

Involving Marginalised and Vulnerable People in Research: A Consultation Document

1. Introduction

This document has been written for the purpose of stimulating thought and discussion on the issues surrounding the involvement of vulnerable and frequently excluded groups of people in research and development. The need for this piece arose from discussion in the Empowerment sub group of INVOLVE (formerly Consumers in NHS Research). This discussion widened through recognising the need to address the implications of including a broad range of vulnerable and often excluded groups in general. This is because these groups have something important to offer in terms of involvement in research.

The Research Governance Framework includes references to this:

‘Research and those pursuing it should respect the diversity of human culture and conditions and take full account of ethnicity, gender, disability, age and sexual orientation in its design, undertaking and reporting. Researchers should take account of the multi-cultural nature of society.’ (2.2.7)

‘Research (should be) pursued with the active involvement of service users and carers including where appropriate, those from hard to reach groups such as the homeless’. (Box B: Standards in quality organisations undertaking research: Ethics).

1.1. Range of vulnerable and often marginalised individuals

The issues surrounding the involvement of vulnerable and marginalised people in research are broad in range, and so, rather than attempt to comprehensively address these, I have sought to identify and discuss some general principles and ideas which I think will be helpful across the board.

‘Vulnerability’ and ‘marginalisation’ can mean different things to each of us, but the range of individuals and groups who are sometimes described as ‘vulnerable’ or ‘marginalised’ by service providers is very large. It may be that some of these people would not describe themselves as vulnerable or marginalised at all. Whether or not you are perceived or perceive yourself as vulnerable or marginalised will probably depend on where you are standing at the time, and in relation to who, or what. Who’s context is it? Any social or organisational group is a context; for example, from their own context, travellers may see the NHS as hard to reach and marginal to their culture.

The following list includes **some** of the groups who may be occasionally or frequently excluded from involvement in research because they are perceived

to be vulnerable or difficult to reach by the research community. The list is not an attempt to be comprehensive, but serves to give an example of the range of people who are often described as, or who might describe themselves as vulnerable or marginalised:

- People experiencing Mental Health problems/personality disorder
- Brain injured individuals
- Children in general
- Children in care
- Young Carers
- Carers in general
- People with a Learning Difficulty
- Ethnic Minorities
- Asylum seekers and refugees
- Travellers
- Homeless people
- Frail Older Persons
- Older persons in general
- Those experiencing forms of dementia
- People for whom speech and/or hearing is not their principle means of communication
- Visually impaired people
- People suffering from a life limiting illness
- People whose voices cannot be heard
- Disabled people
- Drug addicts
- Single parents
- People who cannot read or write in English
- People who cannot speak or understand spoken English well
- People in poverty
- People who need, but are not receiving health or social care services
- People whose lives are affected by the complex repercussions of disability, long term illness, or social care needs, who encounter different services that do not 'join up'.
- People in receipt of forensic mental health services
- Prisoners

It would be impractical for the purpose of this piece to go into every detail of every practical, social, ethical and legal consideration needed to include all groups of vulnerable or marginalised people in research. Every situation is different, and individuals are different in the scope of their needs and abilities no matter which category or group best describes them. Further, there are also individuals and groups whose experience of vulnerability can be temporary and circumstantial. Indeed, some of the discussion which follows could be pertinent to *any* person who *feels* vulnerable or marginalised when joining a research group.

Whilst recognising the breadth and diversity of this subject area, a generic approach that is concerned with the awareness needed when engaging with

vulnerable and marginalised groups and individuals, may be the most helpful. It seems important therefore to start with revisiting and then unpacking some principles and ideas associated with the idea of inclusion.

2. General Principles: Inclusiveness and empowerment

Actively involving the public in research is about inclusiveness, and however we look at it we are asking a group or individual to 'join in' in a recognised process involving others, a 'culture' we broadly call 'the research community'. This may involve service users being actively involved on a variety of panels and committees. All of these are groups of some form or other.

2.1 Inclusiveness

What do we mean by inclusiveness? We cannot assume that we have included someone in a group or organisation until such a time as they feel able to contribute as fully and equally as they would wish, within the overall group purpose or 'terms of reference'. To be included is to have an equitable opportunity to have one's individual perspectives and needs accommodated, absorbed and integrated by the group or organisation.

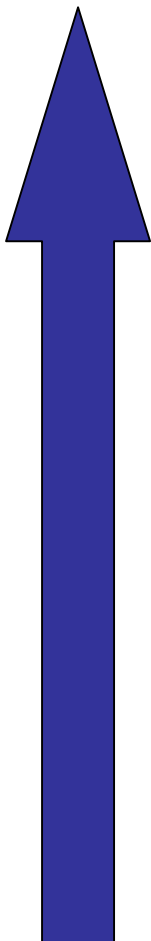
A research group that decides to recruit a service user on a panel because it is perceived to be a 'good practice' but does not otherwise change its practice, is not going far enough. Tacking on someone from the 'outside' because it is politically correct to do so is not inclusion. This is tokenism. To accommodate a new element, the whole dynamics of any process/structure must necessarily shift as a whole to some degree. It is this ability to shift, which determines the inclusiveness, or the lack of it, in an organisation or group. In other words, an organisation or group must be prepared to adjust its processes, attitudes and dynamics in order to properly include a new participant. This can be and often is done unconsciously to a degree anyway, although not necessarily adequately or competently. It is imperative that it is a conscious process when dealing with potentially vulnerable or marginalised individuals and groups.

The following extract from "Users as Researchers: Issues arising from a health service research project." (Woodward & Matthews, 2000) describes 'The Travellers Project', a project about sexual health services used by 'New Age' travellers:

“This project was amongst the first to involve users following the launch of the national R&D strategy, so there were few examples to which those involved could refer for guidance. However, the difficulties which emerged during the course of the project are not unique to research involving service users. Many might equally arise in any project involving a range of stakeholders with differing expectations, values and experiences. Such is the nature of collaborative and participatory research. Whilst risking over simplification, many of this project’s difficulties stemmed from poor communication and a failure to openly and honestly address the fundamental issues of power, accountability and mutual responsibility. “

An illustration of inclusiveness in relation to a vulnerable individuals is the following ‘Ladder of Participation’ from ‘*Children’s Participation: from Tokenism to Citizenship*’ by Roger Hart, UNICEF 1992 adapted from Arnstein. It also serves to demonstrate a process that any vulnerable adult might experience.

Top of ladder



- **Child initiated and directed** – The children have the idea and decide how they want to carry the project out. Adults are available but do not take charge.
- **Child initiated: Shared decisions with adults.** – Children have the ideas, set up the project and invite adults to join with them in making decisions.
- **Consultation and information** – Adults may have developed the initial idea, but the children are involved in every step of the planning and implementation. They are listened to and are actively involved in taking any decisions.
- **Assigned but informed** – The children are asked to take part in a project which the adults have designed. The children understand the project and know who decided they should be involved and why. Their views are taken seriously.
- **Tokenism** – Children are asked to say what they think about an issue. However, they have little choice about the way they express their views or about how frank they can be about any concerns. They may not know what will be done with any views they express.
- **Decoration** – The children are part of an event. They may sing, dance, listen, but again they do not really understand the issues or the purpose of the event.
- **Manipulation** - Children do or say what adults suggest they do. They have no real understanding of the issues, although they may be asked for their views. They do not know what influence their views will have on any decisions that are made.

Bottom of ladder

The example takes us from a group of 'vulnerable' individuals being manipulated to levels where they have degrees of empowerment and 'ownership' of a project or process. 'Ownership' and empowerment need not always involve total control of a process. It can mean an interest, will and ability to participate and share control and responsibility with others for a mutual purpose. This is interdependence.

Assumed paternity within a group culture can be a major barrier to any involvement, and can be actively excluding, indifferent, or even dangerous to other stakeholders. The Royal Liverpool Children's Inquiry Report on organ retention at Alder Hey Hospital is a record of this happening in a health research culture. Whatever the level of vulnerability of an individual, and whichever responsibilities others may have in relation to them, that individual has a right to have information, to make informed choices, to express their views, and, at the very least, have them actively taken into account.

An organisation or group needs to actively facilitate an individual with the information and means needed for them to be a full and effective participant. The individual should be enabled to take part and to meaningfully contribute by being armed with an awareness of the purpose, needs and perspectives of the group or organisation. Without this there can be no effective dialogue. The idea of an information pack is an example of how this can be achieved. Mentoring by an experienced group member is another powerful way of doing this. Having the appropriate information to know how, why and what to do is one of the ways in which empowerment of the individual comes about. It is ultimately beneficial to all.

2.2 Empowerment

'Empowerment' is a word open to a range of interpretations, and used to support a range of agendas in public, voluntary and private organisations. The idea that we can 'empower' others is a contradiction in terms. An environment can be created in which individuals can empower themselves, but empowerment cannot be 'done' to someone. Fundamental to empowerment is the opportunity to exercise individual choice and take effective action. The barriers that might prevent this can be removed in so far as those who represent the dominant culture of a group are aware that they exist, and to the extent that they themselves are willing and able to make changes. However, they can only achieve in so far as the structure and culture they themselves are obliged to work within allows. For this reason, empowerment is everyone's issue at all levels, not just a problem for the vulnerable or marginalised group or individual. To take this on board is to see empowerment as a process in which we must all be actively involved in order to achieve the best possible outcomes for others and ourselves in any given situation.

2.3 Marginalisation

Those who are marginalised are outside the dominant culture of a group. The group could be a professional group, a social group, or a whole society. An individual may be marginalised out of choice, but more often it is because the dominant culture is unable to accommodate a particular group or individual.

Every group has its tolerances and intolerances whether overt or covert, conscious or unconscious. In society, the law generally defines conscious intolerance more or less successfully. Covert and unconscious intolerance takes the form of prejudice and unequal opportunity for some individuals even if this is against the law. Any group might behave this way because the same dynamics apply. This could be a research steering group, a representative group of professionals, or a service user group, and any of the organisations within which they operate.

Exclusion can be active or passive. Where it is active, it is likely to be conscious or unconscious intolerance. When passive, it is more likely to be about conscious or unconscious ignorance.

Whether overt or covert, institutional or individual, the attitudes of others generally have a strong effect on a vulnerable individual and can therefore be fundamentally empowering or disempowering. Such attitudes can be subtle or obvious.

Everyone has needs. We have general needs which we tend to have in common with others and are more or less fulfilled by the way we live from day to day. We also have 'special' needs which make us different but which we all have from time to time, and some people have all the time. A common occurrence in the healthcare field is when an individual's general needs, they have in common with any other human being are overlooked or ignored because attention goes solely on their special (health) needs. For example, we may experience conditions as less than 'human' when we are waiting for hours in an overstretched A&E department for treatment for an injury (special need). But this is where attention to general needs is usually only temporarily suspended. Where special needs are attended to exclusively over a sustained period, it can eventually lead to chronic institutionalisation, marginalisation, loss of 'humanity' and self-esteem. In extremes, an individual can become identified only in terms of special needs to the exclusion of all else, and lose their commonality, and therefore connection with others.

This can be the effect of institutional attitudes. Everyone is subject to institutional attitudes to some degree, but for some it is more fundamental and 'disabling' than it is for others:

“For many years doctors, social workers and other people have told disabled people that they are disabled because of ‘what is wrong with them’ – their legs don’t work, they can’t see or hear or they have difficulty learning things, just to give a few examples. This is known as the medical model of disability. It says that it is the person’s ‘individual problem’ that they are a disabled person.”

“ What we say is that yes, we do have bits of us that don’t work very well, this we call impairment: for example, a person who cannot hear very well has a hearing impairment. What we say is that it is not this impairment which makes us disabled. Society does not let us join in properly – information is not in accessible formats, there are steps into buildings, people’s attitudes towards us are negative. So society puts barriers before us which stop us from taking part in society properly – it disables us. This is known as the social model of disability”

Greater Manchester Coalition of Disabled People. Young Disabled Peoples Group (1996), Resource Sheet 1.

In relation to a research project, the following example demonstrates how practice was changed to include a vulnerable group, and counter the effects of medical attitudes:

“The key to any UFM (user focussed monitoring) work is a local group of service users.....The first step for the project co-ordinator is to recruit group members. This involves going to day centres, work projects, and so on....Some people in these settings are immediately interested in getting involved. At the same time, we are often met with many that lack self-confidence. A majority of users in these initial talks think that the project is too difficult for them. Overcoming this lack of self-confidence is a task that continues throughout the life of the project. We have come to the conclusion that mental health services are very good at telling people what they cannot do. On a more positive note, it is almost always the case that those who begin the project go on to complete their work.” **User’s Voices** – (Rose et al., 2001)

A question any of us can ask ourselves is, what makes *us* flourish and participate to the full? What attitudes and processes are helpful or unhelpful to us? Which are encouraging and discouraging, and can we do anything about it? When do we feel included or excluded? What might affect us in health and strength, and to which we probably adapt without thought, can be a major barrier for someone who is vulnerable. Being aware of how different attitudes, environments and processes affect us can help us anticipate potential effects on others, provided we understand that these effects are not always the same for everyone. We also need to be prepared to enquire.

3. Practical Considerations

There can be a range of practical matters that need consideration when involving someone who is normally marginalised or vulnerable. Practical considerations are as broad as the needs of all individuals who might get involved with research and they cannot all be anticipated beforehand. An excellent but lengthy guide which looks at specific needs of people from different backgrounds when involving them in shaping services is **'Asking the Experts – A Guide To Involving People In Shaping Health And Social Care Services'** published by the Community Care Needs Assessment Project and available from their website: <http://www.ccnap.org.uk>. .

Where vulnerable individuals are concerned it is important to ascertain their needs well in advance. It may be important to arrange for a translator, signer, advocate, guardian or nurse to be present with them, to name a few considerations. Matters like religious belief may affect arrangements, such as the date of a meeting. All these take time to arrange. It is important to continually check that an individual is able to participate as much as they would wish, and to be prepared to resolve problems which are both anticipated and unanticipated. Below are some general practical considerations.

3.1 Payments

Offering payment for participation in research should be taken into consideration, particularly with groups on low incomes. This is only fair, and reduces the barriers of financial inequality within the research group. Expenses should be paid as standard, and it should be borne in mind that for a 'vulnerable' person expenses may be higher than usual. It is important that people on state benefits understand that payment from being involved in research may affect their entitlement. It is the individual's responsibility to check how their benefits might be affected, but the research group are responsible for pointing this out, and to offer support if it is requested. When approaching a benefits office or 'job centre plus' it is important that people have all the information with them, and are prepared for both helpful and unhelpful responses. The benefit office also run a telephone helpline so people can check their position anonymously. It may be necessary to identify a suitably experienced advocate who will help them make these checks. For independent advice the individual might approach their Citizen's Advice Bureau.

The issue of payments has been covered in more detail in **'A guide to paying members of the public who are actively involved in research'**. Second edition, INVOLVE 2003, and Scott J. (2003) **'A Fair Days Pay'** Mental Health Foundation.

3.2 Consent & choice

Consent is something which is rightly given a high priority when considering the recruitment of research participants or 'subjects'. However, it is also very important when intending to involve vulnerable people as active partners in research projects. They must have the opportunity to give their *informed*

consent. In other words, they must be fully aware of the issues surrounding the choices they are making including, the expectations, consequences, the potential pitfalls and benefits, and the alternative choices and courses of action available to them before deciding to become actively involved in research. They must be informed in a way that they are able to understand.

If the individual is by law a dependant – a child, or someone under legal guardianship/Court of Protection, then the consent of the appointed legal guardian must be sought in addition to that of the child/person under guardianship.

When approaching a vulnerable individual, they may need an opportunity to think about whether they want to become involved, and time must be allowed for this. Further, the way a vulnerable person, is approached will of course depend on a wide range of factors, and information needs to be conveyed in a way which is acceptable to them and can be readily thought through. Often the approach will be made through a parent/carer/support worker in the first instance. The vulnerable person needs to be able to make a clear choice for himself or herself. They must know exactly what they will be asked to do if they say 'yes' to becoming involved in a project and what the benefits and drawbacks are. It is important to ascertain that the choice is theirs and not one made to please a guardian. The vulnerable person will need to be sure they can independently and safely say 'no' or 'yes' in any given situation.

If the individual is subject to a legal order such as a Mental Health Act section, or Probation order, then the general rule is that consent must also be sought from the officer responsible for enforcing the order.

In respect of mental capacity and consent, a recent Law Lords Commission Report says:

'An "inability to make a decision" means "(1) an inability to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision, or (2) an inability to make a decision based on that information."

The term "mental disability" means "a disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning".'

There are ethical dilemmas thrown up by the issue of capacity and consent. A recent EC directive under consideration has attempted to enshrine this in law in respect of participation in clinical trials. It will have considerable implications on research into Alzheimer's disease for example.

It should not be assumed however that someone with Alzheimer's disease or a learning disability (for example) would be unable to contribute to research. The Alzheimer's Society include those experiencing this disease on a research steering group with carers. The Mental Health Foundation have run a project with people with learning disabilities who came together as a social group to help researchers prioritise topics. It was explained to the participants

what the group was for, but the crucial information came from their social discussion, which often returned to their anxieties about their ageing carers and the participants increasing responsibilities in becoming carers themselves. This helped the researchers identify the most important issues for research. Some people with learning difficulties have undertaken their own research.

3.3 Advocacy

The importance of independent advocacy cannot be understated. Whereas an advocate cannot override the decision of a legal guardian, they can ensure that the individual concerned has a voice. The advocate's role is to represent the interests and views of the individual as if they were their own. To do this, a period of time is needed for the individual and advocate to work together in order to get to know each other, discuss the issues and build trust. The advocacy relationship should be empowering, in that the advocate is not there to do all the talking but to ensure that where they feel able, the individual can speak up for themselves.

Advocacy services are generally local. Some specialise and others are generic. Some areas may not have an advocacy service at all. A research group may however be able to identify potential advocates themselves.

3.4 Reaching Marginalised Groups

UK National and local popular media are powerful in ignoring certain groups or promoting public opinion against them. It follows that public media may not be the best route in reaching those groups unless through a specialised magazine devoted to inclusiveness. Probably the best way of reaching these groups is through local networks.

Including marginalised groups in research requires a tenacious pro-active approach. Not only is this important in reaching these groups, but it is also important when enabling them to participate once recruited. It is vitally important to be pro active in anticipating specific needs and to remove as many barriers to meaningful participation as the group are aware of.

There is a range of possible routes for reaching marginalised groups, but by definition some are more difficult to reach than others. How difficult they are to reach depends on how hard you are prepared to try. A useful route is to utilise local networks in the community in the statutory sector (i.e. local councils) and especially the voluntary sector. Council/Community Voluntary Services (CVS) usually have good information on a whole variety of group activities across their area. Local libraries and community centres are often also a good source of local information and may carry newsletters or leaflets from relevant groups. There may also be a national organisation which may be able to help or to signpost your enquiry to the appropriate people. There are databases of both national and local organisations that are an effective start, but sometimes footwork such as attending relevant forums, conferences and gatherings can be necessary to reach a particular goal. Word of mouth local networking can sometimes be the only way, and enlisting the help of local community leaders

can be fruitful. Many marginalised groups may not access literature or have the reading or language skills where they would see an advertisement.

Having located the groups concerned it is important that local networks you are utilising or building are appropriately supported. Networks need maintaining and that usually means ongoing resources are needed, whether this is transport, a newsletter, time, postage and telephone costs, appropriate venues to meet, etc.

3.5 Use of language

Language can be used, intentionally or otherwise in ways which can either be powerfully marginalising or powerfully inclusive. Clearly problems arise when language is developed and used to tackle complex specialised issues, such as in research. Whereas it is most often used with the positive intention to produce helpful practice, specialised language by definition is marginalising for the non-specialist. It is important in using specialised terms in the presence of non-specialists, to be conscious of whether meaning is being conveyed in the most effective way for the purpose of the group.

Again from the Research Governance Framework 2.4.1:

<p>‘....there should be free access to information both on the research being conducted and on the findings of the research, once these have been subjected to appropriate scientific review. This information must be presented in a format understandable to the public’.</p>

Health information couched in the language of specialists was for a long time ‘institutionalised’. It was assumed that non-specialists (the public) would not understand health issues and in the paternalistic culture it was generally assumed they could not be of interest to ‘ordinary’ people. With the changes to a more information led society, the problem seems to have become as much to do with the language itself, and not that the public cannot or do not want to understand health issues. Despite improvements in the last few years, the NHS still sometimes produces information in language which can sometimes be difficult even for many educated white middle class people. It is no wonder it is difficult for some ethnic minority groups to know about how to use the health service.

Similarly, in research, there is a danger of tokenism in including non-specialists if the issue of specialised language is not addressed. Service users in research must at least have the opportunity to broadly understand the issues under scrutiny, and the associated papers. Information must therefore be communicated in a way people can understand. This might be achieved through simple practical measures such as asking a researcher to produce a front piece to a research proposal that summarises the paper in appropriate language for all. It may be necessary to put this on tape, have it read and explained or have accompanying pictures which help explain things. This all takes extra time and resources, but if research is to be meaningful it needs to allow for this.

4. Implications for Research Practice: A summary of Ideas and Recommendations:

4.1 Reaching vulnerable and marginalised people

- Reaching marginalised and vulnerable individuals and groups will take time and careful thought
 - Tapping into existing community networks, both formal and informal is often effective, if done with sensitivity and respect. A good starting point may be organisations which work in local communities
 - Be aware that marginalised groups may not use the methods of communication you are used to
 - Offer to meet people informally on their own ground and take time to build trust. Be open to learn from them
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4.2. Consent

- Organisations should be aware of the legal status of children & young people proposing to join a research group. It may be that consent to participate needs to also come from a parent, carer, or professional
 - Clear and comprehensive information should be available to the person before they commit to becoming involved. Use plain English or consult organisations who are used to working with particular groups as to appropriate forms of communication. Given clear information people can then take responsibility for making an informed choice
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4.3. Accessibility

- Specialised language needs to be used self consciously rather than spontaneously by researchers where there are non-specialists present
 - Papers may need to be summarised in lay language
 - Research groups should be prepared to make adjustments to accommodate the level of knowledge and level of learning ability of the individuals involved
 - Additional time will need to be allowed depending on the needs of the people involved, i.e. for medication, for explaining things, for broader discussion, for translation etc. In some cases the actual time and date of a meeting may need to be changed to accommodate particular needs or religious beliefs. For example, some disabled people have difficulty in getting to meetings first thing in the morning, and may need to leave because they are tired by mid afternoon, so a meeting in the middle of the day in this case would be appropriate
 - Additional resources will need to be available depending on the needs of the individual i.e. for a translator, carer, advocate, signer, special transport etc.
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4.4 Inclusion

- Group chairs have a responsibility for ensuring everyone has an equal opportunity to participate

- The group and particularly the chair of the group needs to be pro-active in ensuring that individuals are aware they can ask for clarification of anything they do not understand. In some cases an advocate or mentor can be helpful to an individual. If so, someone of their choice should work with them
 - For long-term groups, a rolling membership is likely to be healthy, provided there is some overlap. Overlap with an experienced service user member of the group and an incoming service user member could be very supportive where vulnerable and often marginalised individuals are involved. It also provides opportunities for more vulnerable individuals to get involved over time, and helps to promote an equal opportunities ethos. Attention should also be given to the problems which can arise for an individual when leaving a group. This can sometimes be quite traumatic for them
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4.5 General good practice

- Group chairs have a responsibility for ensuring everyone has an equal opportunity to participate
 - Ground rules for meetings can be agreed by all involved when starting a new group. These can then be written down so that expectations are clear. For example, a ground rule could be to 'respectfully listen to another's point of view even if you disagree with it' and/or 'to observe the confidentiality of any disclosure by a group member'. In any case, a written document on expectations for all participants in a group is likely to be helpful, particularly for new members, and can usually be negotiated
 - A mentor system is likely to be helpful for new members in a group, and in helping a lay representative understand the issues being discussed. An allocated mentor could be an experienced member of the group who takes responsibility for making sure the lay members needs are met in general, and that they are able to participate as fully as they would wish
 - For longer-term projects an '**induction pack**' and a negotiated '**job description**' would be invaluable for new members
 - Payment of expenses should be offered. Further consideration should be given to payment for the time contribution of the member of public.
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4. Conclusions

5.1 Improvements in the way a group operates in order to incorporate the views and needs of a vulnerable or marginalised individual are likely to help every group member in the long term. Although it may mean that additional thought, preparation, time and money is needed, it is also likely to mean that the project becomes more effective in terms of its overall aims. Making the dynamics of partnership easier in order to include a vulnerable or marginalised individual is likely to mean that everyone finds it easier in the longer term, even if having to operate in rather different ways. 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 purpose of an effective piece of research.

5.2 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. Above all we need to be able to value all as equals and experts in their own experience.

5.3 People become vulnerable and marginalised for a reason. Sometimes the causes are subtler than we at first realise. There are often complex combinations of interdependent factors bearing on each individual or situation. Tackling the causes once they are identified may mean re-examining 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.

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