

# **What helps women who have learning disabilities get checked for cervical cancer?**

**Elaine Monteith**

**ENABLE Scotland**

**Final Report: July 2015**

## **Project background**

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities which include cervical screening (Emerson & Baines, 2011). Furthermore, health screening programmes provided for the whole population, such as cervical screening, are not accessed routinely by women with a learning disability (Health Needs Assessment Report, 2004). The health of people with learning disabilities is an area where, from the perspective of a social care practitioner, may not always be seen as a high a priority in comparison to the overall population. The main emphasis is usually on the individual's learning or intellectual disability rather than the prevention of health issues. There is a belief that women who have learning disabilities and not as sexually active in comparison to the rest of the female population and are, therefore, at a lower risk of developing cervical cancer (Langan et al. 1994). Furthermore, whilst there is recognition that cervical cancer is associated with a sexually transmitted disease, in particular the Human Papilloma Virus (HPV), there are also a number of risk factors such as multiple sexual partners and smoking which can determine the outcome of women being diagnosed with cervical cancer (Yu and Rymer, 1998). This research project will compare the views and opinions of the findings of the studies of Yu and Rymer and Langan et al with a view to identifying if there have been any changes to the myths surrounding cervical cancer and the causes of this.

NHS Scotland is keen to ensure that everyone in society is able to access health services regardless of their specific needs. There is a belief that that any barriers preventing individuals accessing services should be identified in order that these [barriers] can be removed as far as practically possible (The Healthcare Quality Strategy for NHS Scotland, 2010). Concerns about such issues have been raised for some time now, which is eloquently expressed in this statement:

*'People with learning disabilities have been found to have untreated medical conditions that would normally have been identified and resolved for other members of the community, these can be minor conditions but also include serious concerns such as breast lumps or diabetes'*

(Gordon, Graham, Robinson, & Taulbut, 2010)

In June 2013, the Scottish Government published the Keys to Life Strategy (The Keys to Life - Improving Quality of Life for People with Learning Disabilities, 2013) which follows on from 'The Same as You?' which was published thirteen years earlier (The Same As You? A review of services for people with learning disabilities, 2000). The Keys to Life has recommendations in place, many of which focus on the health and well-being of people with a learning disability. Specifically, there is a recommendation that 'a targeted health screening programme for people with learning disabilities across NHS Scotland' is implemented.

Working within social care there was an opportunity to gain an overview on the thoughts of colleagues both within and beyond my own organisation. I initiated this work by first collating practitioner views on whether they were of the opinion that women with learning disabilities routinely accessed cervical screening services? This issue was discussed with staff members within the work place. This allowed the opportunity to gain first hand feedback, views and opinions from social care staff who work directly with people who have a learning disability. The feedback received stated that this was not a service which was accessed routinely. There was a belief this 'wasn't necessary' as women with learning disabilities are not sexually active or it would 'cause too much distress and anxiety'. Predominantly the focus on health care for women with a learning disability focused on the 'obvious', for example; epilepsy and other prevalent health conditions which are commonly seen in this group. Within the quality themes, which are inspected by The Care Inspectorate, there is a focus on ensuring the service supports someone regarding both their health and well-being. It was important to ensure that the research proposal was relevant to Scottish Government legislation and that the target was focused on perceived unmet health needs for women with learning disabilities.

Therefore, my overarching research question was:

*'What are the barriers and enablers for women with learning disabilities in accessing screening services?'*

## **Aim**

To identify what prevents women with learning disabilities accessing cervical screening, and what could assist them in accessing this service.

## Methodology

The methodology that was employed through the project was a broadly qualitative approach. Initially, quantitative data was used only as a method of establishing the numbers of women with learning disabilities in Scotland and other data was used as a comparison on the general uptake of cervical screening compared to the general population. Whilst there is value in terms of gathering data in terms of numbers going through services and overarching health statistics, this research project is dealing with feelings, beliefs and attitudes. The need for further analysis on the explanation behind these statistics was a critical part of the research project, building on the data that showed that women with learning disabilities were less likely to access screening services. Edgar Stones described educational research during the 1960s in a way which was 'measuring people' (Stones, 1994). The research process would be required to explore the concept that women with a learning disability are less likely to access screening services than the general population. Within the social research methods text the 'integrity... generated by a piece of research' is discussed at length (Bryman, 2012). A process of open, then axial coding, was used to analyse the data in order that themes could emerge and build (Strauss, 1987). Therefore, a mixed approach in terms of analysing the data by using not only the spoken word, but of identifying the themes and relationships which emerged from the transcription process.

As the research project is focusing on the enablers and barriers for women with learning disabilities accessing cervical screening services there was an assumption that the uptake is low within this client group. In order to gain a further understanding on the enablers and barriers of women with learning disabilities accessing cervical screening services, one-to-one semi-structured interviews was considered to be more beneficial given the sensitive nature of the subject being researched. In addition, the use of questionnaires may have a limited response leading to a decreased amount of data. This could be for a number of reasons, including difficulty understanding the questions as well as a lack of clarity into some of the language used. In order to ensure the women interviewed felt comfortable, the attendance of their personal assistant (PA) or support worker was encouraged. This allowed for further discussions on the views and opinions of direct support staff. In total six people were interviewed; three were women randomly selected and all were over the age of twenty-five (the age where women should have been invited to attend at least one cervical screening appointment) with learning disabilities; one of whom had accessed cervical screening services and three personal assistants who had supported woman with learning disabilities during their career. There was a particular focus around the views, opinions and beliefs of PA's in supporting women with learning disabilities in terms of accessing cervical screening services. This allowed a correlation to be drawn in identifying the views of direct support staff and if this impacts on the uptake of woman they support in terms of accessing cervical screening services. The research project gathered data in an attempt to analyse and consequently understand why women with learning disabilities were less likely to access screening services than the general population. As previously mentioned, a potential limitation was considered in terms in the use of language, therefore, an easy read information sheet was prepared (Appendix 1) in order to aid clarity of the questions being asked. In addition, a discussion took place at the time of the interview to ensure all participants were clear on the subject matter and to ensure they were comfortable in being part of the project. A Consent Form (Appendix 2) was also prepared in a more accessible

format. The use of a voice recorder assisted in approaching the research interview in a more of a conversational way, recording the audio that could then be used to identify themes and trends, but not recorded verbatim. All women interviewed had full capacity to understand the concept of cervical screening or they had this explained to them in easy to understand language. To ensure full confidentiality pseudonyms were used for the women with learning disabilities. Personal assistants will be referred to as; PA1, PA2, PA3. They all had a range of different experiences of working with women with learning disabilities, from less than one year to over ten.

Whilst the women with learning disabilities involved would have capacity to understand the questions and to respond independently in terms of providing support, a family member, carer and a support staff member could also attend. The importance of using open questions was recognised given the area of discussion, although a list of questions were prepared to start the interview process. It was also recognised that the interviewer should not lead the person being interviewed on their own views and opinions. Other methods of gaining data could have been through focus groups. Focus groups are a practical way of gathering data from a larger amount of people, although they rely partly on the interaction of the facilitator with the participants in order that discussion can be generated. This method would allow the opportunity to view the differing opinion of those present (Kitzinger & Barbour, 1999). However, the sensitive nature of the subject being discussed meant that this may not be the most appropriate method of gathering data and a view that individuals would be more likely to share information in a one-to-one setting was employed as a more appropriate method of data collection.

## **Ethics**

The research project requires discussion on sensitive issues. Everyone who took part was made aware of the confidentiality of the data and also that no information which could identify them would be published. Every person that participated signed a consent form and was made aware that they can withdraw from the study at any time. The self-audit checklist template within ENABLE Scotland's own Ethics Policy was used to assess the potential risks to both participants and researchers.

## **Literature review**

Gathering data and information on the number of people with learning disabilities in Scotland who were registered with GPs proved difficult. There was no overall national data available to compare how many women with learning disabilities accessed screening services compared to the general population. Learning Disabilities Statistics Scotland (LDSS), 2013, have gathered data on the amount of women over the age of 25 with learning disabilities who are known to health boards in Scotland, which amounts to 8889.

Other literature reviewed concluded that women with a learning disability have less access to cervical screening services compared to the general population and that '5-year uptake rates for

cervical screening of 13–24% compared to 77–88% for the general female population’ (Djuretic T., et al, 1999 BMJ 318:536). A number of literatures reviewed examined data available from GP statistics. Due to people with learning disabilities tending to have higher levels of health needs compared to the rest of the population, there was an expectation that there would be more attendance at GPs from this client group, although this was found not to be the case (S.A. Cooper, 2011).

Furthermore, a study which took place within GP settings in parts of Edinburgh where health practitioners based within GP settings were interviewed (Wood & Douglas, 2007). The study was aimed to evaluate current practice in, and to explore primary care professionals’ views about, providing cervical screening to women with learning disability across two areas of Edinburgh. In the Wood and Douglas (2007, Pages 84-92) study, there was an acknowledgement that there was a low uptake from women with learning disabilities accessing screening services ‘although is not primarily because they are excluded from invitation for screening’. In addition, several questionnaire respondents within this study commented that cervical screening for women with learning disability per se was not seen as a priority problem within practices. The final data I compared this research project with was from a study which took place in June 2000. The study was by Broughton, S and Thomson K, both Community Nurses for Adults with Learning Disabilities based within the Lifespan Health Care NHS Trust, Princess of Wales Hospital, Ely, Cambridgeshire, England. This study focused on risk behaviours and experiences of the cervical screening test. Whilst, in comparison, this was a larger study, nonetheless the theme of the difficulty in attracting women to participate was consistent. Fifty two people in total took part, thirty four of the participants being carers. Whilst the findings in this research project do not focus on ‘risk behaviours’ a similar methodology was used in terms of gathering data on the actual smear test itself ie through semi-structured questionnaires (Broughton, S. and Thomson, K., 2000).

The analysis of the data gathered from one-to-one interviews would compare and contrast the findings of the above studies. This would allow further clarity on the reasons why there was a lower uptake of women with learning disabilities accessing screening services given that in the Edinburgh study it was identified by health professionals that this client group were not excluded from receiving an invite to screening.

## **Findings**

From the interview transcripts and notes taken during the interview process themes in terms of repeated words used and responses to questions were interpreted. Themes focused on feelings, beliefs and perceptions of women with learning disabilities, along with feelings, beliefs and perceptions of personal assistants/support workers, and the recurrent use of certain words and emotions which transpired during the interview process.

All of the women had mild or moderate learning disabilities and were of an age that they would have been invited for a cervical screening test. Of the three women with learning disabilities who were interviewed there was a common theme of negativity associated with cervical screening,

including recurrent use of language such as ‘embarrassment’, ‘pain’ and ‘cancer’. All women understood what cervical screening was, either through discussions with their personal assistants or through their own awareness. All of the women interviewed confirmed they were registered with a GP and visited at various times throughout the year for a variety of health issues, although none relating to sexual health. Of those interviewed, two had received invitations for screening, both had attended but only one agreed for the procedure to be carried out. One of the women (Elizabeth) had received an invitation for a cervical screening test but advised she had only managed to get so far into the procedure before refusing to go any further. It was difficult to ascertain exactly how far the cervical screening process had gone. Elizabeth’s view was that this was ‘too painful’ although had not gone through the full procedure. It was difficult to ascertain how she knew this was painful and she was unable to articulate the reasons herself. Elizabeth advised, after this attempt to get a test, she had asked her GP surgery not to send an invite for further screening and confirmed she has not received any further invites. Margaret advised she had the procedure carried out but found this embarrassing and painful. She described this as ‘it was embarrassing. It was uncomfortable. It was horrible [And that] it hurt a wee bit as well’. Margaret has been reluctant to attend for any further screening although mentioned that she did receive regular invites. Both Elizabeth and Margaret were asked to describe their experience within the GP surgery and what this involved. Both advised they weren’t made aware before the procedure what was involved and one said they didn’t want to ask. The third woman, despite being in the age range of between forty and fifty years old, stated that she had never received any invitation for screening. All women believed the test was testing specifically for ‘cancer’, two believing that any irregularity meant they had cancer. Margaret who had a smear test, commented that she was reluctant to open any correspondence relating to the findings of the test. Margaret’s response on receiving a follow up letter was:

*‘...they would just say you’d have to come back blah, blah, blah or whatever. I’d panic. I’d panic. I wouldn’t even phone them, I’d be too scared to phone them. If I got a letter in I’d panic. I would-nae tell anyone I’d just panic and just brush it under the table.’*

(Margaret)

From discussion with all three women it was clear that they believed the cervical screening test was to test for cancer, and not for potential signs that pre-cancer cells may be present and be treatable; therefore reducing the chance of cancer of their cervix developing fully. All three women giggled at times during the interview and said ‘it’s embarrassing’. One of the women, when asked if they would go to their GP for a test if they had been invited, said she would go but also mentioned that ‘I’m embarrassed {and laughs...}’. The use of the word ‘sex’ also brought similar reactions. The final woman (Jean) to be interviewed had been married and, despite being between the age of 40 and 50, she commented that she had never received a letter to attend for cervical screening and had never discussed this with her GP.

None of the women were aware of the signs and symptoms of cervical cancer, although Elizabeth advised she had a friend who developed breast cancer and regularly checked her breasts for signs of ‘lumps’. All three women were asked if they knew Jade Goody, a celebrity who had died of cervical cancer in 2009. Given the awareness this topic raised during the period of the diagnosis

and subsequent death of Jade Goody an insight into the women's understanding of the press coverage of this time would provide further insight. All three women confirmed they knew she had died, two knew she had died of cancer, although none knew she died of cervical cancer.

In order to gain a better understanding of how women with learning disabilities would be most likely to access cervical screening services all three women were asked what could assist them to make this process easier for them. Elizabeth advised that:

*'I'd find it too sore. You'd need to knock me out so I wouldn't feel it' and 'they would need to put me to sleep so I wouldn't feel anything. I hate pain. Honestly I hate pain.'*

(Elizabeth)

Furthermore, whilst Elizabeth agreed she would go along this, it would only be 'as long as I could get them to put me to sleep and wake me up after it' and repeated her view that this was 'too sore' although confirmed she had never had the procedure. Therefore, a conclusion here could be that there is a clear notion of perceived pain in a cervical test. Margaret said that it needs 'explained better' and in a way that she herself could understand. She advised if she wanted to find out anything she would 'Google it' rather than ask the Nurse or GP she visited.

Three personal assistants were also interviewed as part of this process. They were interviewed with the person they were supporting who also attended for interview. PA1, PA2, PA3 all had different ranges of experiences of working with women with learning disabilities, from less than one year to over ten. The three PA's were in the age range of 20-40. PA 1 had supported three or four women with learning disabilities over the time working in social care. She advised that she had never supported anyone for a cervical screening test, nor was she aware of any women who had attended a cervical screening test with the exception of one. Screening checks were never discussed with people she supported, family members or other agencies who also had responsibility for supporting the individual she did. PA1 believed the responsibility for ensuing regular screening tests taking place was with the family members or carers of those people who lived either at home or in any other residential settings. Whilst PA1 agreed the importance of routine screening and confirmed she attended all her own routine appointments, she believed there were 'other priorities' for people with learning disabilities and that one of the women she supports would see this as 'far down on the list' [of importance]. On discussing this further with PA1 and asking her opinion as to why women with learning disabilities don't access screening services she advised:

*'I think there is an assumption that people don't really understand then it's kind of just left. It's difficult to make somebody really understand the importance of it.'*

(PA1)

PA2 openly described her own cervical cancer experience at a young age and she was happy to discuss this with everyone else involved in the interview process. Whilst she has limited experience working with people with a learning disability she has worked in other social care settings with young adults. During her time working with young adult women, sexual health and

cervical screening was routinely discussed as part of group work. She said that she had reflected on the research question after this was discussed with her a few weeks previously and advised she was unaware of any female she had supported over the years who had received an invitation for cervical screening. PA1 and PA3 were unaware of the signs and symptoms of cervical cancer, although both said that if had anyone they were supporting informing them that there were changes within their monthly menstrual cycle, they would always advise them to go to the GP in the first instance. All three PAs were asked why they thought cervical screening was not followed up by either health services, family members or the women they supported with learning disabilities. A variety of answers including 'embarrassment', 'not important', 'not a priority' and 'scared' were all cited as reasons. PA2 stated that she had discussed this issue further with colleagues and friends, and anecdotally there was evidence of women with learning disabilities not accessing screening services for reasons such as: 'you're only young' and 'you've not had that many boyfriends.' PA2 believed there was an assumption that only women who were sexually active could contract cervical cancer.

One PA also advised that she believed there was a 'lack of education' for PAs, from her perspective, and more of an awareness and education on this issue was required. There was also a belief from another PA that it could be the staff member themselves who influence the decision on someone accessing cervical screening as they may be 'extremely embarrassed' themselves.

In comparing the findings of the Broughton and Thomson (2000) there were similarities in terms of the views of women with a learning disability who were interviewed. Comments gathered from the studies included:

*'It felt painful and awkward. It was painful after it was done and I bled afterwards'*

(Experience of one test)

*'Does it hurt? How long would it be uncomfortable? Do you have an injection?'*

(Woman not tested)

*'I have tried; it seemed so difficult and a bit uncomfortable, got all tensed up. Doctor said no we will leave it'*

(Abandoned test)

Similarly, when comparing the comments in the Broughton and Thomson, study for carers, including paid carers comments included:

*'We would like more information about women's health issues and some resources that the woman would be able to understand which show the smear test'*

(Paid carer)



*'It's about how you can get things across to people. Its hard at the end of the day.'*

(Paid carer)

Comments from both the women with learning disabilities and carers are generally the same and a consistent common theme from both studies has developed. Despite the study taking place in 2000, views and opinions of women with learning disabilities and their carers are similar, as is the treatment on attending for a smear test.

## **Conclusion**

From the analysis of both the literature review and the findings of the interview process there is reason to believe that cervical screening for women with learning disabilities is not routinely accessed. The data in the quantitative studies confirm this to be the case. Despite this being a small sample, the views, opinions and beliefs of the women with learning disabilities were similar throughout. All three women believed that this was an embarrassing procedure which they did not really understand and did not want to ask anyone about. There was a fear that the test would only identify cancer and there was no understanding of the potential stages before this diagnosis. Furthermore, one of the women perceived that the procedure was so painful that she would require to be sedated before this could occur despite the fact she had never had a smear test. Whilst it was difficult to tease out the specific reasons for this opinion it may well have been that she found herself in a predicament before the test that resulted in her becoming so distressed the thought of continuing was too difficult to bear. There is consistently a message of a lack of information, although the subject matter itself was agreed by the women with learning disabilities to be embarrassing and this may be why this perception is in place. From discussions with PA's and cited in Woods and Douglas (2007), there is a belief that this procedure is not a priority for either the women with learning disabilities, the staff who support them, or the health practitioners who work within GP surgeries. Despite this all three PAs agreed that the screening test was important for all women. In terms of the perceived influence of support staff over the person they are supporting it was noted that a lack of awareness, education and assumptions were in place which prevented this issue being raised. Whilst the PAs present were comfortable discussing the subject there was an opinion that this may be embarrassing for some other PAs. Therefore, if this is embarrassing for the PAs themselves they may be less likely to raise this subject whilst supporting an individual. The influence that PAs have over the person they are supporting is implicit here and is an area which requires further exploring. Given that a close bond can form between someone supported and their PA cervical screening is not a subject which is discussed routinely. There appeared to be an acceptance that women with learning disabilities do not attend cervical screening. A number of reasons for this were given and some of these were anecdotal. One of these was the assumption that women with learning disabilities were not sexually active or this was not a subject which was discussed. The mention of the word 'sex' or "sexual partners" within the interview caused embarrassing giggles and laughs and the subject was not able to be fully explored as those being interviewed were experiencing some discomfort.

Furthermore, despite this being a similar study to the one carried out by Broughton, and Thomson (2000), there is evidence that there have been no changes to the feelings and beliefs of women in accessing cervical screening services. The same issues were noted on both pieces of research and, despite this being 15 years later, the women and personal assistants/carers interviewed answered in similar ways.

The aim of this research project was to identify the enablers and barriers for women with learning disabilities accessing screening services. From the data collated and analysed, the barriers could be pain, perceived pain, embarrassment and lack of information that can be easily understood. To best enable women to attend for screening an awareness and education of the importance of attending the appointment for both PAs and people supported should be raised. Visits to GP surgeries before screening, with an opportunity to discuss the procedure in more detail, would also assist, as would a reassuring PA who would attend the appointment with the person whilst keeping a discrete distance during the procedure itself. There is no single approach which would assist but an awareness and understanding of all of the potential barriers and enablers could be a start in ensuring the women with learning disabilities are able to access cervical screening services in the same way as the general population.

## How to Reference this Report

When making use of this material, use the following reference for this report:

Monteith, E. (2015) 'What helps women who have learning disabilities get checked for cervical cancer?' Scotland: CRFR/IRISS.

## References

- Broughton, S. and Thomson, K. (2000), Women with learning disabilities: risk behaviours and experiences of the cervical smear test. *Journal of Advanced Nursing*, 32: 905-912
- Bryman, A. (2012). *Social Research Methods*. In A. Bryman, *Social Research Methods* (p. 44).
- Djuretic T., Laing-Morton T., Guy M. & Gill M. (1999) Concerted effort is needed to ensure these women use preventive services. *BMJ*, 318: 536.
- Emerson, E., & Baines, S. (2011). *Health Inequalities & People with Learning Disabilities in the UK: 2010*. Department of Health.
- Gordon, D., Graham, L., Robinson, M., & Taulbut, M. (2010). *Dimensions of Diversity: Population Differences and Health Improvement Opportunities*. Retrieved from Glasgow: NHS Health Scotland: <http://www.healthscotland.com/uploads/documents/18111-DimensionsOfDiversity.pdf>
- Health Needs Assessment Report – Summary - People With Learning Disabilities In Scotland. (2004). NHS Scotland .
- Kitzinger, K., & Barbour, R. (1999). *Developing Focus Group Research: Politics, Theory and Practice*. In R. B. Jenny Kitzinger. SAGE Publishing.
- Langan J., Whitfield M. and Russell O. (1994) Paid and unpaid careers: their role in and satisfaction with primary care for people with learning disabilities. *Health and Social Care* 2, 357 - 365
- Osborn, D., Horsfall, L., Hassiotis, H., Petersen, I., Walters, K., & Nazareth, I. (2012). Access to Cancer Screening in People with Learning Disabilities in the UK: Cohort Study in the Health Improvement Network, a Primary Care Research Database. *PLOS ONE*, 7(12).
- Stein, K., & Allen, N. (1999). Cross sectional survey of cervical cancer screening in women with learning disability. *BMJ*, 318.
- Stones, E. (1994). *Quality Teaching: A Sample of Cases*. In E. Stones. Routledge.
- Strauss, A. (1987). *Qualitative Analysis for Social Scientists*. In A. L. Strauss. Cambridge University Press.
- The Healthcare Quality Strategy for NHS Scotland. (2010). Retrieved from <http://www.gov.scot/Publications/2010/05/10102307/8>

The Keys to Life - Improving Quality of Life for People with Learning Disabilities. (2013, June). Retrieved from The Scottish Government: <http://www.gov.scot/Publications/2013/06/1123>

The Same As You? A review of services for people with learning disabilities. (2000). Retrieved from Scottish Consortium for Learning Disability: Scottish Consortium for Learning Disability

The Scottish Government. (2013, June). Retrieved from The keys to life - Improving Quality of Life for People with Learning Disabilities: <http://www.gov.scot/Publications/2013/06/1123>

Yu C.K.H. and Rymer, J. (1998) Women's attitudes to awareness of smear testing and cervical cancer. *British Journal of Family Planning* 23, 127-133.

Wood, R., & Douglas, M. (2007). Cervical screening for women with learning disability: current practice and attitudes within primary care in Edinburgh. *British Journal of Learning Disabilities*, 32(2), 84-92.

## My project



My name is Elaine Monteith.

I work for ENABLE Scotland.



I am working on a project for the Institute of Research in Social Services (IRISS) and the University of Edinburgh.

I hope the project will help people who get support from ENABLE Scotland.

I hope the project will also help people who get support from other organisations.

## What my project is about



All women are asked to go to the doctor every few years for a check for cancer.

I want to find out what women who have learning disabilities think about going to the doctor for these checks.

I think it is important that all women have the chance to go for these checks.

I want to find out why some women who have learning disabilities don't go to the doctor for these checks.

I want to find out what would help women go to the doctor for checks.

I want to find out what women who **have** gone to the doctor for these checks think about them.

## What I will do



I will interview some women who have a learning disability.

It will just be one woman and me at the interview.



I will also interview staff who support the women.



I will ask the women and the staff some questions.



I will record the questions and answers with a microphone.

This will help me remember what people say.



When I have done all the interviews I will write a report.

The report will say what women think about going to the doctors for checks.

Anyone who is interested in the report will be able to read it.



I will not put the names of the people I interviewed in the report.

I will put things they say in the report.

But no one will be able to tell who the people are from what they have said.

## Appendix 2

### Consent form

Please tick ✓ the Yes or No box for each question.

- I know why Elaine is interviewing me. Yes  No
- I am happy for Elaine to record my answers. Yes  No
- I know that if I want to stop the interview I can stop it at any time. Yes  No
- I know that Elaine will not tell anyone else what I say in the interview. Yes  No
- I know that Elaine might write down things I say in her report. But she will not put my name in her report. Yes  No
- I know that no one who reads the report will be able to tell who I am from anything in it. Yes  No
- I know that if I tell Elaine something which might harm me or someone else that Elaine might share this with other people. Yes  No
- I know that once Elaine has written the report she will get rid of any paperwork and delete the recording of my interview. Yes  No

Please sign here: .....

Today's date is:.....