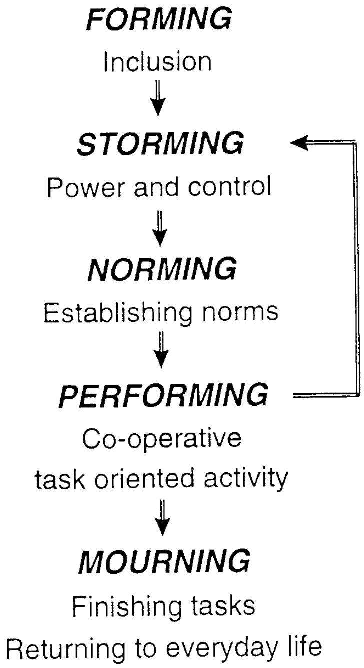
☆ GUIDE THE DISCUSSION TO FULFIL RESEARCH OBJECTIVES

- Introduce the research
- Direct the flow of discussion over important areas (using a topic guide)
- Recognise when group is working well (the performing stage)
- Allow time for the group to wind down

☆ RUN THE GROUP TO ENSURE ALL PARTICIPANTS CAN MAKE AN EFFECTIVE CONTRIBUTION

- Create a conducive atmosphere
- Control dominance
- Draw out quieter participants
- Look at both sides of argument

GROUP PROCESSES



FORMING
Inclusion
↓
STORMING
Power and control
↓
NORMING
Establishing norms
↓
PERFORMING
Co-operative
task oriented activity
↓
MOURNING
Finishing tasks
Returning to everyday life

FORMING

POINTS TO REMEMBER

☆ RECRUITMENT ISSUES

☆ PHYSICAL CONDITIONS

☆ SEATING ARRANGEMENTS

☆ INITIAL INTRODUCTION

☆ CONFIDENTIALITY

☆ TAPE RECORDING

☆ INITIAL QUESTIONS

QUESTIONING

POINTS TO REMEMBER

- ☆ AVOID CERTAIN ISSUES AT THE START
- ☆ BE FULLY AWARE OF RESEARCH OBJECTIVES / TOPIC GUIDE
- ☆ LISTEN ATTENTIVELY
- ☆ ASK SIMPLE OPEN QUESTIONS
- ☆ PROBE ANSWERS UNTIL YOU UNDERSTAND
- ☆ MIRROR PARTICIPANTS LANGUAGE
- ☆ CHECK BOTH SIDES OF AN ISSUE / CHALLENGE VIEWS
- ☆ PACE THE DISCUSSION
- ☆ BE AWARE OF ALL PARTICIPANTS
- ☆ OBSERVE TONE OF VOICE / BODY LANGUAGE
- ☆ TRY TO MAINTAIN A BALANCE BETWEEN PARTICIPANTS
- ☆ REMAIN IMPARTIAL

MOURNING

POINTS TO REMEMBER

- ☆ SIGNAL THAT THE DISCUSSION WILL BE ENDING
- ☆ TRY TO END ON A POSITIVE NOTE
- ☆ THANK PARTICIPANTS
- ☆ REMIND PARTICIPANTS OF CONFIDENTIALITY
- ☆ BE PREPARED TO STAY AND CHAT

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ATTITUDES TO PHYSICAL ACTIVITY

Awareness of the link between physical activity and health is increasing. This is a study which uses focus groups, among different sections of the population to examine:

- **Awareness** of the benefits of physical activity;
- **Attitudes, motivations, experiences** regarding physical activity, and specifically **BARRIERS** to taking it up on a regular basis;
- Suggestions on **ways of overcoming** barriers;

and
- on **how to promote** physical activity.

The study is for the Health Education Authority and will take the form of focus groups with a cross section of the population in different geographical areas. The group participants will represent people of different gender, age, socio-economic and ethnic background.

ATTITUDES TO PHYSICAL ACTIVITY

TOPIC GUIDE

1. Background
   - Age
   - Household composition
   - Employment activity ie working/ not working / full-time education / looking after family, etc
   - What exercise or physical activity they do nowadays, if any? (briefly)
     - What activity(s)?
     - How often?
     - Part of the daily routine? Scheduled into the day/week?
     - Done alone? / With someone else? - Who?

2. What do we mean by `physical activity'? *[brief section]*

   - What counts as `physical activity'?...
   - *PROMPT IF NECESSARY:* Eg: Does Walking count? Gardening? Housework? Dance? The kind of paid work they do?

3. Beliefs/knowledge about physical activity + awareness of the benefits *[key section]*

   - Is physical activity important?...
     In what way? (Why bother? Why do it? What's the point?)
     DO NOT PROMPT INITIALLY
     Is it important: - for **health**? for **fitness**?
     - heart? *(Any link with Coronary Heart Disease?)*
     - any other health aspects?
     - for **weight control**?
     - for **mental health**? for spiritual peace?
     - for **general well being**?
     - for physical **independence in old age**?
     - **other reasons?**

   - How does physical activity compare to other things they might do for their health?
     PROBE: Is it more or less important than:
     - diet?
     - not smoking?
     - not drinking?

- Is `fitness' different from `health'?...
  What do they understand by `fitness'?

- Does it matter:
  - what sort of physical activity they do (for health/fitness)?
  - how much physical exercise they do to keep fit/healthy?...
  - how intensely they do it?... Does it matter .. if they get breathless? Or feel heart beat?

  DO NOT PROBE INITIALLY

4. Activity levels now vs past *[brief lead-in to barriers]*

- How does physical activity that they do now compare with what they used to do, in the past?...
  PROBE: type + level of physical activity done.

5. Perceived barriers to physical activity *[crucial section]*

- What prevents them from being more physically active (doing exercise/sport)?
  DO NOT PROMPT INITIALLY

PROBE:

- PAST EXPERIENCES - Have any past experiences put them off? (What?)

- TIME - Is lack of time a barrier to physical activity? In what way

- TIMES OF LIFE - Are there times in life when physical activity is more difficult/less important?

- MONEY - How important is lack of money as a barrier to physical activity, compared to other things? eg going to the cinema/ hiring a video film

- MOTIVATION - lack of incentive??

6. Overcoming the barriers

- How could these barriers be overcome?...

- How do people who are more active overcome barriers?...

IF ACTIVE IN PAST: How have they overcome them at different times?

- Would active promotion help? *[LEAD-IN TO NEXT SECTION]*

7. Promotional strategies/ideas

- How would they promote it (if they were the HEA)?
  - What would be the best way?
  - What would work for them?

- Do they know of any information or promotional material on physical activity?...
  - Have they heard or seen anything at all? (What? Where?)
  - What did they think of it? How did they respond? Did it have an effect?

- Is there a need for more information/advice?
  Eg Literature or promotions (What kind/why?)

END

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FACTORS INFLUENCING THE USE OF DENTAL SERVICES: A RESEARCH STUDY FOR THE BRITISH DENTAL ASSOCIATION

Introduction to the study

Surveys show that although dental health in Britain is gradually improving there is still a sizeable proportion of the population whose dental health is poor. Qualitative information is required on attitudes to dental care, and to 'going to the dentist', in order to analyse why people don't go and the perceived barriers to the use of dental services.

The objectives of the research are to examine the range of factors which inhibit people from seeking dental treatment, and to seek ideas on ways in which barriers to seeking dental care might be overcome

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FACTORS INFLUENCING THE USE OF DENTAL SERVICES
TOPIC GUIDE

1. Background

- Household composition
- Employment activity ie working/ not working / full-time education / looking after family etc.

2. General Health Beliefs (*Brief*)

- How would they describe their general health
- Any steps taken to maintain their general health

3. Dental Health Beliefs

- How would they describe their dental health
- Any steps taken to maintain dental health
  PROBE: cleaning/flossing/diet etc
  (How?/ When?/ How often?)
- Influences - eg family, dentist, media, good/bad role models?

4. Pattern of Dental Attendance

- Do they have a dentist
- How often do they visit
- Changes in pattern of visits in past/ reasons
- Usual reasons for going to the dentist
- Influences - eg family, dentist, media, good/bad role models?

5. Attitudes to visiting the dentist

- Describe a recent visit to the dentist
- Likes and dislikes about visiting the dentist
  PROBE: - ease of getting appointment
  - getting there
  - receptionist
  - waiting room
  - treatment/dentist's manner
  - dentists/dental nurses/hygienists
- What influences their choice of a dentist

6. **Factors influencing use of dental services**

- What encourages/would encourage them to go to the dentist
- What do they feel are barriers to going to the dentist

7. **Removal of the barriers**

- What would encourage better dental attendance in general
- What action should the Dental Association take to promote better attendance

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GROUP DISCUSSIONS IN QUALITATIVE RESEARCH

A READING LIST

Bion W R, **Experiences in Groups**. Tavistock Publications 1961

Goldman A E & McDonald S S, **The Group Depth Interview: Principles and Practice**.
Prentice-Hall Inc. 1987

Gordon W and Langmaid R, Qualitative Market Research: A practitioner's and buyer's guide.
Gower, 1988. (See chapter 3 '**Group discussions: philosophy, mechanics and process**' and chapter 4 '**Group dynamics**')

Krueger R A, **Focus Groups. A practical guide for applied research**.
Sage Publications 1994

Moore C M, **Group Techniques for Ideas Building**.
Applied Social Research Methods Series. Volume 9. Sage Publications, 1987

Morgan D L, **Successful Focus Groups**.
Sage Publications, 1994

Robson S and Foster A, Qualitative Research in Action. Edward Arnold 1989
(See chapter 3 '**Group discussions**', and chapter 4 '**The dynamics of small groups**')

Tuckman B & Jensen M, **Stages of Group Development Revisited.**
Group and Organisation Studies, 2 (4), pp 419-427. 1977

Walker R (ed), Applied Qualitative Research. Gower 1985
(See chapter by Hedges A, '**Group interviewing**')

hf/1994

Section 2. Clinical Effectiveness and Local Voices

Presentation by

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Introduction

Within the NHS's current priorities and planning guidance there are two policies relating to clinical effectiveness and local voices. The first of these policies tries to ensure that the NHS is based upon interventions which are clinically effective; and the second which tries to ensure that the NHS becomes increasingly responsive to the views of the patients and public which it serves.

This presentation identified some of the dilemmas which arise in practice when these two policies come together.

North Derbyshire has taken *Local Voices* work seriously for a number of years. It is difficult to summarise the approach which has been taken, but the list of "useful words" indicates the range of work which is encompassed within this heading - *Slide 1.*

Local Voices does however create some dilemmas for the implementation of Evidence-Based Practice. Using four case studies from recent work in North Derbyshire (relating to services for disabled people, physiotherapy, cultural circumcision and stroke rehabilitation) the presentation identified a number of ways in which the notions of clinical effectiveness and being responsive to patients may run counter to one another The general lessons from the case studies were identified - *Slide 2.*

Copies of the slides follow.

LOCAL VOICES : Useful words

Advocacy

Patients Participation Groups

Information

Healthline

Local Planning

User Defined Standards

User Expenses

Voluntary Sector

Community Groups

Complaints

Plain English

Communications Strategy

Health Matters

Consultation

Conferences

Focus Groups

Surveys

Community Development

CHC

Lay Representation

Self-Help Groups

Estates Action Committee

Press Relations

Citizens Jury

Primary Care-Led NHS

User Evaluations

Joint Planning

User control

More Information

EBP and LOCAL VOICES : Summary

1. **EBP INVOLVES VALUE JUDGEMENTS WHICH EMPHASISE A MEDICAL MODEL OF ILLNESS**
2. **PATIENTS NEEDS ARE COMPLEX AND HOLISTIC: EBP CAN BE REDUCTIONIST**
3. **TREATMENT HAS A VALUE BEYOND ITS CLINICAL EFFECTIVENESS**
4. **SHOULD EBP ALLOW FOR CULTURAL DIVERSITY?**
5. **SHOULD EBP ALLOW FOR LOCAL CONTEXT/LOCAL FACTORS?**
6. **SHOULD EBP IGNORE CLINICAL CONSEQUENCES IF A TREATMENT IS WITHDRAWN?**
7. **WHAT ARE PATIENT EXPECTATIONS ABOUT TREATMENT?**

Section 3. Information sought by patients

Presentation by

Sarah Buckland
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Copies follow of the slides used in Sarah's presentation.

HEALTH INFORMATION

- Increase in availability and accessibility of health information to the public:
  - hospitals / ward based information
  - health information service helplines
  - self help groups
  - community information centres

- Patients do not get all the information that they need
  - lack of knowledge about illnesses and medical conditions
  - lack of knowledge about where to go to seek information and advice

- Patients do not get all the information that they want:
  - increase in demand for health information
  - consumers are asking more complicated questions

UNMET NEEDS STUDY
Project funded by the Nuffield Provincial Hospitals Trust

- 40 in-depth interviews

- Members of the public in their own homes

- Interviews tape recorded and transcribed

- Quotas: age, sex, socio-economic status, household composition

INFORMATION PROVIDED AS PART OF THE PROCESS OF MEDICAL TREATMENT

- Health care professionals (in particular GPs) are seen as the main source of health information

- Health care professionals (in particular GPs) are seen as being the most credible source of information

- Barriers exist that prevent patients gaining the information they need from health care professionals

- As a result of these barriers, the information received is often limited and is not provided to the level of detail wanted

UNMET NEEDS STUDY

INFORMATION ABOUT TREATMENT

- The amount of information conveyed about treatments was relatively little

- Many people appeared not to question the amount of information they received (despite it being limited).

- The majority of respondents reported that when they saw health professionals they were told what was wrong with them (where appropriate), BUT further explanation was often less forthcoming.

- Where individuals did receive a good explanation, often surprise and appreciation was expressed.

SIDE EFFECTS

- Medical staff appeared to be unforthcoming in providing respondents with either verbal or written information about the side effects or contra-indications of the medicines prescribed.

- The only respondents who gained information on side effects and/or contra indications, had to ask for it, or read it for themselves from the written information provided with the drugs

- Concerns over side effects and risks of treatment were expressed by several respondents.

TREATMENT CHOICES

- There appeared to be relatively little discussion between patients and their GP's or other health care professionals, over possible alternative treatments.

- Even when different options were discussed related to treatments, patients were often not given the choice of the treatments, instead the alternatives were presented as last resorts, with the decision being made by the GP or hospital.

- There are various levels of information that can be provided

- The level and amount of information wanted or needed is not consistent
(dependent on the individual, the illness, timing etc.)

- some people do not want detailed explanations and choices

BUT

- many people do not receive all the information they want or need

- It takes time and skills to talk to patients and elicit their needs

DISSEMINATION OF TREATMENT OUTCOMES INFORMATION

Project funded by the Kings Fund

PHASE 1:

- Questionnaire survey to Consumer Health Information (CHI) Services
    - 73% response rate (53/73)
- Monitoring by services of treatment choice enquiries during a six week period
    - 60% of services (44/73) completed monitoring forms
    - 2,244 monitoring forms returned

PHASE 2:

- Evaluation of 5 pilot projects involved in disseminating treatment choice information

QUESTIONNAIRE

ESTIMATES OF TREATMENT CHOICE ENQUIRIES

- 18% of total enquiries a month were reported to be about treatments

- 42% reported receiving treatment choice enquiries frequently
- 38% reported receiving treatment choice enquiries occasionally
- 2% didn't get any such enquiries

MONITORING FORMS

NUMBERS OF TREATMENT CHOICE ENQUIRIES

- 2,244 enquiry monitoring forms returned during the study period (from 44 services):

- 807 national voluntary organisations
- 847 Regional Health Information Services
- 590 local CHI services

STAGE OF TREATMENT WHEN INFORMATION SOUGHT

- Before recommendation given by health professional - 27%

- After recommendation given, but before treatment decision made - 14%

- After decision made but before treatment commenced - 10%

- After treatment commenced - 28%

MONITORING

MOST FREQUENT TREATMENT CHOICE ENQUIRIES

- Drug treatment (33%)
- Side effects (17%)
- Treatment related self help groups (14%)
- Surgical procedures (11%)

LEAST FREQUENT TREATMENT CHOICE ENQUIRIES

- Clinical trials (2%)
- Mortality rates (3%)
- Screening (3%)
- Rehabilitation (5%)

Section 4. Creating information for patients

Presentation by

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Copies follow of :

a. brief notes of the main points from the presentation

b copies of the OHP slides used in Vikki's presentation

Information to facilitate patient involvement in decision making - some issues

Patient involvement in clinical decisions is increasingly advocated *(OHP1)*. This trend is partly linked with the promotion of clinical effectiveness:

* Information about treatment effectiveness arguably makes choices more meaningful for patients *(OHP2)*

* It is hoped that informed patients will influence professional behaviour by expecting/demanding the most effective forms of health care.

Evidence informed patient choice seems, to many people, appealing and sensible. It will, however, involve some substantial changes in the way health care is delivered, and raises quite a few issues which need addressing.

* There is very little evidence about the effects of sharing research based information about the effectiveness of treatment options with patients, and of involving them in decisions about their care. While welcoming their potential for good, we should not ignore their potential for harm *(OHP3)*.

* In many cases, the available evidence about the relative effectiveness of relevant treatment options will be quite limited *(OHP4)*.

* Tensions may arise between the promotion of evidence based care and the promotion of patient choice. People will not always prefer the option which has been judged to be most effective according to a narrow set of professionally defined outcome criteria.

* Judgements about which treatment option is best are likely to vary with the standpoint of the judge. In particular, there may be discrepancies between the social (public health) and individual perspectives.

* Within a publicly funded health care system, choices may be restricted. This raises the question of whether people should be informed about all technically possible treatments or only about those which are available to them on the NHS. We should also ask whether patients should be ask to consider the cost effectiveness as well as the effectiveness of different options when making their decisions.

* The promotion of evidence informed patient choice has implications in terms of skill requirements among both patients and health professionals *(OHP5, 6)*, resources, and the organisation of health care. *(OHP7)*.

In raising these issues and highlighting some of the difficulties of implementing evidence informed patient choice, I am not arguing that patients should not be given research based information about treatment outcomes and involved in decisions about their care, particularly if they would prefer such information and involvement.

A few thoughts about preparing information for patients

There is little empirical evidence to inform our judgements about which are the "best" processes to adopt when producing patient information, and which information packages are most likely to have the desired effect, whatever that may be.

Potential producers of information about effectiveness for patients should consider, among other things:

- WHO are the intended recipients of the information?
- WHY are you planning to give them this information?
  (Information about effectiveness may be given in an attempt to persuade people of the effectiveness, acceptability or appropriateness of a particular form of care, or to help people make a "free" choice (with as little as possible direction or persuasion).
- WHAT information do you intend to give them? Have you any evidence that they want it and would find it useful?
- WHEN and WHERE will they receive the information? What are the implications of this?
- HOW and BY WHOM will they be given the information? What are the implications of this?
- Are the people who receive the information likely to need any additional support, for example to help them understand the information, or to find out more?
- Has anyone else already produced an information package which would suit your purpose?
- How will you attempt to ensure the quality of the information you provide? How will you ensure it reflects the most reliable research evidence, and is presented clearly in a way which your intended audience can use?
- How much will it cost? Can you afford it?

Purchasers and providers should be able to demonstrate that they have a systematic programme in place aimed at achieving active partnership with individual patients in their own care, in particular seeking to improve the quantity and quality of information given to enable patient choice about treatment options.

(NHS Executive, 1995)

The development of clinical epidemiology creates pressures driving us towards shared decision making. To the extent that we know with some certainty how well treatments might work and the risks and benefits of different treatments for a particular disease, we can offer patients meaningful choices among different therapies for their disease.

(Lantos, 1993)

What are the effects?

- Professional-patient relationships
- Demand for health care
- Psychological wellbeing
- Outcomes of care

Limitations of available evidence

- Some technologies have not been evaluated
- Alternative treatments have often not been directly compared
- A limited range of outcomes have been assessed

Patients need to:

- Acknowledge the limitations and uncertainty of health care
- Understand probabilities
- Recognise personal values
- Engage in a decision making process
- Communicate effectively with health professionals

Professionals need to:

- Recognise patients' abilities and role preferences
- Elicit patients' concerns and treatment/outcome preferences
- Access, appraise and share research based information
- Provide (non-directive) counselling
- Facilitate patient involvement

Systems issues

- **Consultation patterns**
- **Consultation lengths**
- **Continuity of care**
- **Losses of economy of scale**

Section 5. Round table discussions

Some of the main points which arose in the discussions following Sarah's and Vikki's presentations were :

- be clear about the *message* you are trying to convey, i.e. to support patient choice, or whether the objective is persuasion
- ensure that there is a balanced picture - reflecting aspects of care where research based evidence is not present, as well as where it is (including non-clinical aspects of care)
- be sure that the issue is viewed from the patient perspective, and reflect on the sort of questions asked by patients
- aim for consistency in the information that is available - try to avoid conflicting messages
- be aware that information may prompt a demand for a service - is the service able to cope?
- acknowledge that the need for information by patients may vary - some want everything others little or none. There is a need for sensitive prompting of what information is wanted.
- build on the work of others, adapt other material rather than start afresh

- be clear about *when and where and by whom* to provide information at a stage that allows patients to use it - e.g. can they respond if given material during a consultation with the GP?
- acknowledge that the process of providing information to patients takes time
- ensure that the flow of information to clinical staff and patients is matched, avoid imbalance by for example providing information to patients which has not been seen by clinicians

- consider *how* the material can be provided - easy access through primary care, pharmacies, community facilities etc. - take account of where patients might be encouraged to "pick up" leaflets.
- build on the experience of work on chronic conditions such as asthma and diabetes
- explore the prospects of creating signposts and key contacts to information, rather than providing everything, explore whether self help groups can support this process

Section 6. Participants and Contact details

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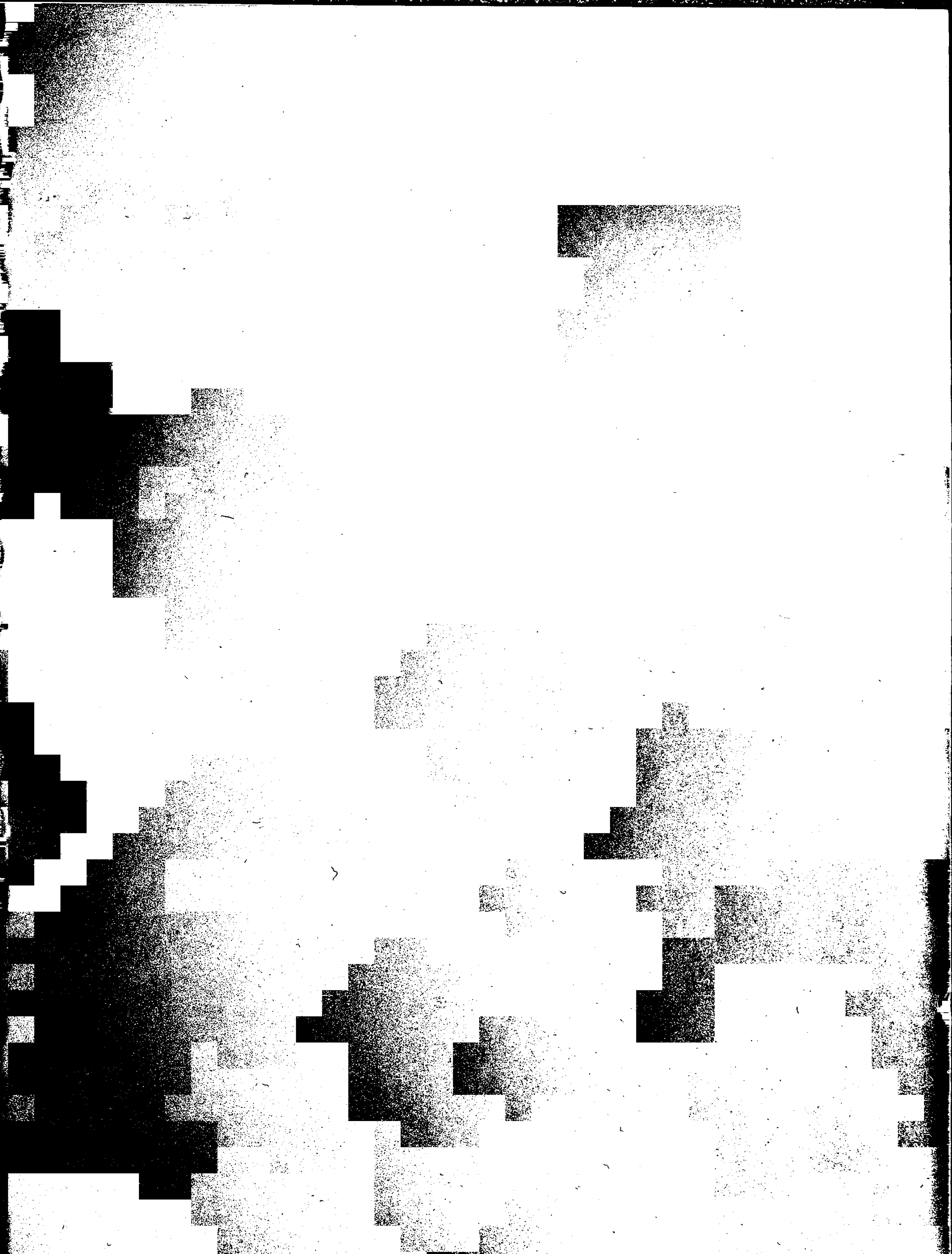

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