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Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability

Final Report

NHS NATIONAL R&D PROGRAMME ON FORENSIC MENTAL HEALTH

Research Funding Scheme 2004

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Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability

Executive Summary

i) Introduction

People with learning disability have historically been the subjects or recipients of research, rather than participants or contributors. Whilst there is considerable literature on issues of informed consent, little is known about what people with learning disability understand about research, participation in research or how to facilitate understanding. Ways of facilitating consent have been offered by a number of studies (Fisher, 2003, Murphy and Clare, 1995, DeRenzo et al 1998) but these studies have not researched the effectiveness of such methods from the perspective of the participants.

Understanding what is meant by research is fundamental to involving people with learning disabilities in research and to developing and maintaining informed consent (Gilbert, 2004). This study set out to discover how men with a learning disability living in a Medium Secure Unit understand research, consent and ethics and what enables them to learn about these concepts. Seven men and ten staff were invited to become co-researchers with two researchers from Northumbria University, over 20 months. Lessons learned from this study about research can now be used to educate other adults with learning disability concerning research, how it can be helpful, and how it can make a difference in the lives of people with learning disability.

ii) Aims of the project

1. identify some of the key processes that enable people with complex learning needs to understand the nature of research, the ethics of research, the possibilities of research, how research findings are used and how to find out about that use.
2. evaluate the effect of engaging the participants as active researchers has had on the process of building knowledge and the outputs of the research.
3. develop a framework for engaging participants with learning disabilities as active qualitative researchers.

iii) Underpinnings

The effectiveness of current methods of obtaining consent from participants in research who have learning disabilities remains under researched. Dye et al (2007), using quantitative methods to assess capacity to consent, challenge the validity and usefulness of current methods and highlight the need for better ways of engaging people in research.

Research participants without learning disabilities find research and research ethics complex subjects. Robust understanding necessitates the ability to understand abstract notions as well as some experience of research approaches (Wiles et al 2004). If this is so in the non-disabled population, it must equally be so for those with learning disabilities.

People with learning disabilities can consent for themselves to participating in research if they are able to understand the implications of such participation (Mental Capacity Act 2005).

It is important to engage people in research which concerns them. Their involvement helps to ensure that the research is not dominated by researchers and their agendas, and that the research does not just look for outcomes that are identified and considered important by professionals, organisations etc. Issues of importance to participants, and therefore to the project, are identified and made priorities, so adding trustworthiness and depth to data collection and analysis. Participation in the research and identifying findings means participants are more likely to be involved in and drive change (Kiernan, 1999; French and Swain 1997; Ward 1997)

The use of a collaborative action research approach involves all participants in the research and supports the process of participants becoming researchers in their own right (Winter, 1998; Reason and Bradbury, 2001; Hart and Bond, 1995). It locates the knowledge development with participants as well as any external researchers. It involves collaborative discussions and a cyclical process of collecting and analysing data. Being longitudinal, rather than a one-off approach, it provides opportunities to revisit thoughts and ideas. It enables participants to help and support each other and builds relationships. As such it was an appropriate way of finding out what men with learning disabilities understood about research and what helps them to understand in a way that enables them to informed consent to participating in research projects (Kiernan, 1999: Thomas and Woods 2003).

Seven men and ten staff were invited to become co-researchers with two researchers from Northumbria University, over 20 months.

iv) Methodology

A Facilitated Collaborative Action Research (FCAR) approach used interviews, workshops, focus groups, field notes and diaries to collect data. FCAR encourages open dialogue among participants to explore diverse opinions and assumptions. Action research is

> "…the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding" (Winter & Munn-Giddings, 2001:35).

v) Phases of the Project

1. Preparation: A DVD was commissioned for use in the workshops. It was developed by the researchers along with an independent theatre company run by people with learning disability. The DVD has scenes about different aspects of research. It was shown in the workshops to aid discussion about difficult and abstract concepts related to research. A day was held with staff to develop their knowledge of action research and address issues related to collaboration in a hierarchical situation. Pre-workshop interviews were conducted to provide basis of current knowledge.
2. Workshops: The men's learning was supported through eight workshops designed to promote discussion on topics related to research, consent and ethics. Working collaboratively in the workshops offered opportunities to hear multiple viewpoints, to engage in and use self-development, learning and knowledge building. The workshops acted as a set of focus groups using an adapted Delphi technique, whereby the information gleaned from each workshop was collected by all participants and revisited in the following workshop to inform the next phase.
3. Finding voice: The workshops were keys to developing understandings and developing confidence to articulate and critique thoughts and ideas.
4. Analysing data: Data analysis took place during the workshops phase using all participants to identify key themes. Summative data analysis was also carried out using NVivo.
5. Outputs: A set of principles for researchers working with people with learning disabilities. The "Understanding Research" Pack designed to support people with learning disabilities written by and for people with learning disabilities.
6. Dissemination: Conferences, Final Report and publications in appropriate journals.

vi) Data Collection Procedures

- Interviews
- Workshop transcriptions
- Diaries
- Field notes
- One focus group

vii) Findings

What the men needed to learn

The men already had some notions about the meanings of participation, research and consent but these were very basic ideas. They were unaware of what ethics meant. They needed to know:

- research is complex, takes many forms and used many different types of method
- the meaning of consent and confidentiality
- what type of questions to ask when deciding whether to participate and why

- the implications of being involved in research for themselves
- ways to say no to research and implications of saying no
- definitions of words and phrases in common use within the research community
- research has to be rigorous and is not just sets of ideas

What helped the men learn about the above?

The key element of the project that enabled the participants to understand issues relating to research, ethics and consent was the collaborative and recursive nature of the approach.

The workshops offered:

- Collaborative engagement with multiple perspectives
- Information presented in a variety of formats
- Opportunities to repeatedly return to issues using differing perspectives
- A longitudinal recursive approach
- Intellectual stimulation
- Valued input from staff
- Opportunities to have their work valued by others
- Engaging in something different from their every day tasks
- Fun and enjoyment; a relaxed and friendly environment

An initial stimulus to thinking on each topic area, a framework for thinking and access to expertise in the field of qualitative research provided by the two facilitators was vital to the process.

The staff support for the workshops provided continuity, security and longitudinal support for developing thinking. During workshops, their support aided understanding, reading and recording but most valued was the opportunity to discuss and reflect on issues raised during the workshops and the support to record thoughts between workshop sessions.

Additional Benefits from Participation

- A sense of achievement and worth was gained by the men through their role as researchers and developing the “Understanding Research” Pack for others. Having their work valued, both within the Trust and beyond raised confidence and self esteem
- Reading, writing and presentation skills were developed
- University accreditation (by choice)
- Enjoyment of the experience
- Impetus to do other similar work

The participation of people with learning disabilities in this research demonstrated a level of capability that was unexpected by professionals who knew them well. Their commitment and enthusiasm to research and the benefits it can bring is evident from the data. It has highlighted the value of engaging people with learning disabilities in research both in terms of the quality of the data collected and the impact on their feelings of self-worth.

viii) Implications for research practice

All the men in this research had been deemed able to consent prior to their involvement. Initial interviews revealed a basic understanding of research as ‘finding out’. None of the men had an in-depth understanding of the implications of participation. By the end of the study all the men had a greater knowledge of the topic area. Most men had gained sufficient understanding to enable them to discuss and address issues related to consenting to research but, despite the intensive input, one man in the group, originally deemed able to consent, remained unable to understand the concept of research.

The ability to understand did not appear to relate to the ability to read and write but was related to the ability to participate in the group, engage in debate and share knowledge and learning. As such it was heavily reliant on facilitators to provide a learning environment. This supports the findings of other researchers in this area such as Dye et al (2004) who argue that current understanding of capacity to consent, based on a dichotomous categorisation of either having or lacking capacity to consent, does not serve to empower the individual. Individuals may well be capable of self-determination if the current framework is reconceptualised to include a more process-based model that stresses the importance of contextually based, person-centred approaches which respect and respond to the needs of the participants.

This small but in-depth research study adds to the nascent research in this area (Dye et al 2007; Department of Health, 2006; Fisher, 2003; INVOLVE, 2004; Knox et al, 2000; March et al 1997). It highlights:

- the complexity of deciding who might be able to make their own decisions in respect of participation
- the need to reconsider the process of gaining informed consent, in particular the format of information giving which is most commonly delivered on a one off, individual basis.

It raises questions about:

- what ‘ability to consent’ means and where it is located - can this be done on intellectual grounds or should this be seen as a formative learning process?
- at what point in the process the decision should be made as to the ability to consent?
- who makes decisions about that ability and on what basis?
- whether everyone currently deemed able to consent can?
- if, through using more collaborative, longitudinal techniques, more people previously deemed unable to give consent may have the opportunity to understand?

ix) Suggested principles for gaining informed consent

It is difficult to estimate people’s abilities to understand research and to consent with understanding. Consent is a complex matter. The evidence gained through this research suggested the following principles for researchers working with people with learning disabilities.

- There should be a presumption of capacity: a key principle of the Mental Capacity Act 2005. Do not underestimate the ability of people with learning disabilities to understand concepts.
- The research has a key role to play in enabling participants to understand the nature of the research.
- Engaging ‘significant others’ aids understanding.
- One information event, using one method of presentation, is unlikely to be enough: multiple ways of engaging with and presenting information aid learning.
- A collaborative recursive process helps people to understand.
- Presenting information in an accessible form needs to be person centred and focused on their requirements; there is not a universal form of accessibility.
- Time, planning and funding are necessary.
- Engaging people with learning disabilities as facilitators supports mutual learning.

x) What next?

Pilot: The men in this study suggested that the “Understanding Research” Pack should be “*tried out*” on other men with a learning disability. They argued that, as they had found supporting the learning of others had helped both that person learn and supported their own learning during the original study, the facilitators for the “Understanding Research” Pack should be people with learning disability who have been through the facilitated sessions themselves. Four men who participated in this study were facilitators in the pilot of the “Understanding Research” pack with other men with learning disabilities. The pilot was funded by the Trust research programme.

Wider opportunities: Other people with learning disability are invited to learn more about research, consent and ethics through following similar principles to those suggested in this study through engagement in the processes outlined in the “Understanding Research” Pack.

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1. Abstract

People with learning disabilities are increasingly asked to participate in research and this means they need to give informed consent. The literature suggests that, to date, there are a number of common approaches used to inform people with learning difficulties about research, such as simplifying information sheets, reading out the information, etc. However, there has not been any research into the effectiveness of current approaches to gaining informed consent. This study identified some of the key processes that enable people with learning disabilities to understand research, ethics and consent and ways in which researchers can work more effectively with people with learning disabilities in order to achieve informed participation in research. It highlighted the benefits of participatory research, both for the participants and for the research process itself.

People with learning disabilities have traditionally been researched ‘upon’ rather than ‘with’, meaning researchers and academics make decisions not only about what is important to research, but also how that research is to be carried out (DoH, 2003; Northway, 2000). This study used a Facilitated Collaborative Action Research (FCAR) approach which involved all participants in the research (the academic researchers, men with a learning disability living in a forensic setting and the nursing staff who work with them) becoming researchers in their own right. The approach involved enabling collaborative discussions and using multiple ways of engaging with presenting and collecting information. It used a longitudinal rather than one-off approach, allowing for repetitions of information and the revisiting of thoughts and ideas (a recursive process) to add breadth and depth to the data. It also involved having fun. The results suggest that the longitudinal collaborative approach was a key to developing understanding in relation to informed consent.

There were additional direct benefits for the men, including opportunities for intellectual stimulation not linked to their health or index offence, skill and knowledge development, improved self esteem and confidence and providing an opportunity for further developing relationships with staff. The staff involved also learnt about research, developed other aspects of their relationship with the men, and have been involved in the revealing of capabilities in the men that have surprised and surpassed expectations. Some men enrolled at the local University to gain accreditation for their work.

The process of doing the research raised issues about how ability to consent is decided. All the men in this research were deemed able to consent. At the beginning of the project it was clear that many of the men had little

understanding about research. At the end of the research at least one man was still unable to understand the notion of research and the nature of the decision that needs to be made when considering participation.

From this work, the researchers have developed
i) a framework for engaging similar populations in thinking about participating in research. Entitled “Understanding Research”, it includes facilitator and student information, written in accessible format, to enable people with learning disabilities to both participate in and ultimately facilitate the framework.
ii) a set of principles for researchers working with people with learning disabilities.

2. Introduction

Research is a complicated and often abstract concept and one which may be difficult to understand (Weisstub & Arboleda-Florez: 1997). When people with learning disability are asked to participate in research they may not have had the opportunity to think about and understand research and what it means and may have little idea about the purpose of research and its effects.

At the core of recruitment into research is the notion of informed consent. As Cummings et al (2006) point out, however, even a fully regulator compliant set of processes and documentation for clinical trials may not be subject-friendly for even the most able of subjects. Knowing what research might involve, the personal effect of your own participation and the wider effect of any outcomes is crucial to the decision-making process on whether to take part. A number of studies have investigated ways of enhancing capacity by implementing various techniques. These appear to have had limited success in developing capacity to consent (Dye et al, 2004; Ascott et al 1998). None of the studies investigated ways to support understanding from the perspective of people with learning disability. People with learning disability have traditionally been excluded from true participation in research. The value of their participation in research that involves their lives is increasingly recognised (DoH, 2003; Kiernan, 1999; Northway, 2000). Central to this study is the participation of men with learning disabilities who gave insight into how to understand and make meaning of research. The men, and the staff who work with them, were involved as researchers and not merely as passive participants.

This research set out to engage a group of men with learning disability and the nursing staff with whom they work, in a Facilitated Collaborative Action Research (FCAR) with the intention of capturing how to support people with learning disabilities in understanding research, consent and ethics. It was a local study with a particular group of men in a specialised medium secure unit. Whilst it could be argued that such specificity reduces the generalisability of the outcomes and outputs from this work, the research approach (facilitated collaborative action research) the recursive nature and the longitudinal time frame, produced in-depth, rich and triangulated data. It can be argued therefore that this complex and layered study supplied the conditions for an account of a specific situation that enabled it to get:

> '… sufficiently close to its underlying structure to enable others to see potential similarities with other situations'. (Winter 2000:1)

The study adds to our knowledge and acts as a stepping stone towards informing and improving practice. It should be used alongside the educative process of its application in practice and the work of other researchers such as Dye et al, 2007; Fisher, 2003; Gilbert, 2004; Knox et al 2000; March et al 1997; Minkes 1995 who are investigating the complexities of informed consent and people with learning disabilities.

2.1 The aims of this research

i) to identify some of the key processes that enable people with complex learning needs to understand the nature of research, the ethics of research, the possibilities of research, how research findings are used and how to find out about that use.
ii) to evaluate the effect of engaging participants as active researchers has had on the process of building knowledge and the outputs of the research.
iii) to develop a framework for engaging participants with learning disabilities as active qualitative researchers.

2.2 Objectives of this research

- To know more about
  - what men with learning disabilities might know about research
  - what they need to know more about
  - what enables them to know/understand more about it
- Produce an active framework for engaging men with research
- Inform researchers working in the field

This project builds on work done by Minkes (1995) and March et al. (1997) where, in collaboration with a researcher, individuals with learning disabilities designed and implemented their own pieces of research, offering significant insight into how participants prefer information to be presented.

The researchers were also guided by the work of Faulkner and Morris (2003) who outlined issues that must be considered when involving people with learning difficulties. These included:

- the need to consider the training needs of researchers / research supporters and user researchers
- the development of trusting relationships between non-user researchers and people with learning difficulties
- ongoing reflection concerning the power imbalance between non-user researchers and people with learning difficulties, particularly those who live in secure settings
- the exploration of confidentiality
- creative means of communicating and exploring issues, e.g. pictures, tape-recording, video, posters and stickers
- ensuring that researchers with learning difficulties get something out of the process e.g. payment, fun, social activities or trips
- awareness of the difficulties of ending projects and the close relationships that develop during the process of research
- accessible dissemination of findings
- the need to give plenty of time and take plenty of time and obtain appropriate funding to allow for this.

2.3 Use of Terminology

The participants in this study include men who have a learning disability and are being held under the Mental Health Act (1983) in a Medium Secure Unit (MSU), the nursing staff who work with them and two academic researchers. The terms commonly used every day to describe this population of men in the MSU are ‘patients’ or ‘people with learning disabilities’. This study wished to not discriminate among the participants, who all act as co-researchers, unless absolutely necessary, in order to enable a more collaborative approach to the research. Therefore, the participants will not be defined individually unless necessary for purposes of clarification and shall be referred to as follows:

- The men with learning disability who participated will be termed ‘the men’
- The nursing staff who work alongside these men and participated in the study will be called ‘the staff’
- The academic researchers who facilitated and participated in the study will be referred to as ‘the facilitators’.

The term learning disability, as opposed to learning difficulty, is generally used throughout this report. This was the term used most frequently by the men when referring to themselves and is the main reason for this choice. Where men, staff or respondents used ‘difficulties’ interchangeably with ‘disabilities’ this has not been changed in the text of this report. The authors of this report acknowledge, however, that both learning difficulty and disability have what Goodley (2001) terms epistemological and political baggage and that such identifications have contradictory personal and political implications for people so-labelled. The phrase “people with learning disabilities” is, however, in common use. When organisations like People First asked people what they would prefer to use, their choice was “People with Learning Difficulties”. Whether to use “learning disabilities” or “learning difficulties” to describe the main cohort of participant researchers was a dilemma also faced by House of Lords - House of Commons Joint Committee on Human Rights (207-2008). The use of terminology was discussed in the publication from that committee, with the debate over the definition of learning disability highlighted and characterised as a preference rather than a clear delineation

> “some people prefer the term “learning disabilities” and others prefer the term “learning difficulties” (House of Lords/House of Commons, 2007-2008, p8).

In their call for evidence the Joint Committee had not adopted a specific definition but ultimately chose to use the term “learning disabilities” as it reflected the language used by the Government in its policy papers and was used by the Disability Rights Commission. In writing their report they were guided by the definition set out in *Valuing* People (2001) which defines learning disability as including the presence of a significantly reduced ability to understand new or complex information and to learn new skills. This starts before adulthood, has a lasting effect on development and manifests as a reduced ability to cope independently. This definition covers people with an autistic spectrum disorder who also have learning disabilities, but excludes those with average or above average intelligence who have an autistic spectrum disorder, like Asperger Syndrome. The British Council of Disabled People and other user-led organisations argue, however, that if you are referring to someone's medical condition, or health problem, the term impairment is more acceptable as the appropriate phrase. Disability is the disadvantage or restriction of activity caused by society when its organisational systems exclude people from the mainstream of social activities" and is thus an externally imposed state.

2.4 The Setting

The hospital hosting this research is a specialist provider of disability services. It has a commitment to enquiry and is research active with staff undertaking a range of research projects, both qualitative and quantitative. The MSU is a purpose built unit housing four separate "flats", internal "outside" spaces, and education, occupational and leisure facilities. The average number of residents is 30 with each patient occupying a bedroom with en-suite facilities. All treatment takes place within the unit. The treatment philosophy is based on patient-centred individual treatment plans directed by a psychiatrist and using a named nurse system. The patients are generally referred from the community via the courts, from prisons or directly via the NHS. The mean age on admission is 26 years old but admission age ranges between 16-49 years. Approximately 75% of the residents fall within 20-40 aged band. All the men have learning difficulties and are held under the Mental Health Act (1983).

- 93% have a criminal record
- 13% diagnosed schizophrenia/paranoid
- 13% depression/post traumatic stress disorder
- 60% have a history of alcohol/substance abuse

The men are escorted at all times and cared for by Registered Nurses for People with Learning Disability or unqualified Nursing Assistants and a multi-disciplinary team of other professionals.

Due to the nature of the specialist unit, it attracts considerable interest from external researchers. The varied abilities of the men offer considerable challenges to researchers in terms of; explaining the nature of their research, what they are being invited to participate in, what they are consenting to and how research findings might be used in the future.

3. Background literature

3.1 Informed consent and people with learning disabilities

It has been argued that the notion of true informed consent, where study participants are given a full explanation and are able to reach a clear understanding of what participation involves, exists more in rhetoric than reality (Wiles et al 2005). Whilst there have been a number of innovative approaches to gaining informed consent in recent years, research into its effectiveness is lacking. To give informed consent, individuals must understand the full implications of research participation, which includes analysis and dissemination of results. At present, because people with learning disability tend to be assigned a passive role within research, and their involvement ends with participation (Walmsley, 2004, Dyer et al, 2004). Given this limited experience of research, and the difficulties with discussing abstract conceptual ideas, researchers do not know how much of the research process people understand. This raises the question of whether they have given full consent to the entire research process (McCarthy, 1998).

The Mental Capacity Act 2005 was introduced to ensure that, as far as possible, all adults can take decisions about their own lives. "Mental Capacity" refers to the ability to take decisions for yourself about your own life. The basic principle of the Act is that a person must be assumed to have capacity. A person is not to be treated as unable to make a decision unless all the practicable steps that have been taken to support them have been unsuccessful. No-one should be stopped from making a decision just because someone else thinks that decision is wrong, but designated others can make a decision for that individual if they think that individual "lacks capacity". There are strict rules and checklists governing the circumstances in which such a decision can be made.

Historically, consent has typically been sought through presentation of written material to prospective participants deemed able to give their consent with the ability to give consent based predominantly on cognitive ability. People with learning disability may have been excluded from participating in research because they have been deemed unable to give informed consent using the current ways of delivering information about research. On the other hand, people with learning disability may also have consented to research when they are unaware of exactly what they are consenting to, of the consequences of their participation or that they can decline to participate in research. Dye et al (2004) state that capacity to consent has rarely been studied and suggest that there are several limitations with the current concept of consent. Currently, definitions of informed consent centre on the general abilities of the participant rather than on their ability to directly understand the study in question and the methods that would best help them to achieve this understanding. A review of the literature uncovered concerns about the process of gaining consent and how this is undertaken. There is a lack of information about how people with learning disability understand the notion of research and how they can be supported in assessing the pros and cons of participation in research. No comprehensive research has been conducted into how informed consent with people with learning disabilities can best be achieved (Ramon, 2003 and Ramon et al 2004). Fisher (2003) also notes that there are no empirically based guidelines to help researchers in this process. Most researchers merely make adjustments to current practices, such as simplifying written information sheets, reading them out to the prospective participant and offering them a number of opportunities to ask about the research before asking them if they might agree to participate. This still presents inherent difficulties as, for example, we know that without help many people with learning disabilities have difficulties in processing information and making choices about abstract concepts. Consent requires the engagement with complex and interrelated concepts, such as hypothesising ("If I do that then…") and critical reflection, that may present problems for a person with a learning disability. It requires the ability to understand the nature of various research procedures, to appreciate the consequences of a decision and to communicate the nature of that decision (Weisstub & Arboleda-Florez: 1997). The complexity of language and level of information may well be difficult to understand but, despite this, the person is still ultimately asked to make a 'choice' about participation. Adopting an approach to obtaining consent that utilises relative strengths (what people can do) when gaining consent is advocated (Wong et al.,1999). From their research into consent in clinical trials with people who do not have learning disabilities, Cummings et al (2006) argued that a key issue was the need for the informed consent process to focus on the subject and their requirements.

3.2 Participation in research and people with learning disabilities

A growing body of literature acknowledges the role of people with learning disabilities in research and the encouragement of their active participation, but this participatory paradigm is still very young. Involvement of individuals with learning disability in research should, if one adopts the perspective of promoting empowerment in disability research (Barnes, 1996), cover the entire research process. A review of the literature has highlighted the passive role and lack of power people with learning disability have in research: research has been done *on* them, rather than *with* them (Ward, 1998). Data analysis and interpretation is aimed at the academic audience with research results framed for and reported to other researchers, consultants or key workers, but not to the participants themselves. This suggests researchers are making an assumption about what people with learning disability can understand (March et al., 1997) and the option to know about findings is taken away from them. Upon analysis of the results, the ownership of data is traditionally viewed as being held within the academic community, and not with the research participants. This is reinforced by the use of an inaccessible language style and presentation format and journals that are inaccessible to people with learning disability.

In hospital settings in particular, the lack of autonomy has been even more pronounced. Prior to the Mental Capacity Act 2005 professionals have been in a position to decide which individuals have the capacity to participate in any given research project, thus affecting the person's right to volunteer for research (Milliken, 1993). Standard practice has been to interview the person's key worker or parent for information about the person with learning disability and their experience. This invalidates what the person themselves has to say about their experiences and issues that are important to them (Rodgers, 1999).

If we are to enrich the research process to incorporate research that is of value and reflects the pressing issues in the lives of people with learning disability, people with learning disability need to be helping to set the research agenda and shaping the direction of future research. Work by researchers such as March et al. (1997) and Minkes (1995) have attempted to move the focus of research away from third party experience and perception towards working with the understandings of disabled people. In collaboration with a researcher, individuals with learning disability designed and implemented their own piece of research, which focused on self advocacy (March et al., 1997) and gender issues (Minkes, 1995). Whilst these are important starting points, those who have been involved in developing opportunities for this type of research suggest that further evaluation of the process is required as we need to hear more about the views and experiences of people with learning disabilities who have been involved in research (Stalker, 1998).

There is a growing interest in evidence-based policy and practice in health to improve the quality of services. Central to this is an extension of the involvement in research of people who use these services. However, marginalised and vulnerable people (such as people with learning disability living in secure settings) have traditionally been excluded from meaningful involvement (DoH 2001: February). Northway (2000) discussed the ways in which people with a learning disability in research have, in the past, not been involved directly in carrying out research, but have participated merely as the subjects of research. As Shemmings aptly states

> *"Participation must surely involve more than being present; if it does not then we each participate in our own funeral.' (1991:18):*

INVOLVE, an organisation that promotes public involvement in NHS, public health and social care research, defines user involvement as:

> *"…an active partnership between consumers and researchers in research… We do not mean the use of consumers as the 'subjects' of research"* (INVOLVE, 2001; 2).

To be engaged in research, people need to participate in the process, planning, data collection, analysis and dissemination and not simply answering questions or taking a tokenistic part in research which concerns them. The principles and practices of participatory approaches to research, doing research 'with' rather than 'on' people, have only recently been addressed (Swain, 1995). Recent moves towards participatory research, have, however, shown that people with a learning disability have a valuable contribution to make (DoH, 2006; Knox et al, 2000) and that people with learning disability are increasingly in control and involved in research (DoH, 2006). There has been a shift towards understanding the need for the engagement of people with learning disability, not only as participants in research, but as researchers themselves. Despite this progress, however, user-led research in the field of learning disability still lags behind other fields (Globe, 1999, Walmsley, 2001). User involvement and control are the main creed of empowerment and best practice (Beresford and Croft, 1990, Wilson, 1995) but current practice in research seldom reflects this. Few people with learning disability have been given the opportunity to become research active.

4. The study

This study, designed to engage people with learning disabilities in research, not merely as participants but as researchers, aims to explore approaches that enable men with learning disabilities to both understand the nature of the research they might be involved in and the implications of that involvement. The outcomes and outputs of this study have the potential to inform the practice of others hoping to engage a similar population in research activity.

4.1 Methodology

A facilitated collaborative action research (FCAR) methodology was chosen. Whilst discussion abounds about the key principles of action research and what its role and function might be, for the purposes of this project it was conceptualised as being aligned with processes of research that strives to develop self-knowing, learning and change alongside knowledge building. Action research concerns the people who are in the research, their lives and the possibilities for their lives. It offers opportunities for in-depth exploration of understandings and meaning making. It aims to work towards

> "…helping practitioners to develop a critical and self-critical understanding of their situation… (towards) transforming situations …" (Kemmis 2001:92).

Action research is

> "… the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding" (Winter & Munn-Giddings (2001:35).

In FCAR, the role researcher/facilitator is to encourage open dialogue among participants so that diverse assumptions and opinions may be explored (Hogan, 2002:10). The facilitator provides a supportive but questioning arena to enable participants to contribute to the debate and move it forward into new areas for discussion and data collection. Collaborative enquiry requires facilitators to work together with participants to examine a situation, with all participants being acknolwedged as experts pertaining to their particular experience and skills. It offers greater insight into practice and its conceptual and philosophical underpinnings from the perspective of the user. It can tease out the complex and temporal meanings that form the basis of current practice and supports a thorough identification of important issues surrounding practices as they are experienced. Where multiple perspectives tell different stories about the same issue, the use of collaborative discussion, exploration and reflection as a critique puts common understandings to the test. It supports the unearthing and then synthesis of complex and varied meanings from a range of perspectives. Differences in perspective and emphasis across stakeholders are teased out and engaged with. FCAR is complex as social interactions are complex. Working collaboratively offers opportunities to gather and use multiple perspectives to enable all voices to be valued.

In this action research project, having multiple viewpoints, where each new view and theory is a springboard for further reflection, was one way of developing a process through which theory was continually created rather than merely being utilised. Finding a way of keeping thoughts active, of engaging and using self-development, learning and knowledge building, ultimately led this project towards identifying a process, or a set of principles, for engagement that will be of use to others in respect of learning about research and consenting to research. FCAR takes into account

> "…the need to integrate the construction of knowledge with its enactment in practice, [as this] is more likely than other research methodologies to recognise and take account of 'instability' of generalisations (or social theories)…" (Somekh 2002: 91)

At the core of the work is a quest to support participants (including the facilitating researchers) in contextually relevant critical thinking and learning for development and change. Through collaborative endeavours, multiple perspectives can offer new ways of seeing and can puncture long-held firm beliefs, views and understandings carried by participants, leading not only to change in practice but changes in the ways of valuing practice.

User involvement in research provides the following benefits to the research process and outcomes. It:

- helps to ensure that the research is not dominated by researchers and their agendas. Issues which are important to participants, and therefore to the project, are identified and made priorities
- supports the identification of new/unexpected aspects helping to ensure that research does not just look for outcomes that are identified and considered important by professionals, organisations etc.
- adds depth and strengthens data collection
- enables participants to help and support each other – and builds relationships
- means participants are more likely to be involved in and drive change
- acknowledges that participants have some good ideas and insights
- builds confidence and self-esteem

4.2. Methods

4.2.1 Workshops

A set of workshops, each lasting approximately 2 hours, tape recorded and transcribed, were the key data collection tools.

The workshops acted as a set of focus groups and used an adapted Delphi technique whereby the information gathered from each workshop was collected by all participants and revisited in the following workshop to inform the next phase.

The choice of workshops matched with the research approach of FCAR which prioritises working together to delve into individual understandings of situations and events in the light of the perspectives of others.

> “Other people’s thinking, based on their experience, is a key resource in enabling us to think creatively about our own, to think critically about the thoughts we started with in order to construct a new cognitive space, into which we might, provisionally, decide to move” (Winter 1998:67).

The programme of workshops was not merely a method of data collection but part of the development of understanding and finding of a voice to articulate thoughts and ideas.

4.2.2 Evaluating the workshops

At the end of each workshop there was a brief evaluation, using an appreciative inquiry approach, to plot any new understanding, how people think these have been reached, and what we might focus on in the next workshop (see Appendix 1).

4.2.3 Individual interviews

Individual interviews, each tape recorded and transcribed, were scheduled to take place with all participants both before the workshops and once they had been completed. Whilst workshops have many advantages in terms of delving into ideas and providing rich and developed data, they may inhibit participants who are either less articulate, less confident, or who wish to say something they do not wish others to hear.

4.2.4 Focus groups

One focus group was scheduled to take place with members of staff at the end of the research process and was also tape recorded and transcribed.

4.2.5 Diaries and field notes

All researchers (staff, men and the facilitators) were invited to keep diaries and field notes.

4.3 Overview of the research process

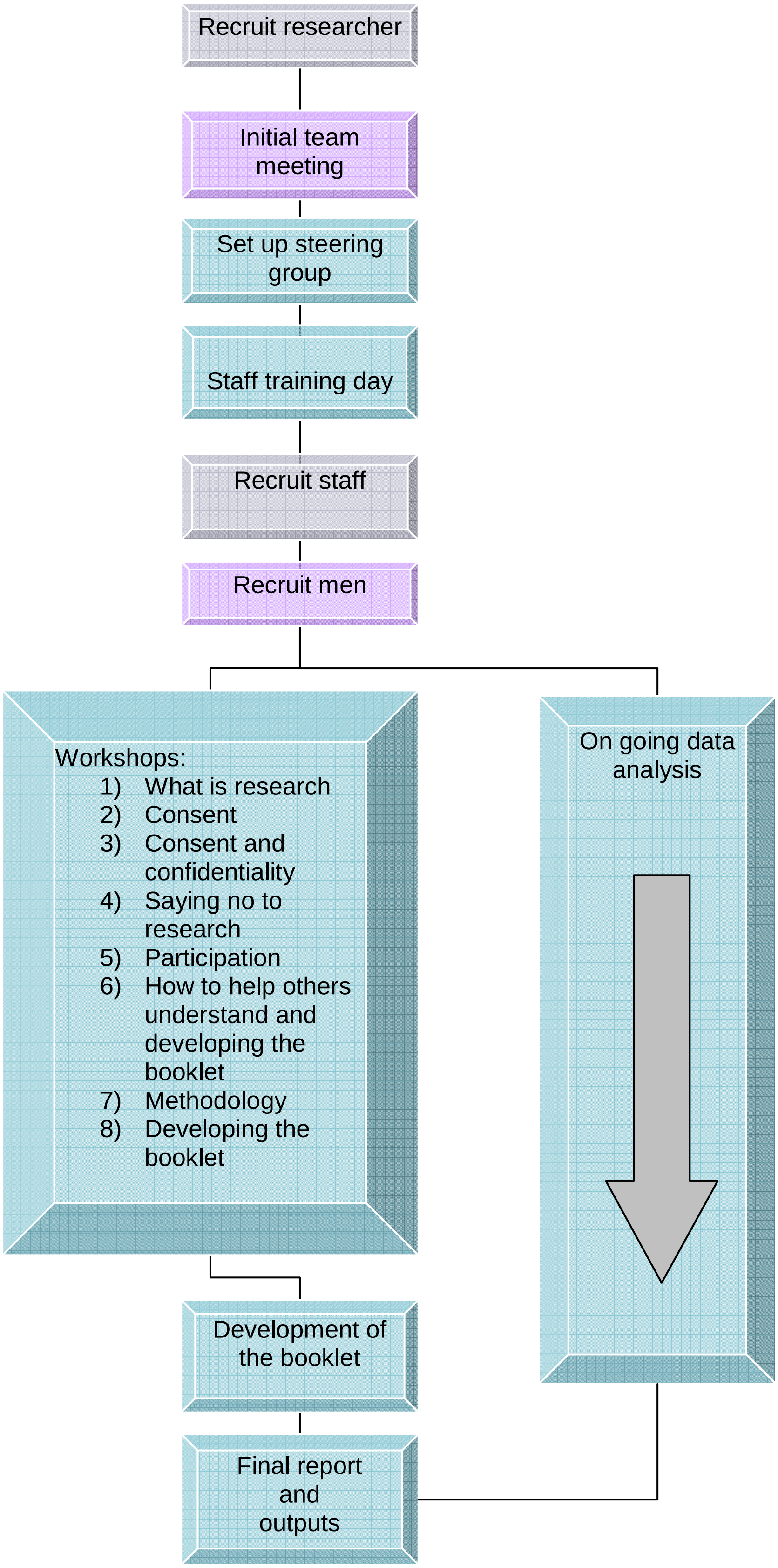
Recruit researcher
Initial team meeting
Set up steering group
Staff training day
Recruit staff
Recruit men
Workshops:
1) What is research
2) Consent
3) Consent and confidentiality
4) Saying no to research
5) Participation
6) How to help others understand and developing the booklet
7) Methodology
8) Developing the booklet
On going data analysis
Development of the booklet
Final report and outputs

Figure 1: Overview of the research process

5. The research in practice

5.1 Preparation

The principle researcher was recruited and an MSc Student was briefed to work on the initial stages of the project. Together these researchers laid down an initial outline for the development of the project.

5.1.1 The Steering Group

A steering group was formed to act as a sounding board for the project team and ensure that the requirements of the research brief were being appropriately engaged with. Members of the steering group were invited on the basis of the following:

- Knowledge of substantive issues in relation to people with learning disabilities
- Knowledge of issues in relation to research approaches
- Local knowledge (hospital-based)
- Practice-based knowledge – to support the smooth running of the project within the hospital
- Provide links with other organisations
- External overview

The members of the steering group were:

Ann Crosland – Member of Northumberland Research Ethics Committee
Graham English – Forensic Service Manager, Northgate Hospital
Gregory O'Brien – Consultant Psychiatrist and R&D Lead for Programme Research in Learning Disability, Northgate Hospital
Andy Stafford – Member of The Lawnmowers Forum Theatre Company
John Taylor – Consultant Psychologist, Northgate Hospital

5.1.2 Working with managers

Meetings were held with Trust senior management to develop further understanding in the project. This included working with the senior staff at the MSU to make arrangements for both the training of staff in the research approach (see below) and the practical arrangements that were necessary for the work to take place. Being an MSU means that at times it can be difficult to arrange staff cover for extra activities such as this research, and the research team had to look at flexible arrangements to enable the work to progress without putting undue pressure on the staff. That this project has gone ahead at all is entirely due to the absolute support of the senior staff and the commitment, dedication and enthusiasm of staff who worked with the men. They always made time for this work which, for some, included volunteering to come in on their off duty time.

5.1.3 Participants

The key participants in the research were a group of seven men with complex needs, 10 staff members who work with them and two experienced researchers (the facilitators) from a local University who have a background of participatory research and working with people with learning disabilities.

Participant Roles	Original Participants	Recruited	Withdrawn	Present Total
Men	7	0	2	**5**
Staff (nursing)	8	2	0	**10**
Facilitators	3	0	1	**2**
Total	**18**	**2**	**3**	**17**

Table 1: Participants

The men live in a medium secure unit within a hospital setting for men with learning disabilities who have offending behaviours. They are detained under the Mental Health Act (1983) and have a range of diagnoses additional to their learning disability (see pages 17-18). For most of the men this is a relatively long placement with a mean length of stay of 3.5 years.

The staff who participated in this research were all either qualified Registered Nurses for People with Learning Disability or unqualified Nursing Assistants.

The research facilitators have a background in working with people with learning disability, one as a teacher and the other as a nurse. Both are experienced researchers and facilitators. Over the last 12 years this research team has used action research for a variety of purposes: for self development, service development and evaluation, knowledge-building, development and change *within* systems and change *of* systems, the benefit of participants (both short and long-term benefit) and the benefit of organisations.

5.1.4 Recruiting Processes

a) Staff

The staff were recruited through senior management who talked to all the staff and gave them information sheets (see Appendix 2). The staff then had the opportunity to discuss the research with the facilitators and think about whether they wished to participate. In this closed environment the staff who chose to participate could not keep their participation confidential as rotas and accompanying the men would be a visible expression of their involvement. Staff were aware of this and whilst the information sheets were distributed by senior management, there was no implication of the need to participate and the senior management team then remained removed from direct involvement with the ongoing discussions with facilitators. Two staff from each of the participating wards consented to participate. Four of the staff were qualified nursing staff with specialist skills and knowledge, and six of the staff were unqualified nurses with experience and skills in working with this population in forensic settings and supporting the men in their daily activities. The staff had to be committed to the project as the time and effort it included was demanding but important.

- Time Commitment:
    - Initial meeting with facilitators to discuss possibility of participation.
    - 1 whole day seminar.
    - Attendance at eight workshops with the men.
    - Ongoing work with the men between workshops.
    - One interview prior to involvement, one interview after the end of the workshops.
    - One focus group after the end of the workshops.

Once core staff had agreed to take part, and before the workshops with the men began, a day-long seminar was organised for them to develop their understanding of participatory research and the principles behind collaborative research. This enabled them to work alongside the men, supporting them where necessary but also contributing to the research in their own right. The facilitators designed a full day seminar to explore the topics of action research, collaboration, hierarchy and power, respect and values. Practical activities and discussions were used to develop thinking and raise questions and issues. With the permission of all participants, the seminar was tape recorded, transcribed and used as data to be analysed. The staff then decided whether they wanted to continue to participate in the whole study.

b) Men

Part of the discussion that took place at the staff workshop surrounded the recruitment of the men and what might be considered to be important in the recruitment process. It was important for the research that there be a range of abilities represented in the project in order to collate relevant data. However, it was equally important that the men could participate, enjoy being part of the work and that it would not have a detrimental affect on their treatment or care. The staff and senior management felt that whilst the research would benefit from a range of participants in terms of age and ability, other criteria would need to be considered to ensure the research project could run to term. The criteria they used included;

Mental health status: The staff thought carefully about the stability of the men's mental state. Those who were currently experiencing more acute mental health issues were considered unsuitable, as participating in the research might add extra pressure for the men and might also mean they had to withdraw from the project before completion. It was recognised that despite careful consideration at the beginning, the men's mental health status could change and this would be monitored at all times. Acute/volatile mental health was an exclusion criteria and it was clearly stated that changes in mental health status could affect participation.

Behaviour: It was important for the project, especially as it was a Collaborative Action Research design, that the men felt physically and psychologically safe to explore issues. Therefore, a friendly non-threatening atmosphere was required. The staff considered the likely behaviour of the men based upon their knowledge and work with them. Men that were thought to be likely to disrupt the group, or cause others to feel uncomfortable because of their complex behaviour were not offered the opportunity to participate.

Mix of the group: Related to the point above, the staff had to consider the mix of the group. Some men might not get along with others and cause disruption to the relaxed atmosphere. Some men with very complex needs may find it difficult to get along with others in a group over long periods of time and they were not invited to take part.

Commitment: In order for the project to succeed, the men would commit to participate, carry out individual study and continue until the end of the project. Of course all participants were able to withdraw at any time, but it was more conducive for the project if the men who participated were committed to the project and the extra workload this would bring them.

Those likely to be discharged: If the men were due to move on it was not appropriate for them to be considered as the project was over 20 months long. Further, being considered for discharge, or change in placement, was obviously a very important and stressful time for the men and the project may have added to this stress.

How much the men might benefit: Central to the project was the participation of the men as researchers. Potential benefits for the men would include; intellectual stimulation, social interaction, skills development, improving self esteem and confidence and enjoyment.

Seven men who were deemed able to consent were invited to participate.[1] They were given an information pack with a covering letter and a CD. The information pack and letter were written in an accessible format with pictures (see Appendix 3). The CD contained a voiceover of the letter and information pack to enable the men to listen to the information repeatedly if they chose to, and read along to the CD if they wished. The men were given the opportunity to discuss their participation with staff and with the facilitators from the project. All seven men chose to participate in the project.

The names of the men were changed to protect their identity and to maintain confidentiality. Any particularly recognisable features of their behaviour, character or presentation have been removed. A brief profile has, however, been produced below to help readers of this report. These profiles have been checked with both men and staff who have approved their inclusion here.

David: David is an enthusiastic young man in his twenties who is tall with piercing blue eyes. He maintains close relationships with family members who he often refers to during the workshops. He enjoys a pleasant relationship with the staff and men in the group, often helping others to understand the issues under discussion. David has chosen to take up the opportunity for accreditation at the local University in respect of his work on this project and has worked to produce an extensive portfolio of his work.

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[1] It has been hoped to include some men in this research who were deemed unable to participate as a way of finding out whether this process would support their learning and provide a better understanding of their needs. The Local Research Ethics Committee considered this inappropriate if we could do the research with men who could consent.

Peter: Peter commenced this project as a quiet young man who had recently been transferred to the MSU and so did not know many of the men and staff on the project. He has a good sense of humour and loved to gently tease group members. Although very quiet at first, Peter increasingly joined in the group activity. As his confidence grew he made valuable contributions to the project. He has also chosen to become a student of the local University. He has completed an extensive file of his contributions and skills developed during the project for accreditation.

Ed: Ed is a man in his late forties with a sharp sense of humour and a strong personality. He is a very popular member of the group. Ed has exceptional reading skills which are not always in line his understanding and concentration. Other members of the group have worked to support him in this and he has been invaluable to the project in helping to identify a range of ways of supporting understandings of research. Ed enjoyed the tea, biscuits and cake of every workshop and, because he was acknowledged as the best reader, he always got the job of reading the contributions of the group out loud from the flip chart at the end of each session.

Raj: Raj is a quiet member of the group, who is thoughtful and careful in his approach. Although he enjoyed the group workshops and worked hard throughout his participation, he was unexpectedly discharged and therefore had to withdraw from the project.

Tony: Tony is a man who initially appeared shy and somewhat less confident than some other members of the group. Whilst he sometimes struggled with the concepts he brought fresh perspectives to the discussions with his thoughtful and thought-provoking ideas. After three weeks, Tony decided to withdraw from the project because he had some other very important things to think about.

Keith: Keith is a very enthusiastic man in his thirties who has worked hard consistently throughout the project and researched extensively on other topics for his own development, interest and pleasure (e.g. looking at literature on history, architecture etc.). He particularly enjoyed the collaborative aspect of the work. Keith is very proud of being involved in the project and has chosen to become a student of the local University. He has completed a portfolio which is full of his own extra work and how he has developed skills throughout the project.

Alf: Alf is a very thoughtful man who has taken his participation in the project very seriously. He spent a long time thinking and writing in the workshops, which meant that he had an accurate record of what was discussed. He spent a great deal of time between workshops contemplating what was discussed in order to get to the heart of the issues. Alf contributed greatly to the project, giving good examples and insight into understanding research in an accessible way that helped others. He has also become a student of the local University and has completed a thorough and insightful account of his work and his learning.

The men's commitment to the project included:

- Initial meeting with facilitators to discuss the possibility of participation.
- Attendance at eight workshops with the staff.
- Ongoing work between workshops.
- One interview prior to involvement, one interview after the end of the workshops.
- Keeping diaries about their participation.
- Being researchers.

5.1.5 Making the DVD

It was necessary to find a way of initiating conversation about research that would engage the interest of the participants. A visual approach was decided upon, particularly the use of a DVD. The DVD consisted of a number of short scenarios about research to give the group a starting point for discussion. The aim of the DVD was not to tell participants what research is and is not, but to raise issues for debate.

The technique chosen for the making the DVD was Film Forum, an innovative approach specifically designed to raise issues and successfully used by a local theatre company run for and by people with learning disability, The Lawnmowers. The Lawnmowers have produced a number of DVDs in this genre and agreed to make the DVD for this project. They have some experience in certain types of research and several discussions and meetings took place to help develop understandings of research in preparation for producing the scenarios for the DVD. The broad outline of a set of scenarios and ideas for dialogue were then drafted out by the facilitators and left for The Lawnmowers for dramatic interpretation. It was filmed and acted by members of The Lawnmowers acting group, all of whom have learning difficulties, one day in the University. It was subsequently mixed and produced by members of The Lawnmowers Company, a copy of which is included in this report (See Appendix 11). The six scenarios are:

Scene 1: What is Research?
Designed to evoke discussion about:

- What research is and what it is not.
- Different types of research.
- Different methods of research.

Scene 2: Consent
Intended to lead to discussions about:

- Consenting to research.
- Saying no to research.

- How you might say no to research.
- Consequences of saying no to research.
- Informed consent and the questions to ask.
- The difference between treatment and research.

Scene 3: Confidentiality and Dissemination

Designed to promote discussion on:

- Issues of confidentiality.
- How research is reported and disseminated.
- Ethics.

Scene 4: Being Observed – methods and ethics

This scene was designed to induce discussions on:

- Ethics.
- Methods of research.
- Observation as a method of research.

Scene 5: Focus Group

The last scene was designed as a round up of all the issues discussed in the previous scenarios and raises issues about

- Who can do research.
- What they would need to think about if they wanted to do it.
- Why people may want to participate in research.

The DVD was the starting point for discussion at each workshop but there was space for participants to raise issues they considered to be pertinent as part of the ongoing dialogue as the weeks progressed. Because of the research setting the facilitators were aware that some aspects of the discussion would have to be carefully considered to avoid confusion that might cause difficulties in practice. For example, it was considered to be important to clarify the difference between observation as a research method and observation as part of care and treatment. The men held in the MSU are observed for most, if not all, of their stay. This observation is not for the purpose of research, but for their safety, security and treatment. It was important, therefore, that the men understood this distinction. The difference between treatment and research was also an important issue to discuss in this environment as all of the men were held under the Mental Health Act (1983) and, therefore, may not be able to refuse treatment for some of their stay in the MSU. It was important for the men to understand that they can say no to research, even when this includes or is associated with treatments, but may not be able to refuse treatments.

5.2 Collecting the Data

Data were collected in a number of ways during the project, including baseline and follow-up interviews, workshops, diaries and research field notes, evaluation sheets and a final focus group with the staff.

Type	Number Completed
Group Workshops	8
Interview 1 - Men	7
Interview 2 - Men	5
Interview 1 – Staff	7
Interviews 2 – Staff	5
Interview - Facilitators	2
Staff Focus Group	1
Staff Workshop	1
Diaries and researcher field notes	17
Total	**52**

Table 2: Data Collection Events

5.2.1 Baseline Interviews

Individual semi structured interviews took place with consenting staff and men prior to the start of the project. The aim of these interviews was to give a baseline on what people already knew about research, consent and ethics and their thoughts about working collaboratively. Individual interviews were also conducted at the end of the project to revisit the subject areas.

The main themes for the interviews were:

- Understanding and experience of research
- What they knew about the notions of consent and ethical research
- How they might see the development of collaborative work and any issues that might arise from such work
- Perceptions of their role/position beliefs and ideologies about learning disability and nursing practice
- Feelings about choice and empowerment for people with learning disabilities

(see Appendices 4 and 5 for baseline interview schedules)

Interviews were taped, with permission, and lasted approximately one hour.

Given that this is an MSU the men are not able to be interviewed without a staff escort. The project team felt that this could mean that the men might not feel comfortable about answering certain questions with staff present. A compromise was reached when a University colleague, who worked within the Forensic Division, but not in the MSU, agreed to act as escort for the interviews. Permission for this was sought from the management, and from the men, who all agreed that this would be the most appropriate solution.

5.2.2 Workshops

At the heart of the project and the main area of data collection were the workshops with the men and staff. These workshops aimed to provide what Habermas (quoted in Kemmis, 2001) termed an ‘ideal speech situation’. Here, the exchange of different perspectives (for mutual learning) should not be limited by prior power relationships in which the views of those perceived as having lower status or having less power are rendered inherently less valuable, less plausible, less useful and less well founded than the views of those with higher status.

The practical task of the workshops was the development of an information pack for other men with learning disabilities who might want to know more about research because they were being invited to take part in research projects. The process of deciding what needed to go in the information packs provided the key data for this project with all discussions and decisions recorded, transcribed and analysed. Thinking and changes in thinking that took place as the workshops progressed were all collected as data to be analysed. This is particularly appropriate for a project that used a method of enquiry that stimulates thinking, development and knowledge building.

Transcribed information, evaluations and written and pictorial information produced during the workshop were collected as data. Additionally, field notes/diaries were kept by all researchers, including the staff and the men, on anything significant to them during the workshop or afterwards. At the end of each workshop there was a brief evaluation, using an appreciative inquiry approach, to plot any new understanding, how people thought this had been reached, and what we might focus on in the next workshop (see Appendix 1: blank evaluation sheets).

The research used a recursive design where participants in the workshops engaged in exploration and making sense of a topic, and subsequent workshops revisited what had been said to build on notions articulated by all participants.

During the workshops, flip charts were used to record information produced through the discussions. The recording system used included words and pictures. All pictures were chosen by the participants on the basis of being the most representative of what was said. Pictures were used in all information used with the men with each picture being agreed by them as appropriate for use in that situation.

The use of ‘difficult to understand words’ and jargon was addressed. In most cases simplification was rejected in favour of explanation. For instance, rather than use ‘consent’ it was decided that “agree to take part” would be more appropriate. There was a general agreement and insistence on the importance of understanding words and not just making them simpler. It was also thought more appropriate to learn the meaning of the words, for instance ‘collaborative action research’, rather than use a longer explanation.

Workshop One: The first workshop aimed to introduce everyone in the group, make people feel comfortable, establish ground rules (see Appendix 10) and discuss what was envisaged for the workshops and the study. The main subject for discussion in this workshop was “What is research?” All of the participants watched the first scene of the DVD, thought about it and discussed what they thought research meant. Some in the group had taken part in research in the past and offered examples of their experience of this. For most this was either researching through enquiry methods such as using the internet, books, etc. or answering questions set by an external researcher. None of the staff or the men had ever encountered FCAR or been a participating researcher before. The notion of research as the capturing of discussions was difficult to understand and triggered many questions and explanations by participants.

During the first session the men initiated a process of supporting each other by trying out different explanations to help a member of the group who had not grasped a particular idea or concept.

At the end of the workshop the participants completed two evaluation forms. One recorded what they had learnt that day and the other the way in which they had learnt and how they felt they had contributed to the workshop. This was done by using pre-designed forms (Appendix 1). Each person either made marks or stuck shapes in the appropriate boxes representing ideas such as listening, discussing, watching etc. The more marks/shapes they placed in the box, the more important they thought this had been throughout the workshop. This was important information for researchers to gather as it helped provide evidence of both what the participants had understood the workshop to be about and the most effective way of engaging them in the learning.

Workshop Two: Each workshop began with a resume of what had been discussed in the preceding workshop. The facilitators gave out a resume for the participants to keep as a record of what had been discussed (see Appendix 8). A few men also kept a record and any necessary amendments were noted and included.

Workshop Two focused on issues surrounding consent. After watching the DVD a discussion followed about what consent might entail and ways to help people understand what consenting means; what questions they might like to ask before consenting and the importance of this to the consent process. It was decided that it is only when you understand what research is about that you can really give informed consent.

An example of the information sheet was handed out. It had been used in a previous research project with people with learning disability. The content had been simplified by making the words easier and sentences shorter. The men discussed whether they could understand it and noted that although they understood what the words meant as words, they were not sure what it was really saying to them. They discussed how the information sheet could be developed to make it more easily understandable. This included both the need to have a background knowledge of research and the use of an easy-read format.

Issues were also raised in respect of saying no to research. This was to be revisited in a later workshop. The workshop ended with the two evaluation sheets as above.

Workshop Three: The third workshop began with the resume (see Appendix 8) and the participants asked to see the last two DVD scenes, as well as the third scene, in order to help them to discuss this week's planned topics of 'information required for consent and confidentiality'. Seeing all the previous DVD scenes each week became a regular start to the discussion.

The facilitators had observed that some members of the group were quieter than others and some needed more time to understand. A discussion was held with staff about the best way to support the men and it was decided to try splitting the group to allow the quieter participants space to contribute.

In the two groups the participants discussed again what they thought research was and went on to identify ways in which it might be helpful to give others information about research to help them decide about participation. The information which the groups thought was important was recorded onto flip charts (see Appendix 9). The flip chart from each group was read out by a volunteer to the whole group at the end of the session. The workshop was evaluated as above.

Workshop Four: Workshop Four began with a resume of the last three workshops (see Appendix 8) and the previous three DVD scenes. As the use of two groups had worked well in the previous workshop, the participants once again split into two groups to discuss issues in respect to saying "no" to taking part in research and how other people might be helped when thinking about saying "no" to research. This topic was chosen as in an earlier workshop the men displayed little understanding of potential consequences to saying no to research when asked to participate by a significant/key person in their lives. During the earlier discussions in the workshops it had become apparent that if the men did say no to participation they were not necessarily thinking through the complexities/consequences of this in sufficient detail. Given that a number of the men in the study had difficulties seeing things from another person's perspective, the idea that saying no might affect the person they had said no to, and so have implications for them personally, was not immediately apparent. This meant that their decision was not taking into account the type of issues others might consider in relation to dealing with someone in a hierarchical or powerful position above you. A large part of this workshop was therefore used raise the issue of difficulties that have to be considered if you want to say no:

- to a friend when they want you to do something with them.
- to someone you rely on for help.
- to someone in a position of power over you.

The key issue was how the other person might feel if they said no to them. Being able to say no in a manner that did not disadvantage you in other circumstances was important and ways of saying no were explored. The key issues were recorded onto flip charts (see Appendix 9) and read out at the end of the session by the men. The workshop was evaluated as above.

Workshop Five: Workshop Five began with a resume of the last four workshops (see Appendix 8) and watching the DVD scene on 'Different ways of doing Research'. Then the group split into two and discussed different ways that people can become involved in research, different types of research, and the difference between research and treatment. They also began to design a "Dictionary of Terms" for an information pack for others who might need to know based on words that they had not understood as a group. Some of these words were particular to research, while others were everyday terms that were understood differently across the group (e.g. text: meaning what has been written down on paper, as opposed to something you send on a mobile phone).

The information which the groups thought was important was again recorded onto flip charts (see Appendix 9) and the man who had gained recognition as the best reader (Ed) was invited by the other men to read it out to everyone. The workshop was evaluated as above.

Workshop Six: Workshop Six began with a resume of the last five workshops (see Appendix 8). The participants watched all the scenes on the DVD prior to discussing what they thought information for other people with learning disabilities who were considering consenting to participate in research might need to consist of. They discussed:

- The aims of an information pack
- What it should look like
- What it should include
- Who should be involved in developing it and delivering the information
- How it should be disseminated

They then considered how an information pack (now being called "Understanding Research") could be evaluated. One man had already written down his ideas which included piloting the information before finalising it for dissemination. It was decided that the best way of piloting it would be to deliver it to other men with learning disabilities. The men were keen act as facilitators to the pilot of the booklet. The pilot is outside the scope of this study but was planned to take place in late 2007. The Trust agreed to fund it.

Information identified by the groups as key to developing understandings was recorded onto flip charts (see Appendix 9), read out by Ed and the workshop was evaluated as above.

Additional workshops: Although six workshops were originally planned, the men requested extra workshops to clarify their understanding of methodology, in particular the difference between qualitative and quantitative research and collaborative action research. In the course of the previous workshops they had looked at a variety of different ways of doing research and had become more curious about the particular approach in which they were participating. They also said they needed more workshops to decide on the most appropriate words and pictures for the information pack (now being called the “Understanding Research” Pack) to edit their work and discuss dissemination of the findings from the study.

Workshop Seven addressed issues of methodology, the differences between qualitative and quantitative methods and FCAR. The latter part of Workshop Seven was used to edit the work done so far on information for other people with learning disabilities (to be developed into the “Understanding Research” Pack) about research and to validate the pictures being used.

The last workshop was used to develop and edit the “Understanding Research” Pack.

5.2.3 Final Interviews

The final interview schedules were based on the initial interview but before it took place the outline was discussed with all participants. The initial interviews had been conducted by the researchers from the University (facilitators) who were not themselves interviewed. It was decided that they should now be interviewed. Three men volunteered to do this. After scrutinising the final interview schedules the men made a number of helpful suggestions and changes were made (see appendix 6). The final interviews had been designed to take a less structured approach. Participants were asked to tell the story of their involvement in the research from the beginning. This approach had the advantage that it allowed the participant to describe the project from their viewpoint and offered space for them to discuss issues that they thought important. However, some of the staff and the men had problems with this approach and asked the interviewer to ask them some open questions to guide them through their story. The agreed questions are outlined in Appendix 6. In addition to interview schedules the interviewer also had copies of the flip charts and pictures used throughout the study, to remind the interviewees about what they had done and help/prompt them to tell their own story about the research.

Whilst these interviews cannot be described as using a narrative approach in the strictest sense, the interviews were concerned with how the participants viewed the project, and how they had contributed and benefited during their collaboration from their perspective.

5.2.4 Focus Group

After all the workshops had been completed a focus group was held with staff members to capture the ways in which they had supported the men's learning between the workshops and the elements of the project they thought the most important. The outline for the focus group discussions is in Appendix 7.

5.2.5 Diaries and Field notes

All participants were given an A4 hard-backed book to note down immediate comments about the workshops and record their ongoing thoughts and feelings. As the project progressed the men used these extensively.

5.3 Accreditation

It became apparent that the men were working at a higher academic level than expected and were producing and engaging in more work than was initially anticipated. The local University have a 10 credit module at levels 3-7 which would enable the participants to use the work they had being doing during the project as the basis for gaining accreditation, if they wished. Four of the men and none of the staff took this opportunity for accreditation.

6. Data analysis

Two approaches were used for data analysis, a thematic approach embedded in research prioritisation and an interpretive approach supported through the use of Nvivo.

6.1 Thematic approach

The fluid and emergent nature of naturalistic, recursive enquiry makes the distinction between data gathering and analysis far less absolute (Patton, 2002: 436). Ideas for making sense of the data, and the identification of key themes, emerge whilst in the field. This was often the case in this project. Patton goes on to say that, as long as researchers do not allow the overlapping of data collection and analysis to overly confine analytical possibilities, such overlapping improves the quality of both the data collected and the analysis (Patton, 2002: 437). In this project participants made the following contribution to data collection and analysis:

1. weekly evaluations of the workshops, where their learning and their contribution to the research process was evaluated (these were graphed by using a Microsoft Excel data base)

2.within their discussion during the workshops when ‘hot topics’ (Ball and Vincent, 1998) emerged and were returned to, refined and redefined and captured as important themes

3. through the development of the booklet in which the data collected was prioritised by its importance for people to be able to understand research, consent and ethics in the workshops; prioritisation being a key element of analysis

Participant researchers were particularly adept at offering insights that revealed important themes; returning to particular aspects of the work developing a sound basis for an issue-based framework for organising the data. The key themes that were produced were then returned to the participants during the workshop sessions, as the basis for more in-depth discussions. In this way the thematic approach was embedded and woven into the data collection and discussion process. This enabled the participant researchers to contribute to the analysis as the rich data produced through workshop discussions was continually explored, questioned, strengthened, clarified and prioritised according to its importance for the men as well as the facilitator researchers.

6.2 Interpretive approach

Textual data from interviews, focus groups and workshops were analysed using QSR NVivo 2 for Windows 200, XP and ME. NVivo aids in the storage, easy retrieval and purposeful searches of the huge amounts of data being collected. This package supported the search for appropriate words and phrases or paragraphs; showing the context in which they were used. NVivo is, however, a data handling software, the data analysis and interpretation is still in the realms of the researcher. Coding data is related to, but not is not in itself, data analysis; it is a practical heuristic approach to understanding data (Coffey et al, 1996) with data analysis and interpretation coming from the full engagement of the researcher with the data throughout the research process. In this project the facilitator researchers and the participant researchers were present at all of the workshops, carried out interviews and focus groups, and formulated analytical frameworks as part of the discussion and collaboration. In this way the important themes and categories were formulated along with the participants as the research progressed.

Nvivo naturally enables data to be organised into coding families in which nodes are linked under names linked to concepts and associated examples of those concepts. in this package this is referred to creating a code (or node) *'invivo'*, and is considered significant as it is taken from the participants own words and measured as closer to the material which is being studied (Flick, 2006). Categories and codes therefore also emerged from the data itself. An example of this is code family 2 'What is research' which includes the nodes; what is action research, what is participatory research, what is the difference between research and treatment (see appendix 17). The data are thus organised into tree and branches type taxonomy which is common in Western Science (Prior. L in Silverman, 2004). There are two levels of coding, the first being broad categories (called tree nodes) and the second more specific parts of the broad categories (called child nodes). The final list of nodes used in the analysis is outlined in Appendix 17.

In NVivo the text is coded at a node which connects related texts (Gibbs, 2002; Bazeley and Richards, 2000). These nodes were developed as the themes. In the first the search for themes was based on broad categories which included:

- Descriptions of men – how others described the men
- Relationships – how the participants viewed their relationships within the MSU
- Description of role within the MSU – what role did they have in the MSU
- What is research – what the participants understood by the term research
- Ethics of research – what the participants understood by the term ethics
- Collaboration – what the participants believed collaboration in research means
- Consent – what the participants understood by the tem consent in relation to research

These were modified and developed in response to the work of the participant researchers and ideas emerging as the analysis evolved. All of the interviews, notes and transcriptions from data collection events were then scanned for relevant phrases, themes and words related to ideas defined in the nodes. Some of these nodes were finally rejected as being inappropriate for the research questions and aims (Flick, 2006).

NVivo helped to analyse connections between the nodes through enabling subsequent searches among the nodes for specific text and tracking related text through thematic codes. A particular strength of NVivo is that the data can be traced straight back to the context in which it was said. This enables researchers to constantly check the context of the utterances and aids the interpretation of text (Wolcott,1990). For example, the staff noted that the men had gained in confidence throughout the study; NVivo enabled the researchers to track back through interviews and workshops to see if and where such ideas were also expressed by the men. Thus the data was confirmed and triangulated.

Open coding, line by line, classified the data into segments with shared meaning, these could be words, phrases or whole sections (Flick, 2006). The data was trawled systematically and the appropriate text was sorted into the relevant categories. Coding in this sense is the way in which the data was categorised and separated, then put together to create meaning (Flick, 2006). Examples of this include: “who had said what”, “in which context”, “to what purpose” “with what intensity” and “at what time”. This process of analysis and interpreting the data started by open coding, became more selective towards the end of the process; referred to as focussed coding (Flick, 2006). This enabled deeper understanding of the data in context and content.

Additionally, through NVivo, documents can also be given attributes. An attribute is a marker which distinguishes documents from one another to allow the researcher to identify groups of documents for comparison. For instance, In this study an appropriate attribute was the timing of the interviews; those carried out before the workshops and those carried out after the workshops. Searching by this attribute enabled a view of what was known about research by participants before the workshops, and what was known after the workshops, indicating had been learned during the study. Another useful attribute differentiated who was being interviewed, which enabled the researchers to differentiate between responses from the men and from the staff.

Throughout the first and subsequent trawls of the data it became clear that the original categories were inadequate and the general categories (or codes/nodes) needed to be further coded into more refined categories. For example, the participants’ thoughts on collaboration included enablers and barriers to collaboration not present in the original outline framework for the analysis. These categories were distinct and were more easily analysed and useful when refined further into discrete codes. These codes were then grouped around broad phenomena which were relevant to the study and included:

- What the men knew about research before the study
- What the men learned
- How the men learned
- Benefits from participating in the study
- What may help others to learn about research
- What was the most enjoyable part of participating

The above codes answered or asked questions about the data and made comparisons about the phenomena being studied (Strauss and Corbin, 1990) and were used as a basis for the results.

Important parts of the data were included in the analysis; quotes, observations, notes to remember a pertinent vignette or story, or insight recorded during workshops, or shortly afterwards and diary entries. Text which particularly caught the essence of what was being said, or that represented several view points or ideas, was used in the results (Wolcott,1990). Some of the data occurred in more than one code and appeared relevant to more than one theme. Any such data was used in the most appropriate way for the results and was judged to be the most appropriate or accurate expression of that idea or theme.

The in-depth and longitudinal approach to data produced data that was outside of the central themes of this study. Such data included text regarding details of security and nursing practice for example, which whilst pertinent to the participants of the study and reflect the complexities of the study, added little to the central themes and are excluded from the results.

The texts in this study were trawled and re-coded and the codes refined until the data showed no further insights were emerging, and that the codes which were developed were filling up with similar text. This is referred to as theoretical saturation which occurs when further coding of data fails to enhance codes or add knowledge to the study (Flick, 2006).

Two researchers analysed the data in NVivo, and inter-rater reliability was tested through several transcriptions.

7. Findings

This chapter identifies the key findings in relation to what the men already knew about research prior to participating in this study, what the research revealed they needed to know more about and the key elements of the project that enabled the participants to learn and understand issues relating to research, ethics and consenting to participation. It goes on to consider what effect the involvement of people with complex learning needs has had on the research and the use of those findings and to identify additional and unexpected benefits of participation.

This study had the intention of using a qualitative approach to engage with the complexity of understandings and meaning help by men with learning disabilities in respect of research consent and ethics. Given this complexity the findings have been presented using ‘thick description’ (Denzin, 1989). Thick Description, often used in phenomenology, provides an account that enables a reader to engage with the feelings, actions and meanings of the people involved in the project and, through the use of deep and dense description, lets the voices of the participants be clearly heard alongside the voices of researchers (Denzin, 1989). This supports the validity of the research in allowing the reader to match the account framed by the writer with the accounts of the participants.

7.1 What the men already knew about research: what they needed to know

7.1.1 Research

The men had already consented to doing this study which meant they had received information sheets, a CD talking about what would happen if they participated in this study and had discussions with facilitators and staff. This may have affected their answers during the baseline interviews by inflating what they already knew about research. However, the results suggest all the men still possessed very little understanding about research with the knowledge they had being somewhat tautological and confused.

> **Research is like everyday life. Mainly research means, like, scientific stuff. Like research can be like trying to find out… It can be like history… Or research can be mental health – researching in that. Or researching day to day living.** Alf .

Having used a relatively standard means of gaining consent to participation (written information sheets supported by a CD of the information, a meeting with the researcher and discussions with staff) the facilitators had not engaged the men in broadening their knowledge during the consent process. As this study focuses on finding out better ways to help people with learning disability develop their understandings of research, even if the men had gleaned knowledge from this, the process of how that can be developed is most pertinent to this study.

The majority of the men had, however, understood that engaging in this research project meant they would have to come to a number of regular workshop sessions and that they would be researchers too.

> **Because what I understand from it is the fact that instead of somebody else doing research on us or anything else, we're actually doing it. So it's going to be quite fun to find out what information we can get and research sounds quite interesting.** David.

Some of the men had carried out their own investigations into things that interested them, like local landmarks, history, their local area or musicians they admired, so they knew a little about how and where to gather information. They knew some of the different ways of gathering information, such as reading, the internet and going to libraries, but did not initially have an appreciation of the value of finding out lots of information from different sources and in lots of different ways (methods).

They were talking about 'searching' rather than researching. This distinction became increasingly relevant as the workshops progressed.

Most of their initial ideas about research were around medical research, for example researching DNA, medication or taking blood to analyse it.

> **I think it's researching into different things like medicines and stuff like that... It helps to find a cure for people to get better.** Peter.

Some men recognised that research might go beyond taking blood samples and included psychological tests that they may have encountered. Some thought it could be about finding out about how the mind worked

> **How their brain works and stuff like that… Some do different puzzles and stuff like that, don't they?... Just, like, I think it's for understanding how the mind works, I think, or something. All the different thoughts and all that, I think.** Raj.

.
Research was generally seen as a positive thing that helped solve problems.

> **Like a doctor doesn't just give you tablets, he takes a blood sample. Because, you see, you don't realise, but there's things in your blood that can react... So what they do is they take a blood sample and put it under a microscope. They then put the drugs, or the quantity of drugs that they're going to use on you, into the blood. The blood will start reacting to it. The research in it would be that they'll be able to determine – with the blood and the tablets – which ones are going to affect you, which ones aren't and which ones could kill or harm you.** David.

7.1.2 Research methods

Whilst it was agreed by the men that research was about finding things out, there was confusion about the way this could be done and the scope of research.

> **Other forms of research is… when you sit an exam they ask you questions like these to determine how strong your mind is.** David.

In later workshops there was some surprise when they realised that research could be 'just talking'

The men reported that in this research project they would be involved in writing, talking and asking questions and they were all sure that this would be fun and would benefit them in some way. They thought that it would help them learn and give them an opportunity to prove themselves.

> **To get a better understanding of something – doing it is normally the best way. Because if you're doing something, you're not just doing it, you're learning. And if you're learning, you're taking information in. And if you're taking information you're broadening your horizons and your mind.** David.

The notion of qualitative research that took a workshop approach, such as the one they were currently involved in, was a difficult concept to understand and was returned to on a number of occasions during the workshop sessions.

7.1.3 Consent and confidentiality

The men have all been through health care and/or criminal justice systems, some of them for many years. This means they are generally aware of their rights and their right to say no. They were aware of the word consent but found its meaning hard to articulate. All of the men said that they knew that they had the right to say no in certain circumstances and that they could say no if they wanted to. The staff doubted that the men would, in reality, always assert themselves.

> **I think sometimes people just put on to them, saying, "Right, we're going to do this." And they say yes. And I don't think they understand that they can actually say no.** Staff 5.

Given that they were not always sure what was and was not research, there was some ambiguity about whether they knew exactly what they could consent to.

The men were also aware that there were some important questions to ask before consenting but the complexity of the type of questions and the implications of participation was not recognised. For example, they understood that they should ask why the research was being carried out and who it would help, but did not realise that the results could effect their treatment or the treatment of their significant others.

Confidentiality was recognised as an important aspect of participating in research, but was not well understood. The men had not realised that confidentiality was not just about not being named in a report but also that people might not wish for others to know that they were taking part in certain research because that might have personal implications for them.

During discussions it became apparent that the men had not thought through the possible consequences of saying no to people that care for you or on whom you rely in other ways.

7.1.4 Notions of participation

Some of the men had been involved in research before so knew they could be researchers.

> **When I was on YTS I was a gardener and I was looking for a full time job and before I could do that I had to study soil and stuff like… I was doing, like, the tests and experiments with the soil to find out which is which for which plants has got to go in which soil… Using some test tubes and liquids… We would get the results. And then we would sit down and discus what would be ideas for that soil to suit that kind of plant.** Keith.

The main things they thought it might involve were:

> **Talking… And all the problems... Writing, yeah. That's it – to help you write and things like that.** Tony.

7.1.5 Dissemination

The men were not sure what happened to the findings of research. None of them reported knowing about the outcomes of research they had previously been involved in. Some men, when asked what they thought was done with the information collected by researchers, thought that it was a secret:

> **INTERVIEWER**
> **So what do you think they do with this information?**
>
> **Keep it secret.** Peter.
>
> **Keep it quiet.....Keep it quiet. Don't tell anybody. Keep it quiet.** Tony.

7.1.6 Summary

Based on the initial interview and first workshop it was evident that most men had a basic idea about research; that it was concerned with finding out things. Their knowledge in respect of how this might happen and the implications of their own participation was confused and variable. The following were identified as important learning areas:

- research is complex and takes many forms
- research has to be rigorous and is not just sets of ideas

- lots of different methods are used in research
- the meaning of consent and confidentiality
- what type of questions to ask when deciding whether to participate and why
- the implications of being involved in research for themselves
- ways to say no to research and implications of saying no
- definitions of words and phrases in common use within the research community

The remaining workshops were developed to address knowledge in these areas and to capture what helped the men develop and understand more about research and consenting to research.

7.2 What the men learnt from the workshops

The rich data from the workshop sessions provided significant evidence of learning. Learning was considered to have taken place when the men could talk freely and appropriately about aspects of research, give examples of issues in relation to research or offer allegories. Data was also collected from their final interview where they were asked to identify what they had learnt. Learning was not considered to have taken place when men answered questions by repeating information given to them in the sessions, by repeating answers offered by other people, or when their answers only included words related to research but did not engage with meanings.

7.2.1 Notions of research

Using the DVD as a starting point, the notion of research was discussed each week. From seeing research as a simple searching process, the men began to understand that research delved more deeply into the subject under scrutiny and aimed not only to find things out but develop understandings about the findings

The men described research as ‘like being a detective’, searching again and again for information, searching in different ways, asking questions and fitting the clues together. The notion of it being ‘a bit like a jigsaw puzzle’ was drawn on a number of times, and how you have to find the pieces and put them together so that the whole picture can be seen.

> **Research is like a jigsaw puzzle… It’s like finding pieces of the jigsaw… It’s looking over and over again. Because sometimes if you look at something once you don’t get to see the full picture but when you come back and look at it again you’ll see something different. And the more times you go backward and forward to it, the more you see. So that’s good.** Alf

Most of the men also understood that research was about revealing new ideas and thoughts and seeing the key principles behind issues.

> **Well research is finding information... Getting to the heart of a problem. And finding out questions that you want to know to just**

> **help you get to the bit where you want to be which is right at the heart.** Alf
>
> **[**Research**] is like getting to the bones and the centre beneath the surface.** Alf – Diary.

The function of the collaborative approach was recognised.

> **Sometimes when you are doing research sometimes they end up connecting together… say one person got 50 bits of information, and two people get 100 and they can all go in together. It's like we are a group of people in this room at this time and we have all got views and ideas of research [**and**]… are coming up with things other people might not even of thought of, or even have known, and we are putting it together, we have started the jigsaw. And it's coming on pretty canny.** David

For one man research remained a difficult concept to understand. He was able to identify the important words used in the workshops and to repeat them in conversations. He remained at a concrete level of thinking and there was generally little evidence of consistent understanding. Facilitators and staff considered that he had now 'made acquaintance' with research, but it was unlikely that he had understood the wider notion. The other men recognised that he was finding it hard to understand and worked hard to help him grasp the subject area. They also realised that their work to support this man was valuable in meeting the aims of our research. Capturing how they worked with this man to help him understand was valuable data and provided material for the Understanding Research Pack.

7.2.2 Methods

To be able to consent to research, the men needed to understand not only what research aims to do, but how it does it. The workshops considered the range of methods, starting from the more concrete questionnaires to the more complex types of research method such as focus groups, as well as medical interventions as research.

The men learnt that research did not always look the same and you could be involved in research if you were simply talking to someone. The following list gives an indication of their knowledge of research methods.

- **We ask questions.**
- **We do interviews.**
- **Sometimes we interview people on the telephone.**
- **Sometimes we send people letters and ask them to fill in forms called questionnaires.**
- **We may also ask people to discuss things in groups or just with someone else.**
- **We may observe people (this means look at them), sometimes without them knowing exactly when. This is called participant observation and non-participant observation.**

- **We can use a camera.**
- **Or we can use a video.**
- **We can look into reports and documents for information, or use a diary.**
- **We can watch films or documentaries.**
- **We can look in books or on the internet.**
- **Some people take blood or genes so they can check it against other blood or genes**
- **People can use more than one method to do research – this is called mixed methods research.**

Alf, who became very interested in methodology, recognised the importance of ensuring the appropriate methods were used in research to enable it to remain focused on the initial research question but also allow for the unexpected so that you can learn about new things.

> **Plus, on the upside, there's loads of forms of getting information. You've got to find the best way that suits you to do it… The deeper you go the more information you get and you'll find out** [that**] other things can come into it.** Alf.

He also recognised the importance of remaining focussed.

> **So, sometimes it's best that when you're doing research you put your mind on one track and only go down another track [**if**] it's relevant to what you're doing research on.** Alf.

He highlighted the difficulties in finding out what people really thought and how they behaved in a research situation. In a discussion about observation as a research method Alf considered both the integrity of the method and issues of consent

> **INTERVIEWER**
> **So, how do you get people to behave normally…?**
>
> **RESPONDENT**
> **There a thing where before you actually start watching them, you let them know you are going to. But you don't actually tell them when you're going to do it. And all of a sudden you just do it out of the blue. Without them even knowing. But they already know that you're going to do it, but they just don't know in which part of life you're going to.**
>
> **INTERVIEWER**
> **So they've agreed to it?**
>
> **RESPONDENT**
> **Aye. So they already know that they're going to be taking part, they just don't know [**when**].**

7.2.3 Consent and confidentiality

Consent: Initially the men were aware that they had a choice to participate in research

> **Nothing can happen unless you do consent and nobody can take your consent from you…** Alf

After the initial interview another man demonstrated that he had understood about his right not only to choose in respect of participation, but to change his mind about his choice.

> **I don't have to do this do I?**
>
> **INTERVIEWER**
> **No.**
>
> **Then I don't want to.**

This man did, however, subsequently changed his mind and came to all the workshops.

It was clear that the men (and a number of staff) had been unaware of the complexities of research and what might be involved. They needed to know more about research methods to help them understand what they might be participating in and hence its implications for them.

> **You need to know what you're getting involved with. What you're consenting to. What it's involving and your understanding of it. Before you can actually say yes. And you've got to understand what consent is.** Alf.

They began to recognise that consent, agreeing to take part in research, was complex

> **There was consent and consenting to give blood and consent to this** [study**]. And then there was objections to consent... Consenting to take part…There was just so much information just on one word.** Alf

The men said that if they were asked to participate in research they would now think this through more carefully, would ask questions about the research and would say no to research that they did not think was appropriate for them.

> **'Consent and ethics', I don't think either of my boys [**two of the men**] would have thought about it – ever. But, they were coming out with…things like "I don't consent to this" and you would hear them on the ward talk about 'consent' and things.** Staff 8

Most men began to realise that it was important to explain why they might not be consenting, for example, they were tired, they had other commitments at this time or they wanted more time to think about it.[2] Peter demonstrated he had now understood both what consent is

> **Well consent is when somebody asks you to take part in research and you're not too sure about it. You can have a think about it and then go back to them and say "Yes, I want to do it" or "No, I don't want to do it." And then if the person says yes to it, then they take part in it. And if they don't, if they say no, that's fine. Because they don't have to take part in it.** Peter

And that sometimes saying no can be more complicated

> **If your friend wants you to go for a drink and they've asked you to go to the pub and… they ask you and you say 'No, I don't want to go', they can think you've upset them… [**but they have**] just misunderstood… but really you just wanted to stay in… [**it**] Makes people feel sad, angry. Answers are important, how we say it. Let someone know you have thought about it. Give them an explanation.** Peter.

When asked 'If you were asked to take part in research what questions would you ask the researcher?' the following answers were offered.

> **I would go and find loads of facts** [about it] **and, if it was as interesting as this, I would jump straight away... [**with humour] **What it's about, what it contains, what are the risks, what are the health benefits, how much you are going to pay me!… [**laughs**] ...And make sure that I've got all of the texts and stuff that I need so I can make an honest and reasonable and an informed decision.** Keith
>
> **I'd have to need more information about it. I'd ask him what it's about and what it's based on and what it involves.** Peter.

Keith described how he had used his knowledge about consent to research to discuss whether he could consent to treatment.

> **He had visited the hospital for some treatment and the member of staff who was escorting him doubted that Keith could consent to this treatment. Keith explained to the staff member that he could consent and went on to describe how he would give informed consent through asking questions, weighing up the pros and cons and coming to a decision.** Researcher Field Notes.

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[2] Part 7 of the "Understanding Research" Student Booklet explores this issue which includes thinking about; how they might feel afraid because they have said no, how the person who asked them to take part might feel sad or angry because they have said no or how they might actually feel ok about saying no (see Appendices 12-16).

Based on their learning throughout the workshops the men then thought about the full range of questions a person might need to ask a researcher if they were asked to participate in research. They included:

> **Are there any dangers?**
> **What do I have to do for this research?**
> **Do I have to answer questions?**
> **What kinds of things do I have to talk about?**
> **Do I have to do activities?**
> **Do I work in a group?**
> **How much time will it take?**
> **How much effort will it be?**
> **What are the researchers planning to do with the information I give?**
> **Is it confidential?**
> **Who will know if I have been involved?**
> **Will it affect my treatment?**
> **Who will see the research when it is finished?**
> **Will the research help anyone?** [3]

Despite this intensive work on consent not all the men were able understand this notion and the implications.

> **INTERVIEWER**
> **Who decides whether you take part or not?**
>
> **RESPONDENT**
> **The doctor... The researcher…**
>
> **INTERVIEWER**
> **The researcher does? What about you? Can you say no?**
>
> **RESPONDENT**
> **Yeah.**
>
> **INTERVIEWER**
> **Oh, you can still say no, though. Even if the doctor still says yes, you can still say no – is that right?**
>
> **RESPONDENT**
> **I think so.**

Confidentiality: Confidentiality, linked with the implications of divulging information, who can you tell things to and what can you tell, is an abstract and contextually based concept. Through discussions and exercises in the workshop most men began to understand that it was more than just keeping your name out of the report.

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[3] See Part 5 of the “Understanding Research” Student Booklet (Appendix 15)

> **When we were discussing confidentiality today David pointed out that if we were reporting on our research then we couldn't describe the people in the group as some of them would be more recognisable than others. He gave the example of me being the only one in the group with grey hair. So, if we described someone with grey hair and reported what they had said, then they could be recognisable, even though we had not used their name. This, he added, was not keeping things confidential!** Researcher Field notes.

Alf discussed confidentiality when considering the dissemination of information

> **Where is it going to be kept confidentiality? Is it just going to be kept in amongst the group? Or amongst the department? And not displayed out, like put in newspapers or magazines or something?** Alf.

David recognised that confidentiality was more than just keeping secrets, it had a purpose in terms of the focus of the research

> **Oh, that's a hard one. Keeping people's secrets. And we also said that in research you don't name names. You normally keep names out of it because you don't want people to base their minds on who was there, you want them to base their minds on what it's actually about and what you're trying to get at. Which also comes with ethics because if it's done wrong it doesn't work at all to your plan.** David.

7.2.5 Ethics

Although they talked about many of the concepts that characterise ethical research, this was the most difficult area for the men to understand. The men defined ethical as:

> **When research is ethical it means that it has been done right.**

When thinking through aspects of consent, confidentiality, respect, methodology, recording data, dissemination and hearing multiple perspectives, the men also discussed the need to make sure the research was valid, that the participants were truthful and the researcher "*was not cheating*". One man articulated the importance of using many sources of information to see if they all came up with the same ideas as a way of ensuring that research methods are trustworthy and that you have captured "the right idea".

> **Because if you have only one person saying that this is the idea, and it's the wrong idea, it is a waste of time. You need others to think it too.** Alf

As a demonstration of their understanding of ethics, they produced the following key points for prospective participants in research.

> **All research should be ethical and should make sure that:**

The Person Taking Part

- **you are informed.**
- **you agree to take part. And that you know you can change your mind.**
- **what you say is kept confidential.**
- **you are treated with respect.**
- **They [**the researcher**] are being honest and open with you about what you have to do in the research.**
- **Making sure that they do not cheat in the research and they do what they said they would do.**

The Researcher:

- **Should be responsible and make sure that people come to no harm through taking part in the research.**
- **Should include lots of people or lots of ways (methods) to find information out so that if someone lies then the research will still be true because the other people are telling the truth.**
- **Should document the research by keeping careful records of what happens.**
- **Should give you a copy of the research report that you can understand.**[4]

7.2.6 Jargon busting and difficult words

Jargon used in research may be discouraging for people who have had little opportunity to engage in research before.

> **…Do not use jargon, this is only a word that [**the**] university understands.** Peter – Diary

To understand more about research the men had to learn what certain terms meant and how certain words were used in the research context. Each time a word was not understood it was discussed and 'translated'. For instance the word 'consent' had not initially been understood, but after the men had seen the DVD, discussed different scenarios and talked together about it, they decided on a word that they would understand that meant the same thing.

> **[**On consent**] Then we worked out that really, a shorter way of saying was that it was basically just to agree [**to take part**]...** Alf

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[4] See the Dictionary of Difficult Words and Jargon "Understanding Research" Student Booklet (see Appendix 14).

> **INTERVIEWER**
> **And you keep saying you've got to document it. You've got to document it. What does document mean?**
>
> **RESPONDENT**
> **Taking notes.** Keith.

Using pictures to represent a word or phrase helped understanding as long as the same process in relation to recognising the meaning of the picture was undertaken as would be when learning or clarifying the meaning of a word. Once the men had agreed on a definition and an appropriate picture this would become accepted as the most appropriate and was checked by asking what others thought it meant, particularly Ed who was the most helpful in this respect.

Through providing definitions for the Understanding Research Pack the men demonstrated their understanding of these terms and the explanations in the pack were those of people with learning disabilities, not the facilitators.

7.2.7 Summary

By the end of the study the men had a greater idea of

- What research is
- The meaning of consent and confidentiality
- Essential questions to ask before consenting
- How to say no to research and some implications of saying no
- What makes research ethical
- Definitions of complex words and jargon associated with research

Most men could articulate this learning in discussion and offer their own stories that illustrated that learning. The process of doing this research raised issues about how ability to consent is decided. All the men in this research were deemed able to consent at the beginning of the project but it was clear that many of them had little understanding about what being a participant might entail. At the end of the research at least one man was still not able understand the notion of research and the nature of the decisions that need to be made when considering participation.

7.3 What enabled the men to learn and understand?

A key aim of this study was to identify how people with learning disabilities can learn more about research and what helped them to do this. The workshops were therefore designed to provide a variety of learning opportunities and to capture what had proved most effective. In their initial interviews, and at the staff training day, the staff were asked what they thought would help the men learn. Their answers are depicted in Figure 2 below.

General Enablers	Enablers for the Facilitators	Enablers for the Staff	Enablers for the Men
• Working as equals • Listening • Communication skills • Not using jargon • Joint decision making • Negotiation skills • Protocols • Assertiveness	• Appropriate expectations • Being flexible • Assessing Risk • Workshop Discipline • Adherence to Security issues	• Communication skills • Existing relationships with the men	• Positive relationships • Mix of participants • Ambience • Rewards • Relevant experience • Level of Organisation

Figure 2: What the staff thought would enable the men to learn

Data, collected throughout the project, demonstrated not only what the men had learnt, but what had helped them to learn. Figure 3 below is based on the evaluation sheets completed at the end of each workshop. It shows the average scores across all workshops for the activities/factors that the participants reported helped them learn.

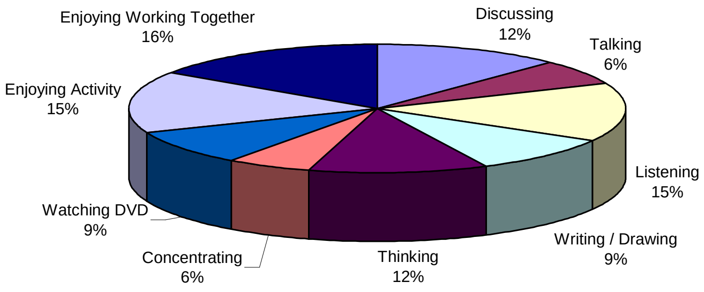


Figure 3: All Factors contributing to participants' learning throughout the workshops

Thinking, listening, discussing and enjoying working collaboratively contributed to 70% of the factors reported.

7.3.1 Enjoyment

> **And I've just had a laugh with it. I've learnt new things.** David**.**

A key message was that you learn best when you are having fun. The men reported having fun in the project and that this had helped them to learn. Their learning took place because they were interested and enthusiastic. They enjoyed taking part in group discussions, learning from each other in a relaxed atmosphere.

> **The most fun was trying to put the pieces together to start off with, I think. The sitting and actually working together. Working as a team getting on with people. Getting on and having a laugh during break times. And having a joke on.** Keith**.**
>
> **Humour. He's very humorous is Ed. He brought humour to the group. Which they needed because… You didn't want too much of "Right, we're going to do consent. We're going to do ethics. We're going to do…" So it was a mix. He joined the mix.** Staff 2.

The design of the workshops to include discussions, different activities, refreshments and to take place in a relaxed atmosphere where the participants felt at ease to speak freely contributed to the enjoyment. Even those who found it more difficult to understand enjoyed the learning.

> **And I think even just the taking part – I mean, some got more out of it than others with regards to what research is. But I still think the actual sessions and that were enjoyable for the patients [**the men**].** Staff 1.

7.3.2 Intellectual stimulation

Most men reported enjoying the learning process itself. They found this project stimulating in a way that other, similar intellectual tasks they had been given had not been. One reason they offered for this was that other group work they had taken part in had been generally related to their treatment or their offences. This was nothing to do with why they were residing in the MSU, their histories or their personal lives. They saw learning for its own sake as a welcome change.

> **Because I just love information. I just love having information and coming up with new things for it. Just love it. And doing this course meant that a) I've been able to study and try and go for a qualification and b) I've got my little drug going where I've had all the discussion and everything going. And information going and flying all over the place. And it's just like, Yessss!... Aye. I just love learning.** David

7.3.3 Collaboration and multiple perspectives

Collaborative research was chosen as a way of gathering and using multiple perspectives to enable all participants' views to be valued. Figure 4 shows what the staff anticipated collaboration might mean for the men and for themselves.

Notions of Collaboration for the Staff	Notions of Collaboration for the Men
Make staff more interested in research. Improve communication and mixing between units. Relationships between staff and the men may improve. Collaboration is positive because: • everyone is included and asked for their opinion. • It will be good to work with the men on something different. • Team work is important for collaboration; everyone moving in the same direction.	Improve communication. • Enhancing therapeutic relationship. • Relationships as everyone gets to know each other better. Collaboration is positive because: • Staff help to empower the men. • It has worked in the past. • It will make the men feel proud and having an outcome will also. • The men like to work with staff, that is something they enjoy. • It will give the men a sense of achievement.

Figure 4: Notions of Collaboration (data from staff session prior to workshops)

The process of collaboration was identified as being significant in developing understandings about research. **Figure 5** shows the importance of collaborative contributions such as asking questions, discussing and listening.

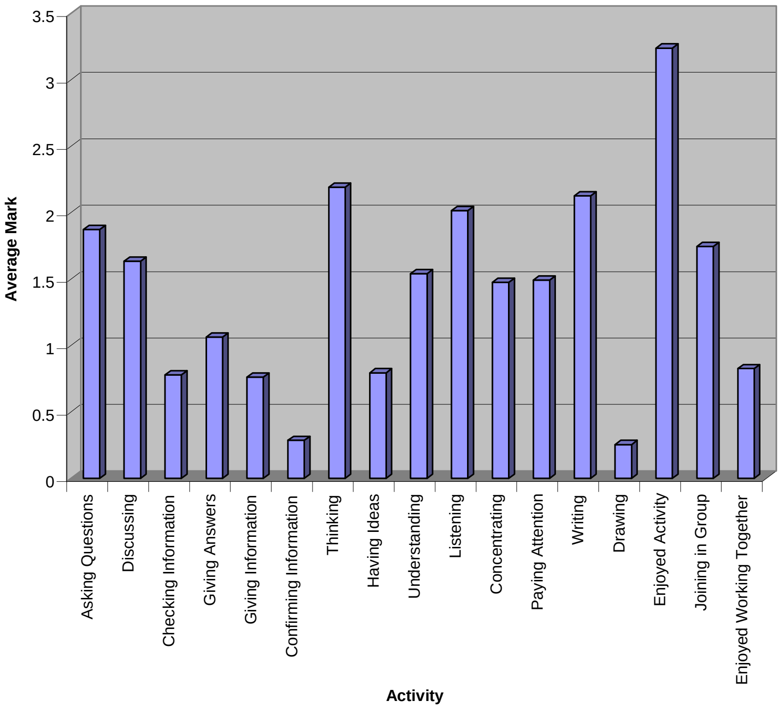


Figure 5: Activities the participants contributed to across all workshops

Figure 6 shows a rise in scores given by the participants in the latter workshops in relation to activities related to collaborative learning. It demonstrates how the importance of collaborative contributions developed over time. In the evaluation sheets collected after workshop one, enjoying working together was given the lowest score, it was approximately midway in workshop 3, and became the highest in workshop 6. This, perhaps, indicates group dynamics and enjoyment improving as the group settled into working together as a team.

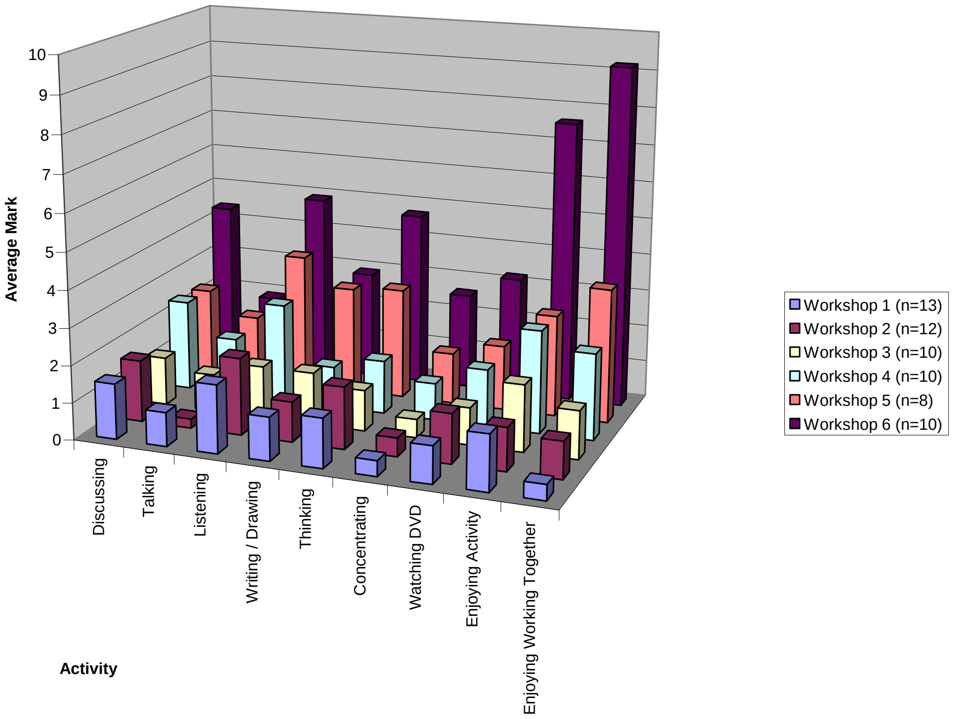


Figure 6: Workshop by workshop breakdown of factors contributing to learning over time

Being able to discuss and talk through issues amongst the group was identified has having contributed to learning, understanding, enjoyment and relationship building. Working collaboratively allowed multiple voices to be heard and valued. It offered participants opportunities to contribute at a number of points and levels. Discussion was characterised as ‘better’ when it was with a number of different people as these people may be able to help in different ways. Collaboration was identified as a key element in supporting understanding.

> **What helped you learn the most?**
>
> **RESPONDENT**
> **Being with everybody. Putting it together. Like, hearing it from what other people have to say on their points of views on it. Because there was different views from what everybody was saying. Not everybody was equally the same. So that was fun.** Alf.

Being given the opportunity to hear multiple perspectives on research helped participants come to their own conclusions.

> **The more things just got blown into the air, the more fun it was because it allowed you take all these building blocks that were just all over the place and you build yourself your own little wall of your own idea and it became your personal goal. Your personal project.** David.

Different and multiple perspectives were used as a springboard for discussion and the assimilation of knowledge. It enabled further reflection and critique to develop ideas and knowledge and answer complex questions, many of which, in later workshops, were set by the men themselves.

> **When we were discussing and debating stuff, during some of the discussion that we had your mind slipped a few times before it settled. It's like you started it off and someone would say something. And it would be like, "Erm, I'm not quite sure of…" And also then it started a bit of a debate up. And then by the time you finished the debate you had most of the answers and then it was like, "Eh, you know, we've just answered it."** David.

There were different dimensions to the collaboration. The researchers, working as facilitators, were instigators of discussions and supported the ongoing nature of that discussion. Whilst initially the men relied on the facilitators for this, the nature of the collaboration altered over time. In the later sessions the men were tabling their own issues for discussion based on their thinking between the workshops. The discussions the men valued most were between themselves as men with learning disabilities.

> **Keith has always been very positive about the benefits of working in a group. Today he said that although he appreciated my contribution he thought the way they all learnt best was when they discussed it amongst themselves. The reason he gave for this, that he said quite proudly, was that they had learning disabilities and I hadn't. I wasn't in the club!** Researcher field notes/diary.

Not all of the men's voices were heard in equal measure. Some were more ready than others to give their opinions, whilst some preferred to think for a while before speaking. Those who took more time to contribute verbally tended to contribute in different ways but often being recognised by the more vocal participants as a spur to understanding.

> **I noticed today how the men are really valuing each other's contributions. In particular, Peter said something that stopped David in his tracks. He [**David**] then acknowledged what Peter had said, and that he had not thought of that himself. He thanked Peter. It made me reflect on other times when this has happened and realise that they are really listening so closely to each other, listening to what they say about research and getting the meaning of what is being said. They are so keen to understand more.**
> Researcher - Diary/fieldnotes

As there was a range of ability levels some men understood more than others, but all men learnt something about research from participating in this way.

7.3.4 Repetition and recursiveness

The DVD which was specially designed to promote discussion of difficult to understand and abstract concepts was used at the beginning of each workshop and proved popular amongst the men. At the start of the first workshop a scene from the DVD was played to the group. At the start of the second workshop, the first and the second scene were played. This continued cumulatively throughout the workshops. The playing and replaying of the DVD offered the chance for the men to learn, understand and consolidate their learning.

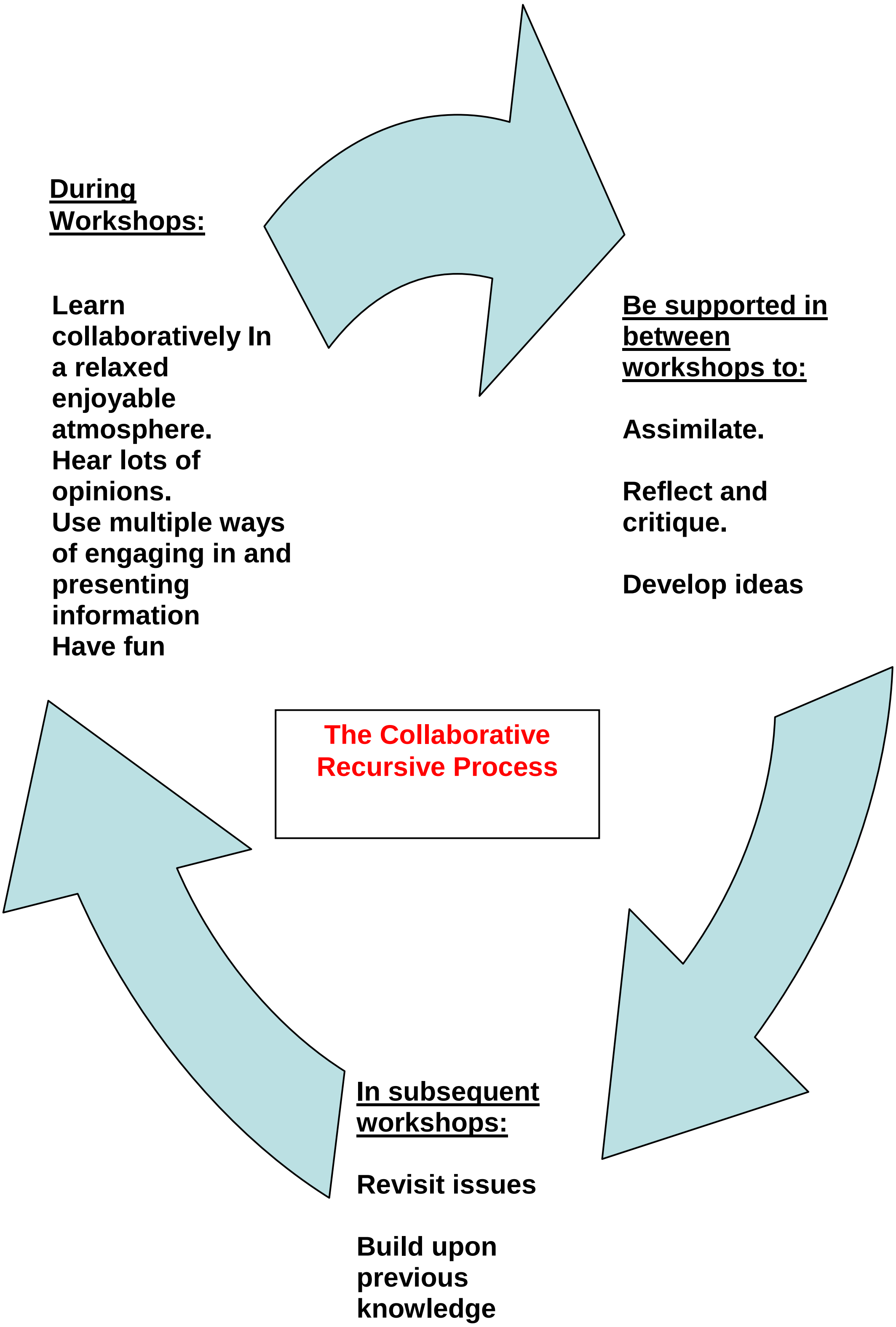
> **In week three I noticed that there was a ripple of laughter about the joke in scene one [**of the DVD**]. They did not laugh when they saw it on week one. It has taken seeing it three times before they got the joke – before they understood. Glad the men asked to see all the scenes each week. If we had done it our way [**each week only showing the scene relevant to the workshop materials**] they would not have got it.** Researcher, field notes/diary

When grappling with difficult concepts the men often referred back to the scenes on the DVD. They reported that the visual and repetitive nature of DVD use had been important in helping them understand about research and that they enjoyed it. The men felt that a similar DVD should be used in information to help others learn about research, consent and ethics.

When they had been invited to participate in this research they had received a CD of the information sheet. Being able to listen to that when they wanted and in their own time was reported as important to enabling understanding.

Repetitiveness in itself was not sufficient for learning. It was not merely repetition, although repetition helped, it was revisiting the same topic in a new way. The discussions and different forms of presentation provided a recursive framework that enabled the men to keep returning to a topic, reframe understandings and explore it in more depth.

> **Because there was so much information to go through and so many angles and so much to discuss and talk about and come up with ideas for and think about. And you came to points where you were having to go away one week, come back next week and just a bit more information and then go away again. And by the time you had finished it you had, like, a mile long list. And it was just incredible. And I did it and enjoyed it so much…** David



During Workshops:

Learn collaboratively In a relaxed enjoyable atmosphere.
Hear lots of opinions.
Use multiple ways of engaging in and presenting information
Have fun

Be supported in between workshops to:

Assimilate.

Reflect and critique.

Develop ideas

The Collaborative Recursive Process

In subsequent workshops:

Revisit issues

Build upon previous knowledge

Figure 7: The Collaborative Recursive Process

The longitudinal nature of the project was important to understanding. It allowed time for repetition, recursive discussion and a variety of ways of presenting materials.

> **If people with learning difficulties were involved in this project, as a researcher, more time is needed to develop their skills even more as a researcher.** Peter – Diary.

Thinking about what had helped him learn, Alf wrote in his diary

> **That it was over 6 weeks and then had time to think about it after the 6 sessions**
> **Liked repetition**
> **Being in a group…**
> **Jotting it down at the time and reading about it later helped me to go over it…I can look at it and think about it every day.** Alf – Diary.

7.3.5 Different and special

The participants reported that the project offered them something different, a break from routine which was different to other work schedules or other courses they have taken part in. They were keen to participate and they felt that it was their choice.

> **Because I've never done something where they call you out before – research and what have you. And it was just a good experience to get in on it. And take part in a group session. Where we were all talking about stuff and what have you.** Peter.

Both staff and the men referred to the project as being something out of the ordinary. It was something which they would not normally have the chance to be involved in.

> **It's very rare there's courses for them [**the men**] to write down and they gain something… But to have a special booklet that's all about them, really, about research for learning disability wise, I think it's been good for them...** Staff 5.

The men really recognised this as their own project and that it was something to be proud of. They were all researchers and enjoyed bringing their ideas to the workshops and shaping the development of the project.

> **They seem to get enthusiastic about it because they're doing proper work.** Staff 3.

> **I just think it's very, very important. I think it's really giving them a chance to show they can actually do something. That they can actually have a booklet, especially on a unit like this when they're in a secure environment.** Staff 5.

> **I think they were made to feel involved. They were made to feel like it was a special group and it was just them.** Staff 1

The men who became students of the University were required to complete a portfolio of learning to gain their accreditation. Their work was also linked to teaching at the University and the initial stages were presented at a conference in America on their behalf. They were very proud of these achievements.

> **It has helped people at [**local**] university to understand has** [how] **we learn about research and this has been talked about at a conference in America the department of health has been to hear about our research**. Alf – Diary

The men who participated enjoyed more positive 1:1 attention from the staff, both during and in between the workshops when the staff worked with them on the wards. This was reported by both men and staff as a benefit of participating in the research.

7.3.6 Helping others to understand

The facilitators had outlined a framework for the development of this study with specific topic areas planned for each workshop session, and by session three the men had already begun to bring their ideas to the group. A number of men tabled issues they wanted to discuss and suggested ways of making that discussion valuable and appropriate. They had very good ideas about how to help someone understand the information needed to make an informed choice about consenting to research. The facilitators had neither asked nor expected the men to take on this level of involvement. Alongside plans made between workshops some of the men recognised that others in the group needed more help during the workshop and spontaneously changed the material to help them.

> **Like I say, there was a lot of group work – in which everybody helped each other. And I think the lads [**the men**] that didn't quite understand - it was explained by the brighter lads.** Staff 3.
>
> **David's understanding of the material was seemingly greater than that of Peter, but he was able to… kind of coach, if you like, and assist him to develop his own answers.** Staff 6.

The 'coaching' provided by the men was captured in the recording of the workshops. The words and ideas they used to aid understanding formed the basis of the Understanding Research Pack. The pack is, therefore, directly linked to the ways in which people with learning disabilities both understand the notion of research and successfully explain it to others with learning disability. It is from their perspective as people with learning disabilities, not the facilitators.

Helping others to understand was recognised as a way of developing your own understanding.

> **Today David said how when tried to explain something to the other men it helped him understand what he was thinking better and sometimes he realised that there were other things he had not thought of and so telling others helped him. He was very excited by this revelation.** Researcher, diary/fieldnotes

The experience of recognising that explaining to others had an important affect on your own abilities was an incredibly powerful revelation for three of the men, all of whom began to discuss how they envisaged their own role in the Understanding Research materials, not merely as developers of the materials, but also as facilitators of the workshops.

7.3.7 The pictures

Pictures were used in the information given to the men and at all the workshops. This is a common way of aiding understanding. However, pictures, like words, can be subject to illusory consensus (Edelman,1964). That is, people think they understand what a picture means and that others will have attributed the same meaning to it, but each may be reading it differently and so, ultimately, would act on it differently. To avoid this difficulty, pictures that were to be used as visual clues were discussed and chosen on the basis of their representational fit and agreed meaning. The meaning was then noted and a dictionary of pictures was developed alongside the Dictionary of Difficult Words and Jargon. Pictures without a discussion of the meaning would not be useful.

> **By giving us pictures and what have you. To learn about more stuff… Because without pictures you wouldn't know what it means, like….. Because without them you wouldn't remember what you've done.** Peter

Pictures needed to be clear and relatively unambiguous. The men used the following criteria to decide whether pictures were appropriate:

- What they believed it represented and why
- How suitable it would be for adults
- Its aesthetic value

They were an aide memoir rather than a substitute for discussion.

When preparing their flip chart feedback at the end of each workshop the men used pictures chosen from a range of pictures the facilitators had provided. As the weeks progressed, some pictures were never used and others consistently chosen. The pictures that were consistently chosen were considered to be the most representative by the men. Towards the end of the project the men who had found it more difficult to understand the concept of research were seen by the other men as '*important test pilots*' for checking which pictures were the easiest to understand and therefore the best ones to use.

7.3.8 Support between workshops to help the men learn

From the Staff

The staff spent time between the workshops working with the men to explain, remind and clarify issues which had been discussed during the workshops. This included:

- Discussing and exploring issues
- Answering questions and clarifying issues
- Enabling access to information, in particular to the internet
- Listening to what the men wanted to say
- Helping the men to record their thoughts and information
- Re-visiting what had happened in the workshops

> **For myself, listening to them, what they'd done on the sessions when I was absent…. possibly helped them by allowing them to explain to me what they'd been doing. Maybe clarifying in their own mind what they'd been doing. Typing various things for them, in their files. They wanted help with spelling and grammar and things so typing it up. Sending letters off to the ethics committee….Explaining different things - words that they weren't too sure with. For all, in the main, they were pretty clear on what they were supposed to be doing for their homework or whatever…I think sometimes they wanted me to read things that yourself or [**researcher name**] wrote, to explain what it was that they had to do on the ward.** Staff member during Focus Group.

The gap between the workshops (originally intended to be one week but often longer due to issues within the hospital setting) was too long for the men to wait for questions to be asked and discussions to be continued. The staff were crucial to supporting learning and preventing frustration due to lack of opportunities to develop thoughts and ideas.

From each other

The men also benefited from being supported by other men and by offering support in turn. Explaining issues to others who did not understand was an important way of learning and demonstrating what had been learnt.

> **Some struggled, some seemed to grasp it quicker than others. And I think there was times where the ones who grasped it quicker were trying to help the ones who weren't... That's probably the best way of getting it across – peer helping peer, as opposed to staff all the time, sort of helping. Which was nice.** Staff 1.

> **It was also important that support was something we all gave. It wasn't just supporters helping out researchers with learning difficulties we all helped each other. It was a two-way thing.** Keith – Diary.

7.3.9 Summary

The following elements enabled the men to learn more about research and consent to participation:

- The sessions were fun, enjoyable and there was lots of enthusiasm, particularly their own.
- They sessions were intellectually stimulating
- The nature of the learning environment
  - Collaborative engagement with multiple perspectives
  - Multiple ways of presenting information
  - Opportunities for discussion
- Knowing their work was valued beyond the MSU
- Engaging in something different from their every day tasks
- Extra positive attention from the staff
- Support from staff during and between workshops

7.4 Benefits from participating in research

7.4.1 For the Men

Confidence

The men gained confidence due to their involvement in the project, particularly during the workshops. Their confidence was evident in the way in which they spoke about their contribution to the project and how they evaluated their own contributions. Most men recognised that their contribution was unique because of their learning disability and not despite it. Having a learning disability put them at an advantage here, as they were the experts.

> **We all worked together as equals…This is important because for many years researchers was done by people who had lots of power to say what life experiences they were researching about….And their researchers were called "experts" and they made their careers by researching people who were called "subjects".** Keith – Diary.

> **It's really giving them a chance to show they can actually do something. That they can actually have a booklet – especially on a unit like this when they're in a secure environment….Like in going away to the conference, how excited they were to speak in front of people. And when they came back [**and said**] "I've been talking to these people, these people." And it was lovely, really… And you think, "Eee, good for you", because I couldn't have done it.** Staff 5.

Self Esteem

A new level of competence in the men was identified; this helped raise self esteem.

> **In a way, because they [**the men**] attended more sessions [**workshops**] and their knowledge was greater of the work that**

> **they'd been doing than my own – a bit of role reversal as well… [**as the men began to explain to the staff what was going on in the study**] …In knowing that's part of my job to raise self esteem of those that have low self esteem. And if it's come through this way of doing it, then that's great.** Staff 6.

Being given attention for their ability rather than because of a difficulty or problem raised self esteem. Pride in participating and presenting at a conference was evident from the way the men discussed their involvement. Staff and facilitators were also proud of the men and they were aware of this.

> **Keith got a feeling of – from my point of view – he got a feeling of worth. He really enjoyed it… If he thinks back, if he wanted to think back, his self esteem and just courage for doing it [**speaking at a public conference**] went through the roof.** Staff 2.

Being involved with the University was an important element for the men.

> **And the incentive of being involved with the university, I think, was fantastic for their self esteem.** Staff 6.

Staff noted that enrolling as a University student, working towards receiving credits for their work and, for some, visiting the University, provided the men with tangible evidence of their abilities and engendered a sense of self-worth.

> **Raising self esteem on this particular unit is a difficult thing to do. It's not always easy... Because of the access to integrate the men into the community is not always easy because of the restriction of the risk they pose to others. Whereas this [**the study**] – I think they felt part of the community because they were linked to the University. I think that's helped. And I mean, had [**the researchers**] not come in, on this particular unit, I don't envisage someone visiting the University with escort of staff. I don't see that happening. With the restraints and the risk they pose.** Staff 6.

The men's notes in their diaries suggested how important it was to them

> **Thank you for letting me do research. It has improved my thinking and understanding and using wards like**
>
> 1. **methard**
> 2. **understanding**
> 3. **consent**
> 4. **Able to show that I also can do research and that to me is importand** Peter- Diary

Enthusiasm

The level of enthusiasm for this project was a key driver of the high level of input from the men and what they achieved through their efforts. The enthusiasm was not merely confined to those men who grasped the subject matter and went on to gain accreditation, but the staff also recognised it in all the men.

> **….people have to have a chance and they have to be given an opportunity to learn something. And to gain some knowledge. Which all of them, even Ed. Even if he's learnt one thing, you know, at least he's learnt something and he's taken time to come up here. And he's never ever refused to come up here. And, like, all the other lads have really never refused to come up here. So I think there should be more courses like this... I think they show an enthusiasm, really, that I've never really seen patients [**the men**] do.** Staff 5.

Staff thought the real involvement of the men in the project was one of the most positive things about the project.

> **...the involvement of the clients, that would be the most positive thing for me personally.** Staff 3.

Skills
Participants acquired skills throughout the study, such as listening skills, reading and writing skills, social skills and relationship skills. Talking about what he felt he had developed whilst doing the research, David identified how, as a participant he had had to improve skills an area he considered to be a particular weakness of his

> **My skills [**that I have had to improve**] would have to be listening. And I'm not a very good listener; I've got to admit… If I had to be at the end of a [**continuum**] for instance it would have to be the discussion and debating bit. And the listening bit would sort of be out of the window somewhere.** David.

A member of staff described how one man, who had initially felt unable to verbally contribute to the workshops, had begun to develop his skill in this area. This development was also noted and reported by other members of the group, including the men.

> **He was wary in the beginning… But later he would come up with things… Would say things. And he would join in the group. And he wouldn't just say something irrelevant. He would put a good point of view across. Because he had thought about it. He was sitting back thinking of something, and then he would put something in. So he got a lot out, from my point of view, anyway.** Staff 2.

Participating in this research revealed unexpected abilities. Staff were surprised at how much the men had achieved, especially in the area of conceptualising issues. They were impressed with what the men and accomplished.

> **At least you know that the research, the booklet, and especially the lads the actual lads [**the men**] who you've worked with have done it, really. I would say the staff has had a minimal part of this booklet, really. I think the patients [**the men**] have… They've done it. Really. It's their booklet.** Staff 1.
>
> **Like, I knew because I've worked on [**unit name**] before [**with**] David… And really he's understood a lot more than what I thought he would, really. You know, and… You think that they have like a less of… An understanding, really. But they haven't. To me, like… They've shown abilities that I didn't think they would be able to do. You know?** Staff 5

At the end of the project, when the facilitators were interviewed by the men, the pre-determined outline questions for the interview were used but they had added some questions of their own. One question added was 'Was there anything that surprised you when you did this research?' The facilitator answered:

> **I've always thought people underestimate people's learning abilities. And I've always thought I was pretty good at not doing that. I thought, you know, that I had a good expectation of what you [**the men**] might be able to do. But you exceeded all my expectations. And it made me think that I had underestimated you as well.** Facilitator.

There was evidence from both staff and the men that improvement in certain skills extended beyond the project to other aspects of the men's lives. The men had been telling others about research and consent and used some of what they had learnt in new situations, as Keith explains:-

> **Like things where like where you'll do something and get yourself into… Where it's not acceptable and you'll get deeper in trouble over your trying to do something for that person. And you can't say no. Because that person wants you to do something…**
>
> **INTERVIEWER**
> **What do you think could be done to help them to understand that they could say no?**
>
> **Get them to overcome their fears. That it's easy to say no... By sitting down with them and role playing through with them. Or sit down with a magazine or a book or something and, you know with pictures in. And show them that way.** Keith.

Staff members suggested that the project is likely to have effects beyond its own lifetime.

> **I think the strange thing is [**this man**] is probably more like to get more benefit from it when it's finished… He's always going to**

> **need lots and lots of help. But he's the sort of man who wouldn't ask for a lot of help... You would have to see that he needed the help. And you would offer the help to Ed. Now perhaps with this getting drummed into him, this will do that – he may ask for help himself in certain areas. Which I think would probably benefit him more.** Staff member during focus group

Relationships

The relationships between the staff and the men were an essential part of the project. The staff knew the men well and acknowledged their relationship as important for the study's success. They escorted the men effectively, security was maintained but the different types of support, such as enthusiasm, patience, encouragement and flexibility offered throughout the project helped build mutual regard.

> **After the session [**the staff**] were, like, amazing... Because they gave you little clues and little things that you didn't think of before. And when you were building your file it came in handy. Because they also gave you words that you wouldn't think of using… And when you actually thought about it they meant the same thing. So in the actual discussion [**in the workshops**] they didn't really play much of a part, but afterwards they were just phenomenal.** David.

7.4.2. For the staff

Job satisfaction

This project offered opportunities for 1:1 time that is not always available to the staff to work with the men during the week. Some of the staff commented that they do not often get the chance to work with individuals in such a positive way, particularly as the men who participated had more stable mental health and behaviour than others on the wards, so they might not receive as much attention as someone who required more staff attention.

> **It was nice to come with Ed. Because it's not very often that you're one to one with people.** Staff 5.

Time spent away from the busy ward and outside of usual routines was a welcome change for staff. They also enjoyed meeting other men and staff who they would not commonly meet as they worked on different units. It was pleasurable to participate in something that would benefit others and that they would not normally have the opportunity to participate in. This study had enabled them to carry out certain roles and responsibilities in a different way.

> **Well I think it's nicer working, rather than when you're in the confines of the ward and you're doing about 20 different tasks at once – answering phones etc. You can only sometimes spare, you know, a two minute answer to one patient, a two minute answer to the other. It's nice when you've got a little bit more quality time to spend with, say, one patient. I felt, you know, you get a lot more rapport and things. That's what I enjoyed.** Staff 1.

The staff reported feeling pleasure from seeing the men develop skills and self esteem during their participation in the project and watching the men enjoy the research. They gained satisfaction from watching the men have and use the opportunity to engage with this work in such a positive way.

> **I got a lot of satisfaction working with the lads... Because they were really interested in it [**the study**]. And they wanted to learn about research. So it was a good thing, I think. They really looked forward to the sessions and everything... Why was it so rewarding to me? Because they were doing something that they enjoyed.** Staff 3.

The staff reported feeling that their relationship with the men, particularly the therapeutic relationship, had improved because of the extra time that they spent with them individually.

> **…if the clients feel empowered by being involved in it and they see me as being involved perhaps that'll enhance my therapeutic relationship with the clients, as me as someone who as helped to empower them... Being able to spend time with the lads. Form greater relationships because of them… Typically you can be prescriptive as opposed to facilitating. There was definitely a "working with" feel to the work that we did – as opposed to the staff were running a session that they had to participate in – kind of a feel.** Staff 6

Most staff reported enjoying the role reversal that this study sometimes offered the men. If they had missed a workshop it was an opportunity for the men to teach the staff what they had missed.

Self development

The staff had given an enormous amount of support to enable the workshops to go ahead and in preparing the men for the workshops. When it came to collaborative discussion, however, many of the staff did not join in. Reasons given for this were that they felt their contribution was to remain in supportive roles for the men believing if they had engaged as learners, this may have meant the men would feel less able to join in discussions. They thought it might have been hard for the men to disagree with staff upon whom they relied. There were, therefore, mixed reports from the staff about how much they had learned about research from their participation in the project with some saying that they had not learned anything more about research than they already knew. The small number of staff who engaged with the substantive discussions in the workshops reported that they had developed their own knowledge about research through that experience and were positive about their own contribution to the work.

> **Well I think it was nice to mix and to get off the ward. You know? And there is going to be a booklet – great. You think, "Crumbs, I've had a bit of input in getting this booklet sorted." You know? I**

> **think it gives you a bit acknowledgement because the staff up here – from my point of view – don't get to do a lot… It's very limited for what courses we do. It's the basic, mandatory training and all that. And so when a course comes along like this it's really – it makes you think that you're actually doing something for a change, you know? There's something at the end of it... Have a little bit of say in the research – you know?** Staff 5.

There was no evidence from the workshops that engagement in debate inhibited the men.

All staff were offered University accreditation but did not take it up.

7.4.3 Summary

Participants suggested that this type of collaborative research, with a practical focus, resulted in the following personal benefits:-.

- A sense of achievement and worth
- Raised confidence and self esteem
- Feelings of being valued both within the Trust and beyond
- Skill development
- Opportunities to enjoy positive relationships
- Enjoyment
- University accreditation (by choice)

Figure 8 shows the benefits involving participants as researchers in this study.

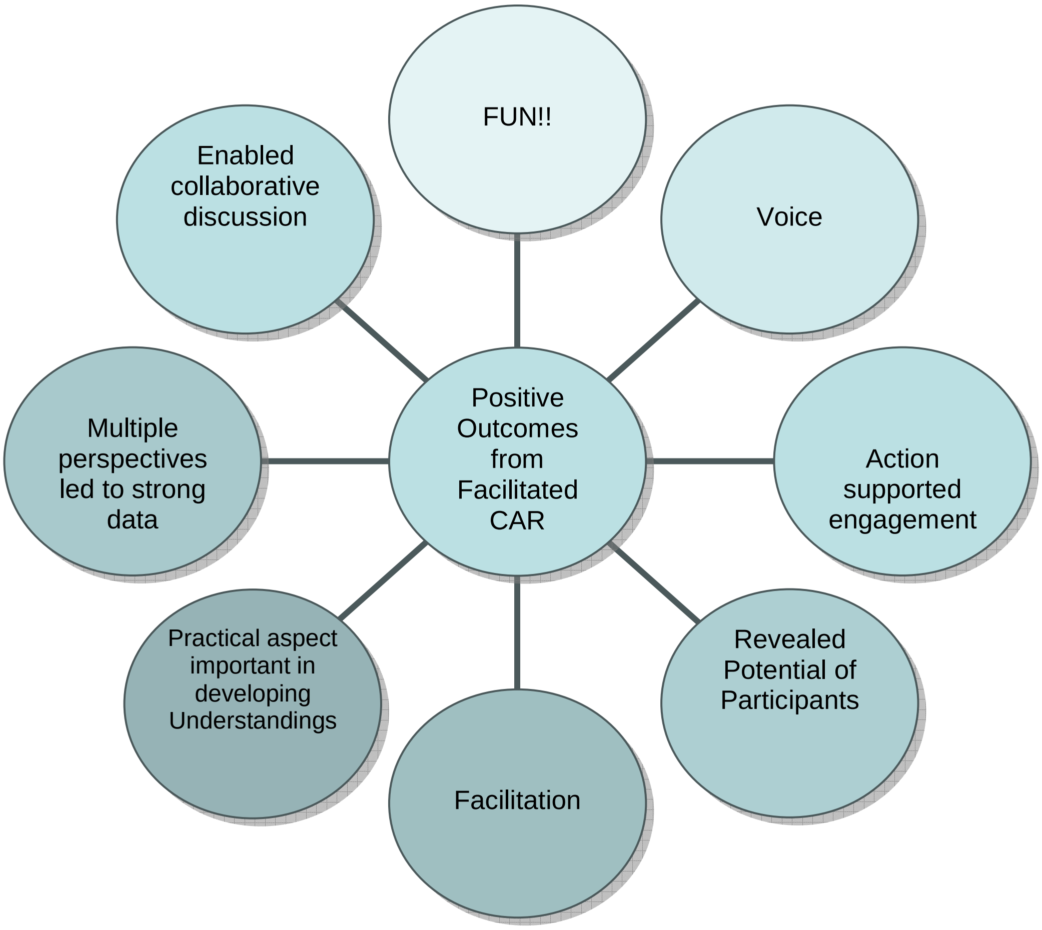

FUN!!
Enabled collaborative discussion
Voice
Positive Outcomes from Facilitated CAR
Multiple perspectives led to strong data
Action supported engagement
Practical aspect important in developing Understandings
Revealed Potential of Participants
Facilitation

Figure 8: Positive outcomes from using FCAR in this study

7.4.4 The benefits of collaborative research for the robustness of the research

Working with the staff, the men and the facilitators as participants brought together different perspectives and enabled the discursive process. Engaging participants in the data analysis through the regular evaluation process at the end of each workshop and returning to key themes at the next workshop for consideration offered triangulation of data and new themes to form.

The practical aspect of the research, developing the "Understanding Research" Pack, was another key element of data collection and analysis. Each word, concept or piece of knowledge was subjected to collected critique before it was considered acceptable for the pack. It involved conversations about what should be in the pack and what the rationale for inclusion was. Working together to critique, to decide what was necessary information, what should count as evidence and who decides was not left to one set of researchers, but agreed throughout the research. This strengthened the validity of the data and contributed to the process of data analysis.

Without the authentic participation of people with learning disabilities, the research would have lacked its most valuable dimension

> **The fact that you want us to explain it to people with learning difficulties…It's no good putting a group of people into a room that have not got learning difficulties because you can't be certain**

> **that by the time that you came up with your booklet that you're going to give it to a person with learning disabilities… [**they'll say**] "Oh, that's very good, that" but they'll probably not even understand it… This is how it is… Without us [**the men**] it would have been a waste of time doing it because by the time you've finished it you would have got to the point where you showed it to, like, 100 people with learning difficulties and they all went "Eh?"** David.

8. Outputs

Two outputs were produced from the findings of this research. The first is the "Understanding Research" Pack, for use by and with people with learning disabilities who need to learn more about participating in research (Appendix 1). It can be used by researchers to support understandings to gain informed consent or as a stand alone pack for people with learning disabilities to work together and learn about research and the issues involved in relation to consenting to research. The second output is a set of suggested principles for researchers to use when wanting to ensure that people with learning disabilities have understood the nature of the research process and are able to give informed consent. The principles could be used with either the whole of, or an element of, the "Understanding Research" Pack.

8.1 The "Understanding Research" pack

The participants in this research study developed the "Understanding Research" Pack as a way of clarifying their own learning and understanding and to help other people being asked to take part in research to learn about research and understand what taking part might mean. The design of the pack is based on the findings from this research that one type of information event for consent is unlikely to be enough. It is an outline of a set of facilitated workshops which can be delivered over time. It includes:

- A facilitator's booklet and a student booklet written in accessible format to enable people with learning difficulties to both participate and ultimately facilitate the framework.
- A participants booklet.
- Exercises to explain and aid discussion.
- A voice over CD.
- A DVD of research scenarios as a basis for discussion.
- A Dictionary of Terms.
- A Dictionary of Pictures.

Each workshop has exercises and activities to explain difficult concepts and aid discussion. It has a voiceover CD to help people to read and revisit the booklet, a DVD of scenes about research issues to aid discussion and examine difficult to understand concepts and a dictionary of terms and picture dictionary to aid clarity.

It can be used as a whole package or dipped into as appropriate.

8.2 Suggested principles for other researchers wishing to work with people with learning disabilities

Drawing on the findings from this study, the following are offered as a set of suggested principles for researchers to use when working with people with learning disabilities.

a. **There should be a presumption of capacity.** Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. This is a key principle of the Mental Capacity Act 2005

b. **It is the researchers' job to enable the prospective participant to understand the nature of the research.** There is a difference between delivering information and enabling understanding. Understanding is determined at a personal level and is a negotiated event between at least two parties.

c. **Informing is not about making things simple but making them understandable.** This offers the greatest opportunities for the person to consent based on understandings. Learning about research needs to include discussion, role play, activities in small groups and, importantly, having fun. Presenting information in an accessible way does not mean merely changing words and adding pictures to predetermined templates

d. **Multiple ways of engaging in and presenting information helps the development of understanding**. People learn best when engaged in a way that suits their own learning styles.

e. **Collaborative opportunities support learning**. Listening to others and working together to build understandings offers a strong basis for learning. Working with people at a similar level allows participants to enjoy finding out and make discoveries together. The practice of one participant explaining their understandings to another facilitates the learning of both participants in the exchange. Discussing, listening and enjoying activities, presented in a variety of ways, especially with peers, provides opportunities for developing conversations and has a significant impact on learning

f. **Informing people about research is a process not a one off event.** Whether researchers develop an information sheet or use several ways to give information, it is unlikely that this will enable people with learning disability to make an informed decision to consent if it is delivered in a single event. A repetitive and recursive process supports learning and understanding. A recursive process allows time to contemplate what has been said and learned and to return to the subject, discuss further, ask questions and build upon that knowledge – to learn in graded steps. The time between information events is important for assimilating and engaging with information.

g. **Participants need a knowledge base prior to consent.** It is customary when delivering information to participants about research, to offer them the opportunity to ask questions. The asking of questions is thought to offer the chance to clarify areas participants might not have understood. In order to ask a question you have to have a basic knowledge of the subject. If prospective participants have no knowledge of research, its form and implications, they will have difficulty asking useful and appropriate questions. For people to know which questions to ask in order to make an informed decision, they have to know about and understand research and the concept of consenting to research.

h. **Peer support is important**. It increases confidence and helps people feel more at ease. It supports conversations and aids learning through repeated clarifications and discussion. It supports the appropriate level of conversations and allows people to discuss and clarify at their own pace and level, rather than that of external researchers.

i. **Engaging "significant others" is helpful.** If the people who work/live with the participant are knowledgeable, they increase the participants' opportunities to develop understandings and make the time between information events a positive learning time. This means that they will need information about the research too, even if they are not going to participate. The researcher needs to build relationships with those who can support the participant in the research.

j. **Relationships are important.** The prospective research participant needs to feel at ease and trust the researcher. It is the researcher's responsibility to engender an enabling milieu.

k. **Time and funding will be required** People with learning disabilities need longer time scales in which to understand about the research they are consenting to. A flexible approach to information events is important. The elongated time scale and the need for changes to both approach and timescale have resource implications and affect project planning. Allowing for this at the planning stage of research is fundamental to its success. Explaining a research project and taking informed consent is a process. This process cannot be reduced to a set of tasks to be ticked off. It is the researcher's responsibility to ensure that the participants have understood about participating in research, not merely that information has been delivered to them.

l. **Consenting to research is a complex matter.** The men in this study were all deemed to be able to consent to participate by those who are in charge of their treatment and care. Ability to understand about consenting to research however relies on a complex interchange of skills. Even when a person is deemed able to consent to take part in research, they may have difficulties in particular areas of conceptual interpretation which mean they will not be able to understand the complex issues which are required to make an informed decision. There will be people who may not be able to make an informed decision whether to consent to research. There may also be people who could consent if given greater opportunities to develop understandings.

m. **Not everyone may understand the implications of saying no**. People with learning disability need to understand the pros and cons of consenting, and of refusing consent in order to make an informed decision.

9. Dissemination

The findings of the report will be disseminated in the following ways:

9.1 Report back to participants

In this study, the participants have been engaged in the data collection, analysis and framing the key themes for reporting. All participants will receive an accessible version of the executive summary. There will be opportunities to discuss this and talk both with each other and the two facilitators. Those who request it will be able to have a copy of the full report. A number of the men who read are particularly interested in this as they have been taking an Accredited Work Based Course at the Northumbria University based on their work during this research project. Four men have attained 10 credits at level three.

9.2 Report back to Trust

The final report will be presented to the Trust Board; both as a report and verbally, with the men form the research being part of that presentation.

9.3 Conference Presentations

It is important that this research is disseminated widely to variety of audiences:

- the general public including other people with learning difficulties
- research ethics committees
- (NHS and Academic)
- people involved in the care of people with learning difficulties

It is also important that, as collaborative researchers, the men from the MSU have the opportunity to participate in that dissemination if they wish to do so. This has been supported by the Trust and to date, two men jointly presented at a conference on Public Involvement in Research (Gateshead), one man has presented at the 7th International Conference on the Care and Treatment of Offenders with a Learning Disability (Preston), another presented at a conference held by Northumbria University on Inclusive Learning (Newcastle upon Tyne) and a third presented at the Annual Northern Forensic Conference (Newcastle upon Tyne) organised by the host Trust for this research, Northumberland, Tyne and Wear in conjunction with Tees, Esk and Wear Valley Trust.

For a full list of conference presentations to date, please see appendix 18.

9.4 Publications

It is intended to write up this research for academic publications such as Disability and Society, Research Ethics Review and Learning Disability Review.

Working in partnership with the men articles will also be written for INVOLVE and Trust Research News.

10 Summary

Action research has been characterised as

> "…the study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding" (Winter & Munn-Giddings (2001:35).

It identifies issues in practice and has the capacity to develop solutions grounded in the emerging evidence, thus improving practice (Meyer (2000:178) but also including the potential to get

> "sufficiently close to the underlying structure to enable others to see potential similarities with other situations" Winter (2000:1).

This study, in taking this approach, has enabled the researchers to:

> i) identify some of the key processes that enable people with complex learning needs to understand the nature of research, the ethics of research, the possibilities of research, how research findings are used and how to find out about that use.
> ii) evaluate the effect of engaging the participants as active researchers has had on the process of building knowledge and the outputs of the research.
> iii) develop a framework for engaging participants with learning disabilities as active qualitative researchers.

Using "the experience of being committed to trying to improve some practical aspect of a real situation as a means for developing our understanding of it" (Winter, 2002:27) offered an approach that enabled researchers to hear the voice of the participants and delve into their understandings. It has enabled researchers to go beyond current thinking and practice and to identify ways of developing understandings that others can use.

In this project, engaging in learning, and articulating that learning, offered clear evidence contributing to the wider knowledge about how researchers can support understanding rather than furnish information in relation to gaining consent. The development of the "Understanding Research" Pack allowed a focus for the work and a practical outcome. It was key to supporting discussion and debate.

Critics of participatory research have argued that such research suffers from researchers becoming too close to the participants to enable a critical evaluation of the data. A counter argument is, however, that without the contribution of those who have learning disabilities, how could we gain the whole picture about what they know, understand, and ways to support learning. Action research enabled the researchers to work together to delve deep into understandings and to tease out the key elements involved in 'informed consent' with people with learning disabilities. It evoked an essence of 'knowing' where multiple perspectives told different stories and supported participant enquiry into what they personally understood by research and consent to research. The use of self-evaluation and self-reflection as critique to put common understandings to the test in a collaborative forum supported the unearthing and then synthesis of complex and varied meanings from a range of perspectives. The multiple perspectives gathered through the discussions and research, plus the varied opportunities for both data collection and analysis, gave strength, meaning and, to borrow a word from a more positivist paradigm, validity to the project. The work has resonance with similar work undertaken by Marra (2004) where the process of building evaluative knowledge was seen to take place only when organisational members reflected on their actions.

This research has challenged some of the existing beliefs about gaining informed consent with the population of research participants, in particular, the practice of simplification of information, the delivery mechanism, the support and the approach to timescales. It has raised the importance of person-centred approaches that are contextually relevant and developmental in that they build on the gradual understanding of people with learning disability rather than imposing predetermined sets of information. The process of undertaking this research has reinforced the difference between delivering information and generating understanding. For informed consent to take place the two must be linked. It has also raised issues about who might be able to consent and the basis for that decision.

This research has demonstrated the ability of people with learning disabilities to address an intellectual challenge. The level of the work undertaken has exceeded all expectations. The support of the staff has been invaluable. This truly has been a team effort and we have all learnt. The lessons we have learned about consenting to research can now be used to educate other adults with learning disability concerning participation in research; this can make a difference to their lives.

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11. Appendices

1. **Blank Workshop Evaluation Sheet**
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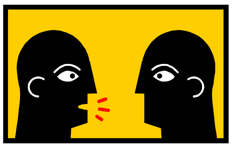
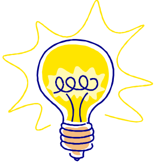
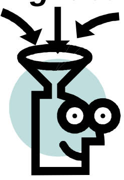
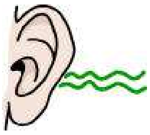
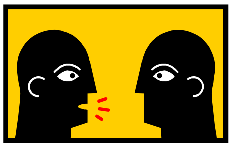
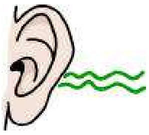
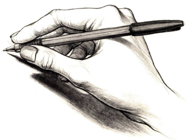
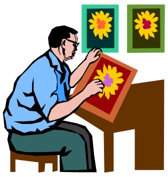
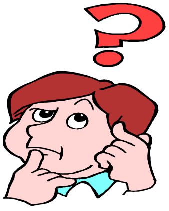
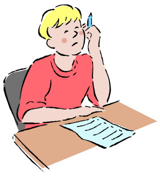
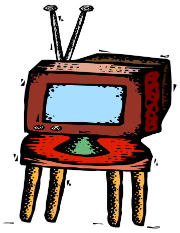
Appendix 1 – Blank Workshop Evaluation Sheet

How did you join in?

Asking questions ***Discussing*** ***Checking information***	***Giving answers*** ***Giving Information***  ***Confirming information***
Thinking  ***Having ideas***  ***Understanding***	***Listening***  ***Concentrating*** ***Paying attention***
Writing ***Drawing*** 	***Enjoyed the activity*** ***Happily joined in the group*** ***Enjoyed working together***

What helped you learn the most?

Discussing ***Talking*** 	***Listening*** 
Writing or drawing  	***Thinking***   ***Concentrating***
Watching the DVD 	***Enjoying the activity*** ***Enjoyed working together***

Appendix 2 – Staff Information Sheet

Version One
December 2004

Information Sheet for Staff

Evaluation of the development of a participant research project in a medium secure unit for offenders with a learning disability

You are invited to take part in this collaborative participatory research project

The aims of the research are:

- To identify the key processes that enable people with complex learning needs to understand:
  - the nature of research;
  - the ethics of research;
  - the possibilities of research;
  - how to make meaning of research:
  - how to use research findings: the possibilities and the limitations and
  - dissemination of research.

- To consider what effect the involvement of people with complex learning needs has had on the research findings and use of those findings

Long term to which this research will contribute:

- Developing a framework for research where by disabled people develop their own focus for research.

- To embed participatory research in planning and development relevant to treatment and care within the Trust.

You are now being invited to take part in the research study. Before you decide to participate in the study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

If you decide to participant in the research your involvement would include:

1. Supporting the men in KDU in the development of the project
2. Collecting information/data during the project provided by the men
3. Where relevant, you would also be the subjects of the research because when we work together we will be finding out what helped you to support the men in their understandings and that will be part of the information that is recorded as data by other research participants.

The work you do will be a public piece of work that will be used to help other people understand research. It is likely that we (Tina Cook, Pamela Inglis and Helen Cording) will also write about the way in which the work was done, how we all worked together and what things have been learnt from it, for professional journals. You may want to participate in this too. We will also run a conference about what has been learnt. This would all be discussed with you if you choose to become part of the project.

The project will last about one year and you would be asked to participate in approximately 10 sessions.

Do I have to take part?

Taking part in the research is entirely voluntary. As explained previously, taking part in the development of the research does not mean you have to take part in the research itself. It is up to you to decide whether or not to take part.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you decide to take part you are still free to withdraw at any time and without giving a reason but we would ask you to think very carefully about this before you agree to take part. It would be most beneficial to the project for participants to engage in all of the work to ensure consistency for the men from KDU. Whilst sometimes things happen which are beyond our control, a commitment to continued participation would be welcomed.

Time line for the research

Date	Participatory Research Programme	Evaluation
December 04	Submission to Northgate and Prudhoe R & D Committee	
January 05	Submission to LREC	
August 05	Recruit Senior Researcher	
Oct 05 – Jan 06	Work with staff involved with KDU and consultants from community to devise appropriate workshop content for developing understandings of participatory research, consent and ethics with patients in KDU Obtain consent to work with project and be part of evaluation from staff	
Feb 06	Establish patient group	
March – July 06	Work with patients on nature of participatory research , ethics and consent. Patient Research	Diary – Journal notes
July – September 06	Produce booklet with patients	
Oct - 06	Final Evaluation	Diary – Journal notes Observations Patient evaluations
Nov 06 – Feb 07	Data Analysis, Report writing and Dissemination	Diary – Journal notes Observations Patient evaluations Patient/staff evaluations Semi structured Interviews Focus groups
March 07	Dissemination Launch Day	

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.'

Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Tape recordings will be made of the meetings and interviews that take place during the research but once these have been transcribed they will be destroyed**.** Any information which leaves the hospital, say in the form of a report, will have your name or other identifying factors removed so that you cannot be recognised from it.

As you will also be a researcher in this study you should always bear in mind that you, as the researcher, are responsible for ensuring that when collecting or using data, you are not contravening the legal or regulatory requirements in any part of the UK.

What will happen to the results of the research study?

Dissemination of ‘booklet’ for patients and research knowledge would be a collaborative decision as to where, when and how (and would have to incorporate the status of patients). Suggestions include holding a stakeholder forum, holding a forum within the KDU, the hospital, N&P Trust wide or with other hospitals and/or organising a conference. If you take part in the project, you would be part of this decision making process.

The project will be written up and submitted to appropriate academic/practitioner journals.

Who is organising and funding the research?

This study is being organised by Northgate and Prudhoe NHS Trust, led by Tina Cook. It is funded by NHS National R&D Programme on Forensic Mental Health: Research Funding Scheme 2004

Who has reviewed the study?

The Study has been reviewed by NHS National R&D Programme on Forensic Mental Health: Research Funding Scheme 2004, Northgate and Prudhoe Research and Development Committee (LD) and Northumberland Local Research Ethics Committee.

Further Information

If after hearing this, you would like further information or clarification about what you might be involved in, then contact Tina Cook (by e-mail: tina.cook@unn.ac.uk or telephone: 0191 2156269) or Pamela Inglis (by e-mail: pamela.inglis@unn.ac.uk or telephone: 0191 215 6311/2156163) and we will do our best to answer your questions.

If you are happy about the idea of the project and want to be involved, please sign the consent form enclosed with this information sheet and return it in the SAE by December 16th 2005.

Centre Number: :

Study Number:

Version One: December 2004

CONSENT FORM
Staff

Title of Project: Evaluation of the development of a participant research project in a medium secure unit for offenders with a learning disability

Name of Researchers: Tina Cook and Pamela Inglis

Please initial box

1. I confirm that I have read and understand the information sheet dated .... ☐ (version one) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, ☐ without giving any reason and without any affect on me.

3. I understand that my contribution will form part of the data collected and that it will be recorded but that my contribution will be anonymised once it is written down and I will not be identifiable in any written reports.☐

4. I know that the tape recordings of my participation in this study will be destroyed once the researchers have transcribed them. ☐

4. I agree to take part in the above study. ☐

Name of Participant ______________________________

Signature _______________________ Date ________________________

Name of Person taking consent ______________________________________

(if different from researcher)

Signature ______________________ Date ___________________________

1 for participant; 1 for researcher

Appendix 3 – Men's Information Sheet

Version Two
February 2005

Patient information sheet, invitation to participate in study and record of agreeing to take part in the study

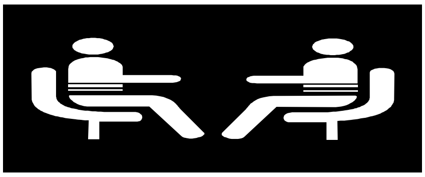
Project Title: Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability.

Version Two
February 2005

Information Sheet for Participants from The Kenneth Day Unit.

You are invited to take part in a research project

You are invited to become researchers



This is a new project that has not been done before. It would involve you working with Pamela Inglis and Tina Cook together with other people in your unit to do some research.

The research we would like to do with you is about **‘how to help people understand more about research and what goes on behind it.’**

And

This research project is slightly different because, **if you would like to join in** with this project, **you will also be a researcher. You would be researching** the best way to tell other people about research.

You would work with the experienced researcher to get a better understanding of things like

- **research**
- **consent to research**
- **the ethics of research**

Thinking about things

One part of the research would be to **find out more about research, why people do it and what the subjects of research need to know**.

Another part of the research would be **to find a way to tell other people about research in a way that they can understand.** This is important work because subjects of research do not always know good questions to ask about the research so they do not always properly understand things like

- **what the research is about**
- **what they might have to do as part of the research project**
- **what might be done with the information they give the researcher**
- **that research is different from treatment**
- **that if you don't answer a researcher's questions it will not affect your treatment**
- **that most research will not benefit them directly, but will help other people in a similar position to them.**

You are invited because you are from The Kenneth Day Unit. If you join you would be part of a group of men from The Kenneth Day Unit who meet about 6 times with the researchers and staff from Kenneth Day Unit to think about research and how to tell people about research.

Each meeting will last about 1hour 30 minutes

You would also be the subjects of the research because when we work together we will be finding out what helped you to understand research, ethics and consent and that will be part of the information that is written down and kept.

Things you do within the project may be noted down by the researcher, but they will always tell you what it is. You be able to see everything the researcher writes down that is to do with you – when the research is written up no-one will know it was you.

The meetings will be tape recorded and the tape recordings will be typed up. No- one but the researchers and the person who types them will hear the recording. Once the person has finished typing the tape recording will be thrown away. Your name will not be on the typed up sheet and if you say anything that gives away that it is you – for instance if you say your old address - this will be removed.

Sometimes in the research people will say things they do not want people outside the group to know and you will have to agree to keep that secret. Researchers will tell you very clearly what you cannot tell anyone else outside the group so you need not worry about that.

The research you do will be a public piece of work that will be used to help other people understand research. It is likely that Pamela and Tina will also write about the way in which the work was done, how we all worked together and what things have been learnt from it, for professional journals. We may also run a conference about what has been learnt.

This would all be discussed with you if you choose to become part of the project.

And that is about it.

If after hearing all about this, you want more information then tell the staff what else you want to know and we will do our best to answer your questions.

Pamela will also come to talk to you about the project. If you want Pamela to come to talk to you about the project, then tell the staff.

If you are happy about the idea of the project and want to be involved, you can tell the staff **and/or** sign this letter at the bottom and give it back to them to send to us.

Remember

You do not have to join in with this project. We would like it if you could because we think it will be interesting for everyone, but we don’t mind if you don’t.

Not being part of the project will have no affect on anything you do or is done with you. It certainly will not affect the way in which you are treated in Kenneth Day Unit.

You will record things that you and other people do within the project and other researchers will be able to see everything you note down or hear things you record - but when the research is written up no-one will know which bits you said or did.

Things you do as a researcher in the project might also need to be kept secret from people not involved in the project - this will be part of your responsibility as a researcher but it will be made very clear to you which bits you must not tell anyone else outside the group.

Centre Number: :
Study Number:
Version One: December 2004

The Record of agreeing to take part in this study.

Patients' consent/agreement form (researcher to delete as appropriate)

Title of the research project: Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability.

I have read/talked with ………………….(a researcher or a member of staff) about the above project.

I have decided I would like to join in.
I know that:

- I will be learning about research and consent and ethics and that I will be helping to develop information for others to understand this better too.
- The things I say and do as part of this project will be written down but that my name will not be shown on information that goes out of the Unit.
- The things I say in this project will be tape recorded but no-one will hear that tape apart from the researchers. Once they have listened to it and written things down it will be thrown away. No one will know it was me who said those things.
- If I decide to join in this project I will be responsible for keeping some things secret but I will be told very clearly which bits they are

- If I decide not to join in that is fine.

- If I decide to join in but don't want to carry on, then that will not affect the way I am treated in Kenneth Day Unit at all.

Signed……………………………..

Print Name:………………………..

Witnessed by……………………………….

1 copy for participant to keep – one copy for the researcher

Appendix 4 – Men's Baseline Interview Schedule

Men's Interview schedule baseline.

Semi-structured interview.

Preamble about the project inserted here.

1) Introductions

- **Just by way of introduction could you tell me a little bit about yourself ?**
  i. How would you describe yourself?
  ii. How would you describe your life?
  iii. Can you describe your relationship with others at the KDU?

2) Beliefs and ideologies about learning disability and nursing practice.

- **Can you describe what learning disability is?**
  i. Do you think you have a learning disability? Why?
  ii. What effect does being labeled as having a learning disability have on your life? Your feelings?
  iii. What do you think may be good about having a learning disability?
  iv. What is it like when people say you have a learning disability?
- **What do the nurses here do?**
  i. Do they help you or others?
  ii. How do they help you or others?
  iii. Is there anything else you think they could do to help you or others?
  iv. Is there anything else they should do?

    v. Is there anything else you would like them to do? Or not to do?

- **How do you feel about the nurses who work with you?**
    vi. How would you describe the nurses here?
    vii. Are they different from other nurses? How?
    viii. What is the best thing about nurses here?
- **The future.**
    ix. What would you like your life to be like in the future?
    x. Where would you live?
    xi. Who with?
    xii. Would you want to work? Where?

- **Do you feel that you have plenty of choice when living in the KDU?**
    i. What choices do you have?
    ii. Which choices would you like to have?
    iii. How might you be able to have more choices?
    iv. Does anyone help you to make choices? How?
    v. Is there anything else that would help you to make choices? Either more choices or better choices?

3) Research

- **What do you think research is?**
    i. Can you describe it, or give examples of it?

    ii. Have you taken part in any research?
        i. Can you explain a little about this and what you did in this research?.
        ii. What did you feel about it, did you like it?

   iii. Why do you think people take part in research?
   iv. Why do you think people do research?
   v. What is research for?
   vi. Have you ever carried out/ done any research?
      i. What was it about?

- **Why do you think it is important that you take part in this research?**
   i. Who else do you think should take part in this research?

4) Consent

- **Do you think that every body should have a choice about whether to take part in research?**

   ii. Do you think that everyone should agree to take part in research or not?

- **What information do you think people might need to make a choice whether to take part in research?**

- **When might you not want to tell people you had taken part in research?**

   i. So, what would happen if that person is taking part in that research with you?

- **Have you ever found out the results of any research you have taken part in?**

   i. Would you like to?
   ii. What would be the best way for you to understand the results? Written? Pictorial? Etc.

5) Relationships.

- **How do you get on with the other men who live here?**
- **What do you think will be the best things that will come out of working with the staff and researchers in this project?**
    i. How do you think that working in this way will effect your relationships? With the other men? The staff? The researchers?
- **Are there any things you think may get in the way of this relationship when we are working together?**
    i. How can we make that better then? How can we fix it?

Appendix 5 – Staff Baseline Interview Schedule

Interview schedule baseline.

Semi-structured interview.

Preamble about the project inserted here.

2) **Introductions**

- **Just by way of introduction could you tell me about your role in the KDU?**
  - iv. How would you describe yourself?
  - v. Can you describe your relationship with others at the KDU?

2) **Research**

- **What do you understand by research?**
  - i. Can you define it, or give examples of it?

  - ii. Have you taken part in any research?
    - i. Can you explain a little about this and your role in it.
    - ii. What is your experience of research?

  - iii. Why do you think people take part in or carry out research?
    - i. How do you think research is most useful?
    - ii. Do you think that research effects/develops practice?
    - iii. How useful is research to people at the KDU?

  - iv. Do you carry out research?
    - i. Can you describe it?

- **Do you know what Action Research is?**
  - i. Can you explain it, or give examples of how it is used?
  - ii. Or why it is used?

- **What do you understand about Participative Action Research?**
  - i. Can you explain it or give any examples of how it is used?
  - ii. Or why it is used?
  - iii. Do you think that PAR is useful?
    - i. What are the advantages and disadvantages of PAR?

    ii. How might it work in the KDU?

- **Do you think it is important that people with learning disability take part in research about people with a learning disability?**
    i. Why?
    ii. What are the advantages and disadvantages?
    iii. Do you think that every body in the KDU should be asked to be involved in research?

- **Do you think that staff and researchers should participate in research about people with a learning disability?**
    i. Why?
    ii. What are the advantages and disadvantages?

- **What are the advantages and disadvantages for carrying out research in a secure setting?**

- **Why do you think that it is important for research projects to follow an ethical code or procedure?**

3) Consent

- **What do you understand about the term consent, when it is related to consenting to take part in research?**

    i. Do you think every body can consent to take part in research?

        i. Do you think that everyone should consent to take part in research?

        ii. Are there any times when it might not be important for people to consent to take part in research?

- **Can you describe the difference between research and treatment?**

- **Why might you want to ask questions about the research you are taking part in?**

i. Do you think it is important who knows that you have participated in a research project?
ii. Why?

iii. Have you ever found out the results of any research you have taken part in?
iv. Do you think this is an important thing to do?
v. Why?
vi. How would you like to have the results presented to you?
vii. What is the best way of disseminating results effectively to you?

4) Issues raised during the research project.

- **Are you looking forward to collaborating in this research as colleagues?**
    ii. What do you think will be the most positive things that will come out of collaborating in this project?
    iii. Can you describe your current relationship with those you will be collaborating with?
    iv. Do you think that this collaboration will have a positive effect upon your relationships outside of this project?
    v. What might these be?
    vi. How do you think others may feel about this collaboration?
- **What things do you think may get in the way of this relationship during collaboration?**
    ii. How can these be overcome?

6) Beliefs and ideologies about learning disability and nursing practice.

- **Can you define learning disability?**
    v. What are the positive aspects of working with people with a learning disability?
    vi. What do you think may be the positive aspects of having a learning disability?
- **What do you believe are the most fundamentally important beliefs that you have about people with learning disability which positively effect the lives of the men who live on the KDU?**

    xiii. How do they help your practice and effect the lives of the men who live here?
    xiv. How do you think these have developed practice?
    xv. How do you think these may develop practice?
    xvi. How do you think they have developed your practice?
    xvii. How do you think nursing practice should develop?

- **Are there any nursing models or theories which underpin your practice, like SRV or the Social model of disability?**
    i. How do you feel about these models or theories?
    ii. How do they effect your practice and ultimately the lives of the men who live here?

- **How do you feel about choice and empowerment for people with a learning disability?**
    vi. How does this work within the KDU?
    vii. How has the choice and empowerment of the men been improved or developed?
    viii. How may the choice and empowerment of the men who live here be improved or developed?

Appendix 6 – 2nd Interview Schedule and Changes by the Men

The interviews will take a narrative approach to collecting information – this means that we don't ask a lot of questions, but just a few important questions, to lead the interviewee through the story (or the narrative, as narrative is another way of saying story telling) of the research from their point of view.

So the questions are:

1. Please tell us the story of being involved in this research from the beginning from your point of view.
2. Please tell us the story of being involved in this research from the beginning from the men's point of view.
3. Do you now know more about research? Like understanding the terms, research, consent and ethics?
4. Do you think the members of the group know more about research? Prompt – men? Staff? Tina & Pamela
5. How do you think you contributed to the research?
6. How do you think others in the group contributed to research? Prompt as above.
7. What have you got out of your involvement in this research?
8. What is the best thing about being involved?
9. Do you think that there may be any room for improvement in this research?

Changes made at the suggestion of men 20/06/06 to create version2.

Appendix 7 – Focus Group Schedule

Staff Focus Group – KDU Project 21-08-2006.

The following are group exercises, however, please use the sheets provided as a guide to discussion and write down your answers, along with the groups, as you go. Please do not put your name on the paper, but you may put your number from the project if you wish.

1. As a group we would like you to Think about the men taking part:
What

Skills?

Qualifications?

Experience?

Personal attributes?

Do they possess that enabled them to take part successfully.

Could any of the men here taken part and been successful – why?

What about other people with learning disability?

2. As a group we would like to think about how you helped the men taking part to take part and learn.

In order to help you to think about this it may be helpful if you discussed the following and came to some consensus about the issues.

Think about your roles here: What
skills ?

Qualifications?

Experience?

Personal attributes?

Do you posses to enabled you to help the men?

Could any of the staff here have taken part successfully – why?

Or other nurses?

Or other staff working with people with Learning Disability?

3. Thinking about your relationship with the men:

What was the most important aspect of your relationship with the men that lead to the success of this project.

What is this relationship which helps you to help the men?
Define it?

Describe it?

Give examples please.

What are the possibilities and limitations of this relationship?

4. So what is it that you did to help the men take part in this project successfully?

What did you do?

What did the staff team do?

What did you say?

How did you act?

Did you do anything that you would not normally do in your role here?

How much time did it take up ?

Give examples please

Please describe the profile for the “perfect” nurse to take part in a project such as this:

What are their
Roles?

Skills?

Qualifications?

Knowledge base?

Experience?

Personal attributes?

You may write or draw this person, or describe them verbally.

Appendix 8 – Workshop Resume

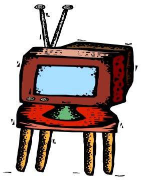
1. Tina talked about the research we agreed to take part in.

2. Pamela talked about the possibility of getting a certificate from the University if you wanted to do extra work.

3. We all received diaries to write or draw in. Things about :
    - **i.** Remembering what we talked about
    - **ii.** Take notes about what has happened in session
    - **iii.** What you have learned, understood, enjoyed.

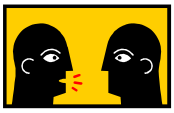
4. Pamela talked about Ground rules, like listening to others and we agreed on some changes to the one that Pamela had.

5. We watched a DVD about research – then talked about what we thought research is:-

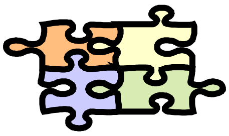


a. Research is about **finding things out**, like being a detective.
b. Where you search a lot of times to find things out.

c. You need to ask more than one person for their view, or get different types of information, from more than one place.
d. And you **ask lots of questions** that come together at the end.



e. These questions are important because they could be parts of what we need to know which we have to fit together– a bit like a jigsaw.



f. If we answer a lot of questions we might get to the heart of what we need to know.

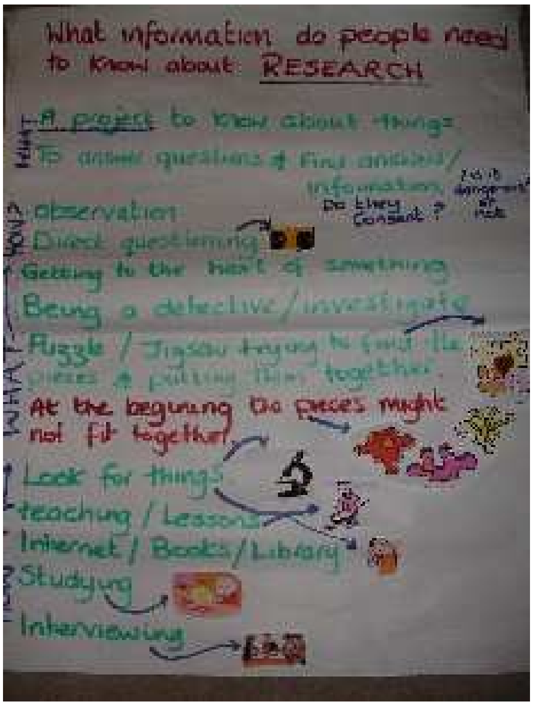
6. Not everyone joined in the discussion and we need to find ways of making sure they have understood what we have talked about and letting them get their point across.

We then talked about what we had learned today

How we contributed to the session.

And what had helped us learn the most.

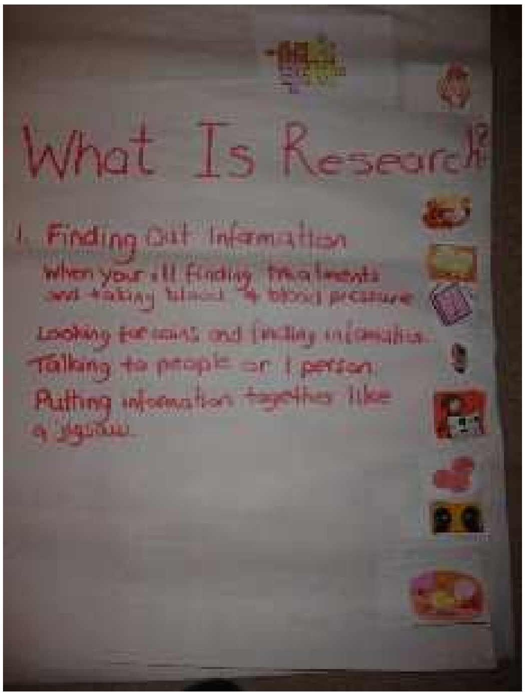
Appendix 9 – Flipcharts



What information do people need to know about RESEARCH

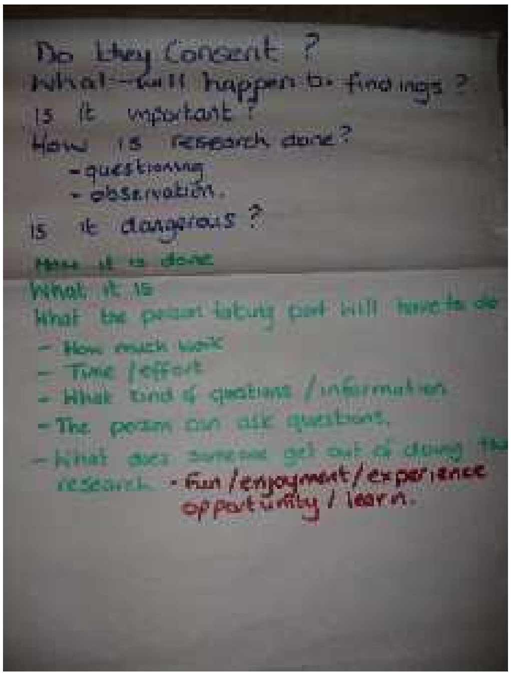
A project to know about things=
To answer questions & find answers/ information
Is it dangerous or risk
Do they Consent ?
observation
Direct questioning
Getting to the heart of something
Being a detective/investigate
Puzzle / Jigsaw trying to find the pieces & putting them together.
At the beginning the pieces might not fit together!
Look for things
teaching / Lessons
Internet / Books / Library
Studying
Interviewing

WHAT
HOW?
WHAT –

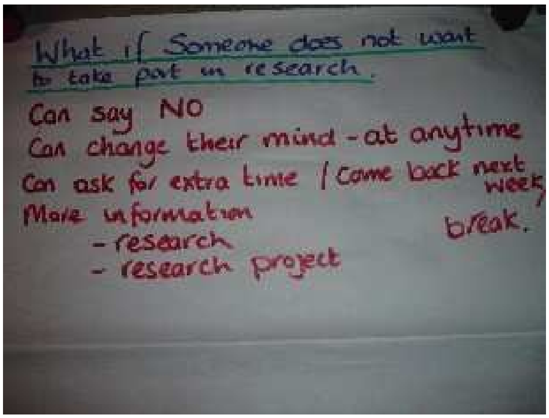


What Is Research?

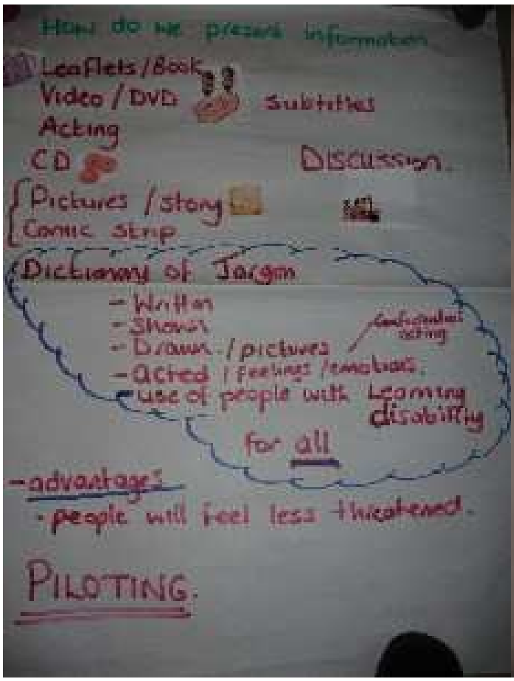
1. Finding out Information
When your ill finding treatments and taking blood & blood pressure
Looking for cures and finding information.
Talking to people or 1 person.
Putting information together like a jigsaw



Do they Consent ?
What will happen to findings ?
Is it important ?
How is research done?
- questioning
- observation.
Is it dangerous ?
How it is done
What it is
What the person taking part will have to do
- How much work
- Time / effort
- What kind of questions / information
- The person can ask questions.
- What does someone get out of doing the research · Fun / enjoyment / experience opportunity / learn.



What if Someone does not want to take part in research.
Can say NO
Can change their mind - at anytime
Can ask for extra time / Come back next week, break.
More information
- research
- research project



How do we present information

Leaflets / Book

Video / DVD Subtitles

Acting

CD Discussion

Pictures / story

Comic strip

Dictionary of Jargon

- Written
- Shown
- Drawn / pictures
- Acted / feelings / emotions
- use of people with Learning disability

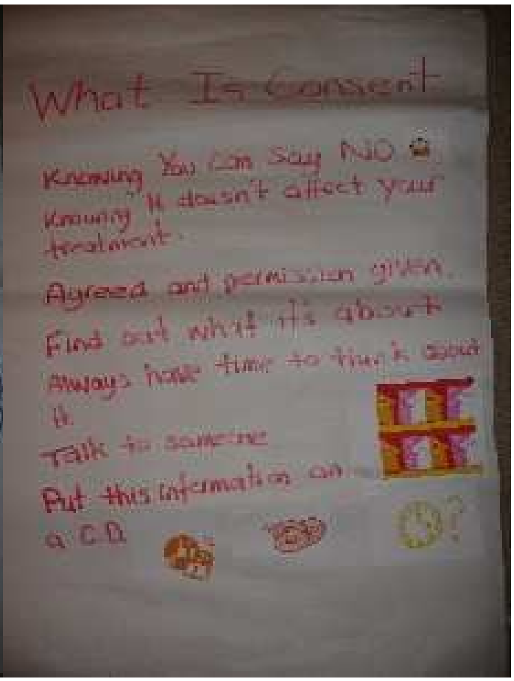
[illegible] acting

for all

– advantages:

· people will feel less threatened.

PILOTING.



What Is Consent

Knowing You can Say NO

Knowing it doesn't affect your treatment.

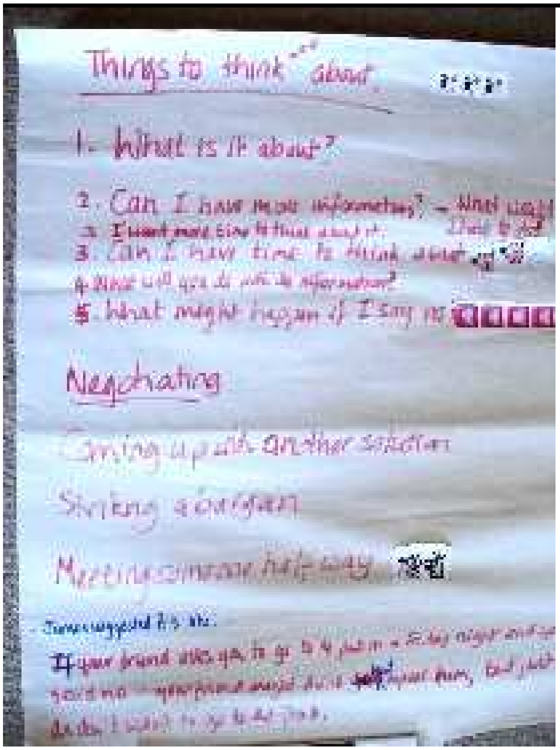
Agreed and permission given.

Find out what it's about

Always have time to think about it

Talk to someone

Put this information on a C.D.



Things to think about

1. What is it about?

2. Can I have more information? – What will [illegible] I have to do

2. I want more time to think about it.

3. Can I have time to think about

4. What will you do with the information?

5. What might happen if I say no

Negotiating

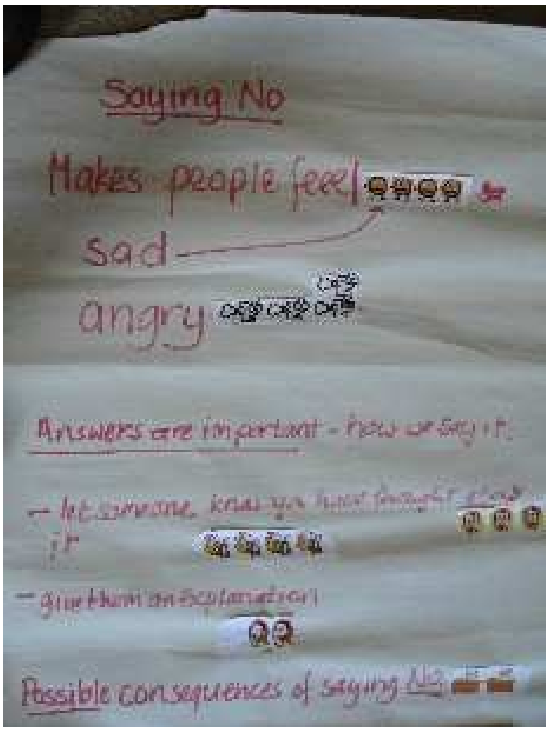
Coming up with another solution

Striking a bargain

Meeting someone half way

– [illegible] suggested this idea:

If your friend asks you to go to the pub on a Friday night and you said no – your friend might think [illegible] upset them, but just [illegible] I don't want to go to the pub.



Saying No

Makes people feel

sad

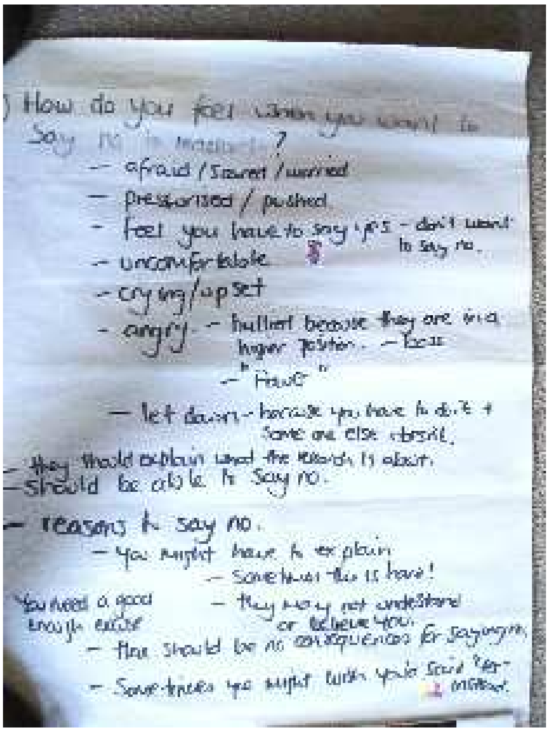
angry

Answers are important – how we say it.

– let someone know you have thought about it

– give them an explanation

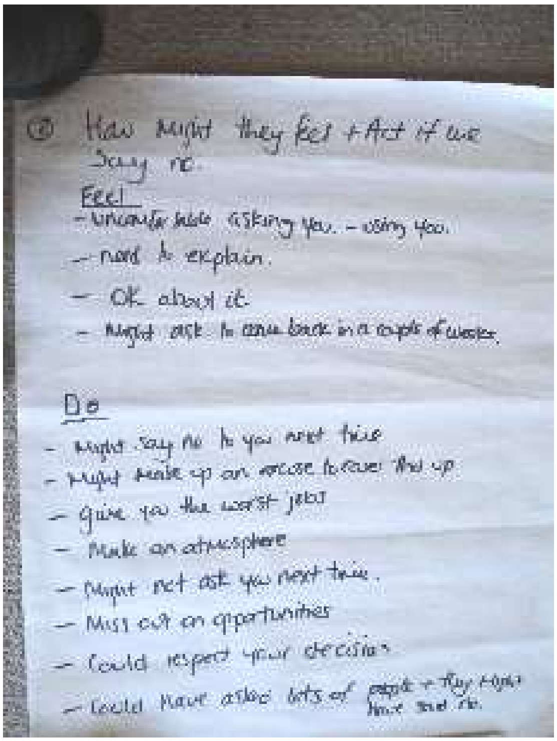
Possible consequences of saying No



How do you feel when you want to Say no to research?

- afraid / scared / worried
- pressurised / pushed
- feel you have to say yes – don't want to say no.
- uncomfortable
- crying/upset
- angry – bullied because they are in a higher position. – boss
  – "Power"
- let down – because you have to do it + some one else doesn't.
- they should explain what the research is about.
- should be able to say no.
- reasons to say no.
  - you might have to explain
    - sometimes this is hard!
  - they may not understand or believe you.
  - there should be no consequences for saying no.
  - Sometimes you might wish you'd said "yes" instead.

You need a good enough excuse



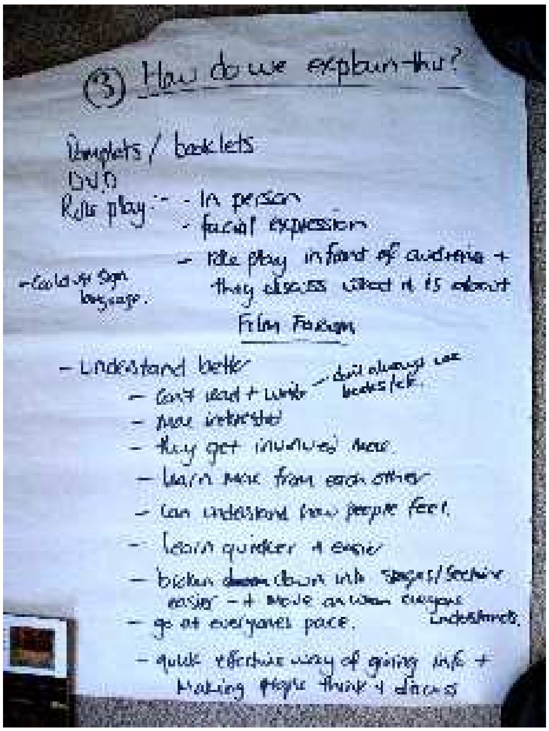
② How might they feel + Act if we Say no.

Feel

- uncomfortable asking you. – using you.
- need to explain.
- OK about it.
- Might ask to come back in a couple of weeks.

Do

- Might say no to you next time
- Might make up an excuse to cover this up
- give you the worst jobs
- Make an atmosphere
- Might not ask you next time.
- Miss out on opportunities
- Could respect your decision
- Could have asked lots of people + they might have said no.



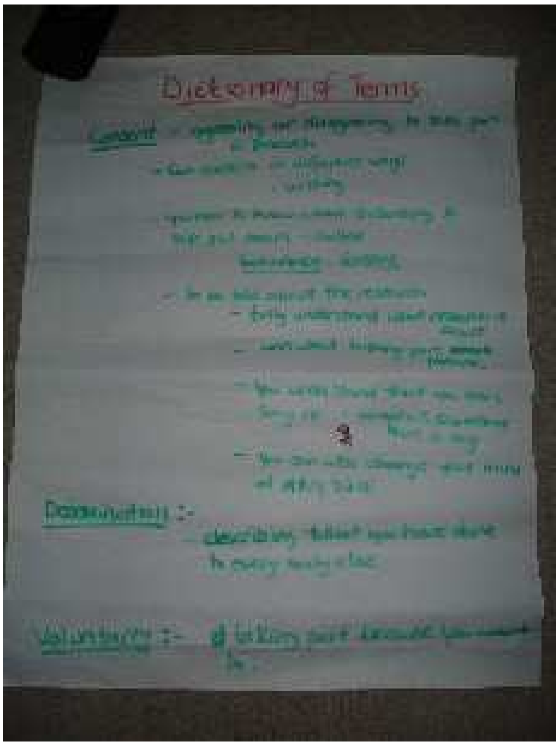
③ How do we explain this?

Leaflets / booklets
DVD
Role play – - in person
- facial expression
- role play in front of audience + they discuss what it is about

Film Forum

- Could use sign language.

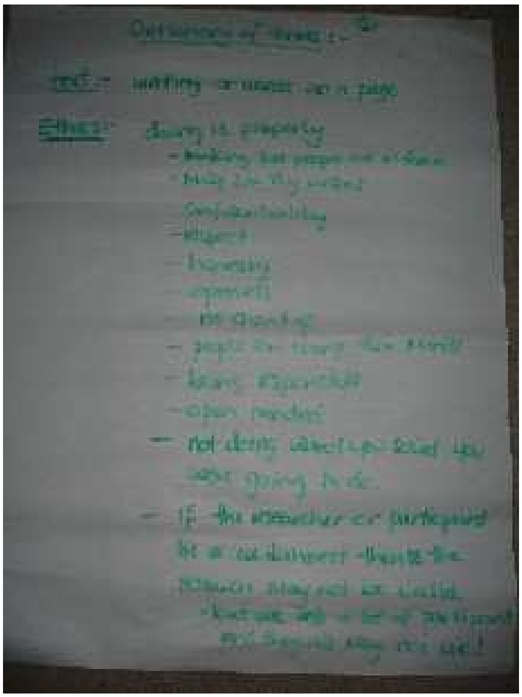
- understand better
  - can't read + write – don't always use books/etc.
  - more interested
  - they get involved more
  - learn more from each other
  - can understand how people feel.
  - learn quicker + easier
  - broken down into stages/sections easier – + move on when everyone understands.
  - go at everyone's pace.
  - quick effective way of giving info + making people think + discuss



Dictionary of Terms

Consent

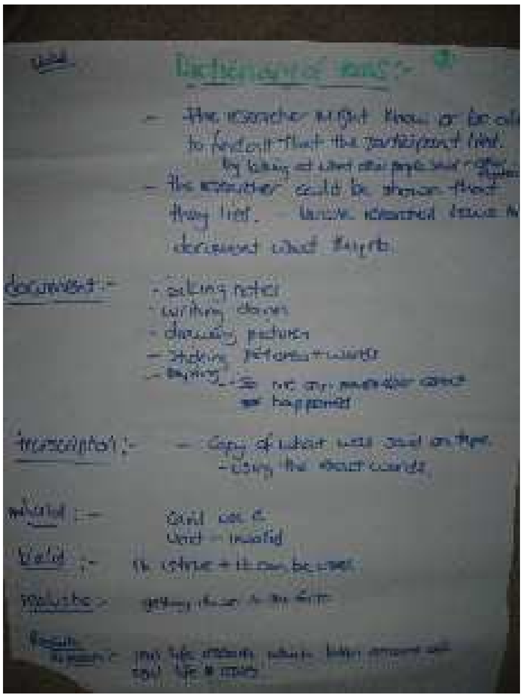
Voluntary :-



Definitions of words :-

text :- writing or words on a page

Ethics :- doing it properly
- making sure people are [illegible]
- [illegible]
Confidentiality
- respect
- honesty
- openness
- no cheating
- people [illegible]
- being [illegible]
- open minded
- not doing what you said you were going to do.
- If the researcher or participant lie or are dishonest - then the research may not be valid.
- [illegible] participant [illegible] may not be valid!



[illegible]

Definitions of words :-

- The researcher might know or be able to find out that the participant lied. by looking at what other people said [illegible]
- the researcher could be shown that they lied. - because researchers have to document what happens.

document :-
- taking notes
- writing down
- drawing pictures
- sticking pictures + words
- taping - so we can remember what happened

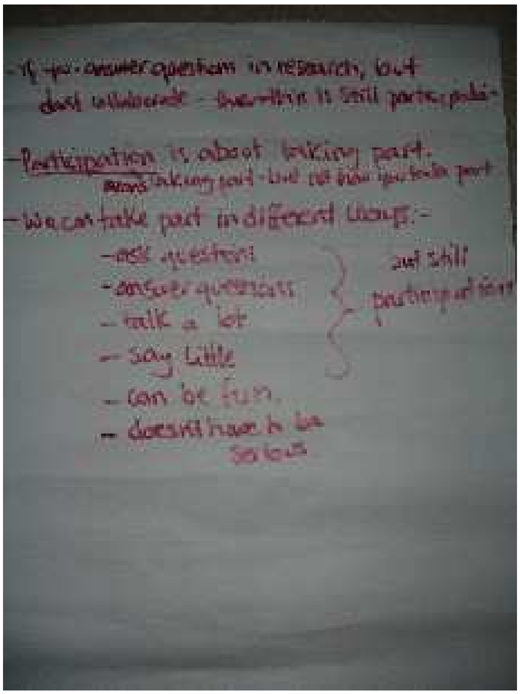
transcription :- - copy of what was said on tape.
- using the exact words.

invalid :- valid use it
Void - invalid

Valid :- it is true + it can be used

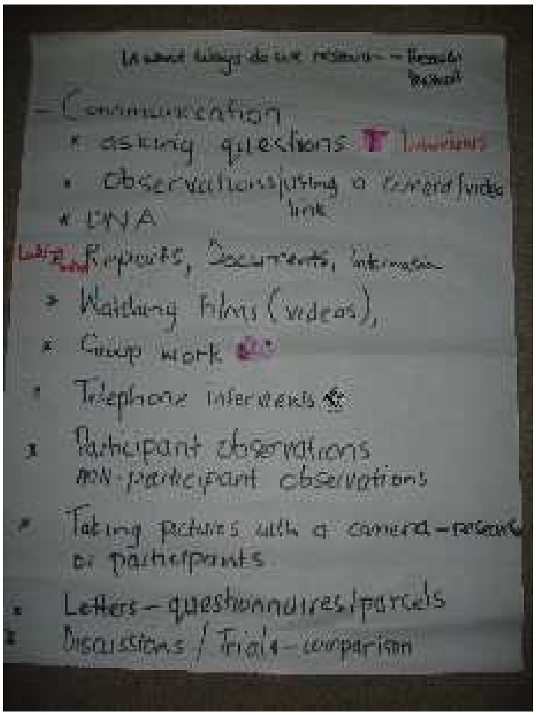
Evaluate :- getting closer to the truth

[illegible] :- [illegible]



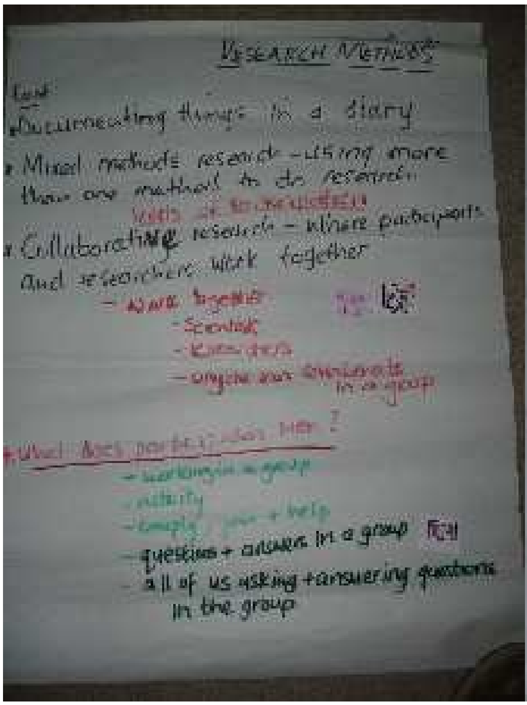
- If you answer questions in research, but don't collaborate - then this is still participation.
- Participation is about taking part.
means taking part - but not how you take part
- We can take part in different ways:-
- ask questions
- answer questions
- talk a lot
- say little
- can be fun.
- doesn't have to be serious

and still participating



In what ways do we research - Research Methods

- Communication
* asking questions [illegible] interviews
* observations (using a camera / video link)
* DNA
Looking at Reports, Documents, information
* Watching films (videos),
* Group work
* Telephone interviews
* Participant observations
NON-participant observations
* Taking pictures with a camera - researchers or participants
* Letters - questionnaires / parcels
* Discussions / Trials - comparison

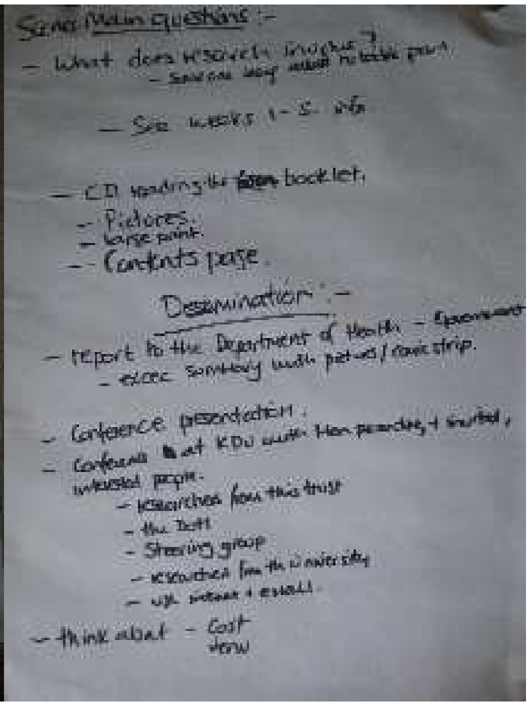


RESEARCH METHODS

[illegible]

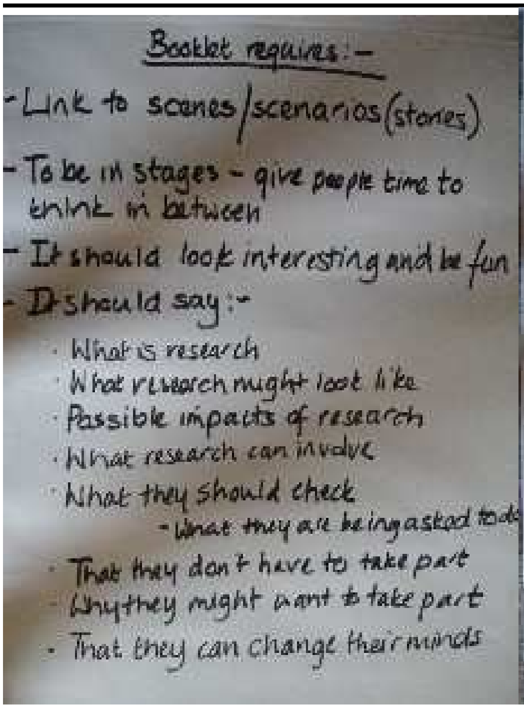
- Documenting things in a diary
- Mixed methods research – using more than one method to do research
  [illegible]
- Collaborative research – where participants and researchers work together
  - work together [illegible]
  - Scientists
  - Researchers
  - anyone [illegible] in a group

What does participation mean?
- working in a group
- activity
- [illegible] join + help
- questions + answers in a group
- all of us asking + answering questions in the group

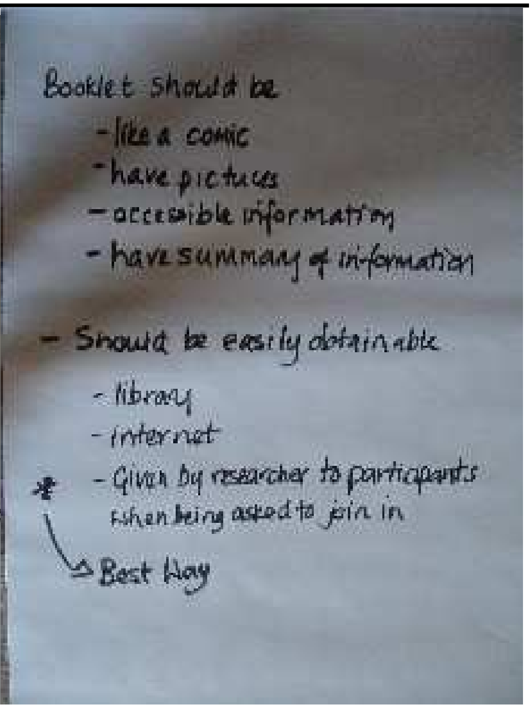


Scenes Main questions :–
- What does research involve?
  - [illegible]
- See weeks 1–5 info
- CD reading the ~~[illegible]~~ booklet.
  - Pictures.
  - large print.
  - Contents page.

Dissemination :–
- report to the Department of Health – [illegible]
  - exec summary with pictures / comic strip.
- Conference presentation.
- Conference at KDU with [illegible] interested people.
  - researchers from this trust
  - the DoH
  - Steering group
  - researchers from the university
  - [illegible] + email.
- think about – cost
  [illegible]

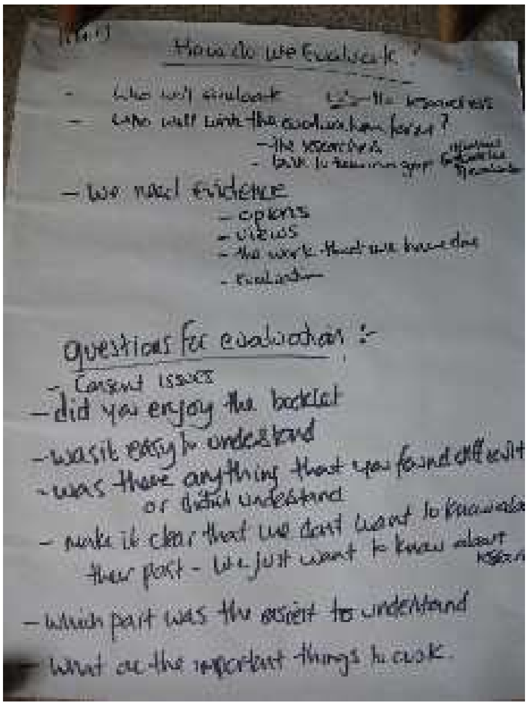


Booklet requires:–
- Link to scenes/scenarios (stories)
- To be in stages – give people time to think in between
- It should look interesting and be fun
- It should say:–
  - What is research
  - What research might look like
  - Possible impacts of research
  - What research can involve
  - What they should check
    - What they are being asked to do
  - That they don't have to take part
  - Why they might want to take part
  - That they can change their minds



Booklet should be
- like a comic
- have pictures
- accessible information
- have summary of information

- Should be easily obtainable
  - library
  - internet
  - * Given by researcher to participants when being asked to join in
    → Best Way

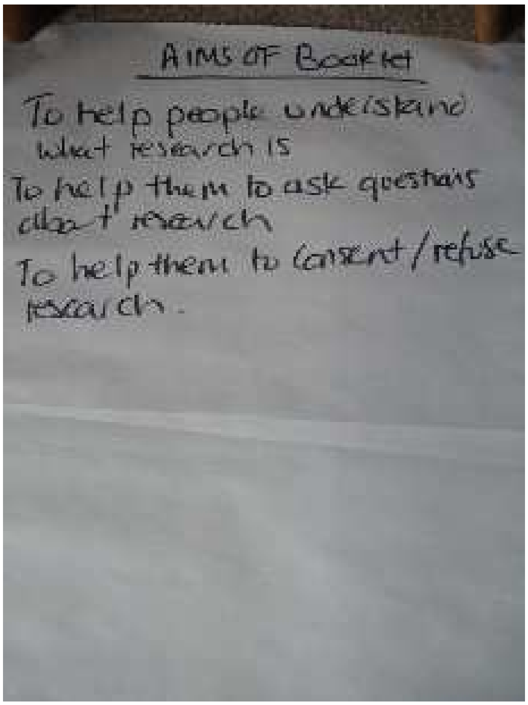


How do we Evaluate?

- Who will evaluate — us — the researchers
- Who will write the evaluation form?
  - the researchers
  - talk to [illegible] group [illegible]
- we need evidence
  - opinions
  - views
  - the work that we have done
  - evaluation

Questions for evaluation :-

- Consent issues
- did you enjoy the booklet
- was it easy to understand
- was there anything that you found difficult or didn't understand
- make it clear that we dont want to know about their past - we just want to know about research
- which part was the easiest to understand
- what are the important things to ask.

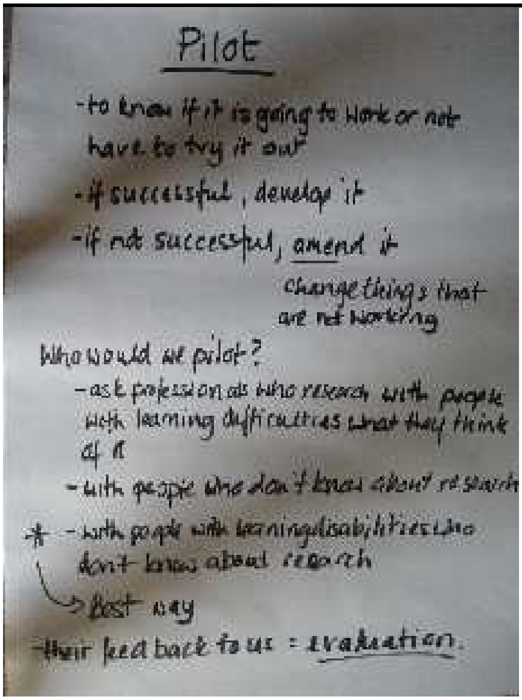


AIMS OF Booklet

To help people understand what research is

To help them to ask questions about research

To help them to consent/refuse research.



Pilot

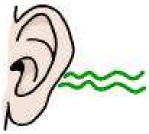
- to know if it is going to work or not have to try it out
- if successful, develop it
- if not successful, amend it
  change things that are not working

Who would we pilot?

- ask professionals who research with people with learning difficulties what they think of it
- with people who don't know about research
- * - with people with learning disabilities who don't know about research
  → Best way
- their feed back to us = evaluation.

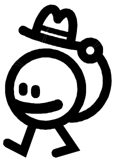
Appendix 10 – Ground Rules

In the session do



Listening

Listen to other people.

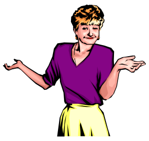


Respect

Respect the views of others even if you disagree with their views.

Honest and open

Be honest. Your views are important so tell us about them.



Do not understand

Use plain English and not jargon otherwise people may not understand. Try to keep what you say to the topic at hand.

Having fun

Try to be positive and concentrate on what is possible not what is impossible.

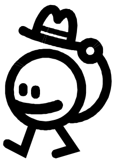
Confidential

Respect each others' confidentiality and what is said in the session stays in the session unless you want to talk to one of the staff who are involved in the study or ask any other member of staff to write or draw something in your diary for you.

In the session don't

Confidential

Don't talk about your personal information or talk about anybody else's personal information.


Respect

Don't criticise others or use abusive or offensive language

Appendix 11 – DVD

Please see DVD sent separately by post

Appendix 12 – Understanding Research Facilitator's Pack

Please see pack attached separately.

Appendix 13 – Understanding Research Facilitator's Picture Dictionary

Please see pack attached separately.

Appendix 14 – Understanding Research Dictionary of Terms

Please see pack attached separately.

Appendix 15 – Understanding Research Student's Pack

Please see pack attached separately.

Appendix 16 – Understanding Research Student’s Picture Dictionary

Please see pack attached separately.

Appendix 17 – Node Listing

Numer of coding families: 19 - Number of Nodes across family codes: 49

Family code no.	node no.	node name .
1	(1)	Description of Role within KDU
2	(2)	What is Research~
3	(2 3)	What is Research~/What is Action Research~
4	(2 4)	What is Research~/What is Participatory Research
5	(2 7)	What is Research~/Difference - research & treatment
6	(3)	Ethics of research
7	(3 1)	Ethics of research/Why do research
8	(3 5)	Ethics of research/Why engage people with Learning disability in research
9	(3 6)	Ethics of research/why engage staff and researchers
10	(3 8)	Ethics of research/Important to ask questions
11	(4)	Collaboration
12	(4 1)	Collaboration/Enablers to collaboration
13	(4 9)	Collaboration/Positive collaboration
14	(4 12)	Collaboration/others' feelings about collaboration
15	(4 13)	Collaboration/Barriers to collaboration
16	(5)	Relationships
17	(5 5)	Relationships/Relationships within the MSU
18	(5 10)	Relationships/Positive effect on relationships
19	(5 11)	Relationships/Relationships with others
20	(6)	Consent
21	(6 1)	Consent/relectance to consent
22	(6 2)	Consent/barriers to consent
23	(6 3)	Consent/enablers to consent
24	(7)	Dissemination
25	(8)	Discourse
26	(8 1)	Discourse/Non professional discourse
27	(8 2)	Discourse/Professional discourse
28	(8 3)	Discourse/Passive role of Patient
29	(9)	Practice
30	(9 1)	Practice/Security
31	(9 2)	Practice/Training
32	(9 3)	Practice/Effect of beliefs on practice
33	(9 4)	Practice/practice developing
34	(9 5)	Practice/negative aspects of forensic nursing
35	(9 6)	Practice/Positive aspects of forensic nursing
36	(9 7)	Practice/Difference of forensic nurses

37	(9 17)	Practice/Models underpinning practice
38	(9 18)	Practice/theories underpinning practice
39	(14)	Definitions of learning disability
40	(14 1)	Definitions of learning disability/Attitudes
41	(14 2)	Definitions of learning disability/describing LD in negative terms
42	(14 3)	Definitions of learning disability/Do you have a learning disability
43	(14 4)	Definitions of learning disability/Effects of term LD
44	(14 6)	Definitions of learning disability/Best thing about yourself - men
45	(14 11)	Definitions of learning disability/Describe self - men
46	(14 15)	Definitions of learning disability/Positive aspects of learning disability
47	(14 16)	Definitions of learning disability/Beliefs about learning disability
48	(19)	Choice
49	(19 20)	Choice/empowerment

There were other codes in which the data was repeated in related nodes and therefore, were not used in the final analysis.

Appendix 18
Conference Presentations to Date

Interesting Ways of Helping People with Learning Disability Understand and Participate in Research. **7th International Conference on the Care and Treatment of Offenders with a Learning Disability** University of Central Lancashire, Preston. Tina Cook, Pamela Inglis and men from and MSU. March 2008.

Inclusion and Inclusive Learning: a researcher's point of view. 1st **Conference on 'Inclusion and Inclusive Learning'.** CETT for Inclusion**:** Northumbria University. Newcastle upon Tyne. Tina Cook and men from the MSU. March 2008.

Facilitated collaborative action research in the KDU: learning through research about research. **Northumberland, Tyne and Wear and Tees, Esk and Wear Valley NHS Trusts: 2nd Annual Northern Forensic Conference - Clearing the Pathways**. Newcastle upon Tyne, Tina Cook, Pamela Inglis and men from the MSU. February 2008.

Consenting to participate in research: issues in relation to people with learning difficulties. **Joint Conference of The Association of Research Ethics Committees and European Forum For Good Clinical Practice**_Edinburgh. Tina Cook. Invited Presentation. July 2007.

Researching Research: A Facilitated Collaborative Action Research Project in a Forensic Setting for Men with a Learning Disability **ESRC Seminar Series: Service Users Agendas in research.**_Open University. May Milton Keynes. Poster Presentation. Tina Cook, Pamela Inglis and Men and Staff from the KDU. April 2007

Consenting to participate in research: issues in relation to people with learning difficulties **The Northern & Midlands Research Ethics Training Event** Leeds: March Delivery of two workshops with LREC members. Tina Cook. March 2007

Researching Research: A Facilitated Collaborative Action Research Project in a Forensic Setting for Men with a Learning Disability **4th National Conference of Research in Medium Secure Units:** London. Poster presentation. Tina Cook and Pamela Inglis. January 2007

Researching Research: A Facilitated Collaborative Action Research Project in a Forensic Setting for Men with a Learning Disability **30th International Conference of the Collaborative Action Research Network** Nottingham. Tina Cook. November 2006

Researching Research: Working together to find out about consenting to research **Public Involvement in Research Conference: Working and Learning Together** Northumberland Care Trust, Northumbria University and Northumberland Tyne and Wear NHS Trust**.** Gateshead. With Pamela Inglis, 2 men from the MSU and Andy Stafford and June Keanyside from Lawnmowers. October 2006
Holding the keys: understanding consent in research. Learning together in a forensic setting for men with a learning disability. **2nd International Congress of Qualitative Inquiry** University of Illinois at Urbana-Champaign. May 2006.

From Client to Colleague: Perceptions of Staff Researching *With* Men with Learning Disability Living in a Secure Setting. **5th International Conference on the Care and Treatment of Offenders with Learning Disabilities.** University of Central Lancashire, Preston, UK, With Pamela Inglis. April 2006

Multifaceted action research with men with learning disabilities and offending behaviours. **International Practitioner Research Conference & Collaborative Action Research Network Conference**. Utrecht, The Netherlands, November 2005