

Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People

**(Based on ‘Involving Marginalised and Vulnerable Groups in Research:
A Consultation Document’)**

Introduction

‘Vulnerability’ and ‘marginalisation can mean different things to different people. The range of individuals who are sometimes **described** as ‘vulnerable’, or ‘marginalised’, by service providers is large. However, whether or not a group is perceived or perceives itself as vulnerable or marginalised will probably depend on its context at any given time.

Involving vulnerable and marginalized people in research requires additional thought, preparation, time, and money. However, it is likely to mean that the research project will be more effective, because these groups have important expertise to offer. Making the dynamics of partnership easier in order to include vulnerable or marginalised individuals is likely to mean that everyone finds it easier, if rather different to what they were used to in the longer term. The vulnerable or marginalised individual is likely to be embarking on an activity that is new to them, and in doing so making many adjustments. They will be on a learning curve, which may at times be uncomfortable. It is not much to ask other members of the project to make adjustments themselves, and be willing to learn new ways of approaching partnerships for the benefit of an effective piece of research.

There is no singular way of prescribing how involving vulnerable and often marginalised groups should be done. We need to be aware of the issues bearing on each situation and be pro-active in addressing them. We need to be able to adjust and learn. We need to be willing to learn from what has been done before, to throw out what does not work, and experiment with what might. We also need to recognise that every person has the capacity to feel vulnerable and marginalised from time to time. Above all, we need to be able to value all as equals and experts in their own experience.

People become vulnerable and marginalised for a reason. Sometimes the causes are subtler than we at first realise. Tackling the causes once they are identified may mean re-examining some of the fundamental beliefs behind our institutions. Involving vulnerable and often marginalised groups is therefore likely to be a challenge for all, both inside and outside research. Ultimately this should empower all involved, even if the process of getting there is difficult and perhaps uncomfortable.

Checklist

The following checklist, in the form of questions, is a tool to help you think through some of the issues concerned with involving 'vulnerable' or 'marginalised' people as partners in research projects:

- Have you given careful consideration to the reasons for involving vulnerable people, and are you clear about why you are doing it?
- Has every avenue been explored to ensure that vulnerable or marginalised groups have had the opportunity to consider being involved in your project, i.e. community networks?
- Is the information you are planning to give in an accessible and culturally relevant form for those you want to reach and engage?
- Is the information you have given sufficient for them to make a fully informed choice about whether or not they want to be involved?
- Have you allowed for additional time depending on the needs of the person or persons concerned (i.e. for translation, broader discussion, medical needs, breaks in meetings etc.)?
- Have you budgeted for the additional resources needed to accommodate their needs whilst involved with your project (i.e. signer, advocate, carer, special transport, accommodation, dietary requirements etc.)?
- Will the venues you will be using be accessible to those you want to involve?
- Have you given due consideration to the suitability of the times of any meetings you may be planning in respect of the individuals you want to involve?
- Where involvement is on a group, such as a project steering group, is the group chairperson fully aware that they must ensure everyone has an equal opportunity to participate?
- Will the research group be aware that they must be pro-active in ensuring that members of the public know that they can ask for clarification of anything they do not understand?
- Will an advocate or mentor be offered to help with this and other support needs where appropriate?
- Will the research group be prepared to make adjustments to accommodate the level of knowledge, cultural familiarity, and learning ability of the individuals involved?

- Will papers be summarised in accessible/lay language?
- Are the professionals in the group aware that specialised professional language needs to be used self-consciously rather than spontaneously?
- Will training be offered to all group members in order to assist with making the *process* of the partnership successful for all involved?
- Will other training be offered to members of the group?
- Have arrangements been made to pay expenses?
- Has thought gone into the possibility of paying people for their time if they are otherwise unpaid?
- Will there be a process by which ground rules for the group can be developed and negotiated at the beginning?
- Will there be an 'induction pack' for people who use services, and will they have the opportunity to negotiate a 'job description'?
- For long term or ongoing groups, has the possibility of a 'rolling membership' of people who use services been considered, with time limits (e.g. two years service) and overlaps between new and outgoing members in order to maintain continuity?
- Has thought been given to the needs of vulnerable individuals leaving a longer term or ongoing group?

Roger Steel
Development Worker
INVOLVE
1st revision March 2003
2nd revision January 2003

With special thanks to Kate Sainsbury, Jabeer Butt, Mary Nettle, Deborah Tallis, and Russell Hamilton of the Empowerment sub group, INVOLVE (formerly Consumers in NHS Research).