

EAR: Engaging in Autism Research - a survey study with the

Survey Information

My name is Sue Fletcher-Watson, and I am a research psychologist based at Edinburgh University, UK, with a particular interest in the study of autism spectrum disorders. I am part of an international group of researchers running this online survey to investigate how the autism community feels about research into the earliest signs of autism in babies.

Before you proceed, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information: sue.fletcher-watson@ed.ac.uk

This survey will gather information from people with an interest in autism research, with a particular focus on:

- Parents of a child with autism
- Autistic people
- Practitioners (teachers, doctors, therapists) who work with individuals with autism

The goal is to find out how these different 'stakeholders' feel about a specific strand of research which is looking for the earliest signs of autism in babies and toddlers.

The questions on the next few pages will ask you about

- You – your gender, where you live (country only), your age, your education and your job
- We will also ask you to define your role in the autism community and ask you specific questions based on that definition. For example, parents will be asked about the ages, genders and diagnostic status of their children. Adults will be asked about their own diagnosis. Practitioners will be asked about their qualifications and client group.
- The main part of the survey will be asking about how you think research into early autism should be done.

We will not ask for any identifying information – e.g. your name, your full address.

Using the survey data, we will be writing a document for researchers to help them respond to the community when designing new studies. We will also write a short, accessible report for everyone who took part in the study. If you want, at the end of the survey, you can fill in your email address to receive a copy of this document when it is completed.

Ethics approval has been given by the University of Edinburgh. Copies of this letter are available if you wish to see them.

Thank you for taking the time to read this Information. If you are happy to proceed please move to the next page and complete the consent form

Consent form

Please read the consent form below:

***1. If you are happy to complete this survey, please complete the consent form by selecting each item:**

- I have read and understood the survey information sheet
- I understand that all data collected from this survey will be anonymously coded and stored confidentially and securely
- I am willing to take part in this research survey

Respondent categories

2. Please provide your gender.

- Male
- Female
- Would rather not categorise myself

3. Please provide your age.

4. Please state the country you are originally from:

5. Please state the country you are living in:

***6. Please choose the one respondent category that best applies to your situation. Please note you can answer the survey in only one way. For example, if you are both a parent and an autistic adult please choose only one category.**

- Autistic Adult
- Parent
- Practitioner (e.g. medic, therapist)
- Teacher
- Other (please specify)

Practitioner respondent background

7. Please provide your job title.

8. Please state the country you are currently practicing in.

Country:

9. Please list your qualifications by ticking all that apply:

- Speech and language therapy
- Clinical Psychology
- Occupational therapy
- Psychiatry
- Pediatrics

Other (please specify)

10. How many years of experience with autism do you have?

- Less than 2 years
- 2 to 5 years
- 5 to 10 years
- More than 10 years

11. Please describe the type of clients you work with (tick all that apply):

- Preschoolers
- Children
- Adolescents
- Adults
- With learning disabilities
- With co-morbid conditions (e.g. ADHD)
- With mental health conditions (e.g. anxiety)

Other (please specify)

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12. Please provide information on the forms of client contact that you are mostly involved in by ticking all that apply:

- Diagnosis
- ABA therapy
- Parent Training
- Other behavioral intervention
- Pharmaceutical intervention
- Therapy for comorbidities e.g. depression, anxiety
- Cognitive Behavioral Therapy
- Speech and Language Therapy
- Occupational therapy
- Other therapies

Other (please specify)

13. Please rate your knowledge of autism.

	Some knowledge	Average knowledge	Good knowledge
Autism generally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early signs of autism (under 3 years old)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. How would you rate the autism support and intervention services available in your region?

	Not useful	A little bit useful	Useful	Very useful
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. How are these services mostly provided?

	Free, provided by the state	For a price, provided by the state	For a price, provided by private services
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. I have answered all questions on this page and I am ready to continue.

- Yes
- No

Teacher respondent background

17. Please state the type of institution you work in: specialist school or mainstream school?

- Autism specialist school
- Other specialist school
- Mainstream school

Other (please specify)

18. Please state the country you are working in at the moment.

Country:

19. What is your role in the school?

- Headteacher
- Department head
- Class teacher
- Learning support assistant

Other (please specify)

20. Does your school offer autism training for staff?

- Yes
- No

21. How many years of experience with autism do you have?

- Less than 2 years
- 2 to 5 years
- 5 to 10 years
- More than 10 years

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22. What kind of pupils do you work with? Please tick all that apply.

- Preschoolers
- Children
- Adolescents
- Adults
- With learning disabilities

Other (please specify)

23. Please provide information on the approaches you are mostly involved with by ticking all that apply:

- Intervention: TEACCH
- Intervention: SCERTS
- Intervention: PECS
- Intervention: ABA (applied behavioural analysis)
- Speech and language therapy
- Play groups
- Social / peer support groups

Other (please specify)

24. Please rate your knowledge of autism.

	Some knowledge	Average knowledge	Good knowledge
Autism generally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early signs of autism (under 3 years old)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. How would you rate the autism support and intervention services available in your region?

	Not very useful	A little bit useful	Useful	Very useful
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educational services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. How are these services mostly provided?

	Free, provided by the state	For a price, provided by the state	For a price, provided by private services
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. I have answered all questions on this page and I am ready to continue.

- Yes
- No

Parent respondent background

28. How old were you when you left full time education?

29. Please tell us about your current or most recent employment:

- Professional: e.g. doctor, lawyer, teacher, manager
- Non-manual skilled: e.g. typist, police officer, fireman
- Manual skilled: e.g. toolmaker, foreman, ambulance man
- Partly skilled: e.g. bus conductor, postman
- Unskilled: cleaners, porters, messengers
- Unemployed for the majority of adult life
- Homemaker
- Supported employment scheme
- Still in full time education
- Other (please specify)

Other (please specify)

30. Do you have/or think you might have an autism diagnosis?

- Yes
- No

31. Please rate your knowledge of autism.

	Some knowledge	Average knowledge	Good knowledge
Autism generally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early signs of autism (under 3 years old)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. How would you rate the autism support and intervention services available in your region?

	Not very useful	A little bit useful	Useful	Very useful
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

33. How are these services mostly provided?

	Free, provided by the state	For a price, provided by the state	For a price, provided by private services
Autism support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intervention services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. If you have answered all questions on this page please tick "yes" and on the next page we will ask you about your child with autism.

- Yes
- No

Parents with autistic children background

35. How many children do you have?

36. How many of your children are autistic?

Please answer all following questions with respect to your youngest child with autism

37. How old was your child (in years) when he/she was diagnosed with autism?

If still waiting for a diagnosis enter 99

38. How old is that child now (in years)?

39. What is the gender of that child?

- Male
- Female

40. Does your youngest child with autism have learning difficulties?

- Yes
- No
- I am not sure

41. When did you first have concerns about your youngest autistic child?

- Less than 2 years of age
- 2 to 4 years of age
- 4 to 6 years of age
- 6 to 10 years of age

At an older age (please specify)

42. Who was the first person to raise concerns?

- Myself
- Another family member
- A teacher
- A doctor/other health professional
- A researcher
- Other

Other (please specify)

43. If you have used any autism support services available to you, which ones have you accessed for or with your child?

Please tick all that apply.

- Psychiatry services
- Clinical psychology services
- Pediatrician services
- Specialist education
- Specialist pre-school
- Speech and language therapy
- Occupational therapy
- Private intervention services
- Other

Other (please specify)

44. Is there anything else you want to tell us about yourself or your family?

45. I have answered all questions on this page and I am ready to continue.

- Yes
- No

Autistic Adult respondent background

46. How old were you when you were diagnosed with autism?

47. How old were you when you left full time education?

48. Please tell us about your current or most recent employment:

- Professional: e.g. doctor, lawyer, teacher, manager
- Non-manual skilled: e.g. typist, police officer, fireman
- Manual skilled: e.g. toolmaker, foreman, ambulance man
- Partly skilled: e.g. bus conductor, postman
- Unskilled: cleaners, porters, messengers
- Unemployed for the majority of adult life
- Homemaker
- Sheltered employment
- Still in full time education
- Other (please specify)

Other (please specify)

49. Are you living:

- Alone
- With family
- With a partner
- With friends
- In a rented house/flat
- In sheltered accommodation
- Other

Other (please specify)

50. Do you have children?

- Yes
- No

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Intro text

The questions on the next few pages will ask you about a specific area of autism research looking at early signs of autism in babies and toddlers. Please read this background information before going on to the next stage of the survey.

Autism is rarely diagnosed before the age of three years old. So there are three important years of development which we know very little about. Also, autism is present in about 1% of the population. This means we'd need to work with 1000 babies in order to find just 10 who turn out to have an autism diagnosis later on. So instead researchers recruit babies with a higher-than usual likelihood of developing autism. These are often babies who already have an older brother or sister with autism, or sometimes babies who are born premature.

You may have been involved in a study like this, or heard about it. It is a big commitment for families, as they are asked to come in for a series of appointments from when their child is very young (maybe just after birth) until they are three years old or more. Families may be asked to wait a long time before they receive any information about their child's personal profile and these studies do not replace usual diagnostic services.

Sometimes the studies involve an 'intervention' - some extra help for parents or children, designed to support positive progress. However more often the studies are 'observational' meaning that researchers record information about the child in the study but don't change anything or make any suggestions to parents.

Reasons for Research

51. Do you think research into the early signs of autism should be done?

- Definitely yes
- Probably yes
- Probably not
- Definitely not
- Not sure

52. What are the most important questions scientists should be asking about early autism?

Please rank the options in order of importance, where 1 = most important

You can rank options by selecting the number in the menu on the left or dragging them up and down into the right place.

<input type="text"/>	What is the genetic basis of autism?
<input type="text"/>	Is autism present before birth?
<input type="text"/>	How does autism develop in early life?
<input type="text"/>	What are the signs of autism in babies?
<input type="text"/>	What aspects of the environment (i.e. things we can change) contribute to autism?
<input type="text"/>	When does autism "start"?
<input type="text"/>	Are all infants who later get an autism diagnosis alike?

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53. What should be the main goal of research into the early signs of autism?

Please rank the options in order of priority, where 1 = highest priority

You can rank options by selecting the number in the menu on the left or dragging them up and down into the right place.

<input type="text"/>	To identify autism earlier in life
<input type="text"/>	To help very young children develop skills which mean they don't later get an autism diagnosis
<input type="text"/>	To provide clinicians with better understanding of the early signs of autism
<input type="text"/>	To help parents who are concerned get a quick and simple diagnosis
<input type="text"/>	To help design intervention programmes
<input type="text"/>	To understand the unique development of autistic children
<input type="text"/>	To help provide services for young children at higher likelihood of autism

54. What practical information could research provide for you or for people in your situation?

Please rank the options in order of importance, where 1 = most important

You can rank options by selecting the number in the menu on the left or dragging them up and down into the right place.

<input type="text"/>	What are the early signs of autism in babies
<input type="text"/>	What is the pathway by which young children with autism develop
<input type="text"/>	What are the most effective early interventions for autism
<input type="text"/>	What are the environmental factors (i.e. things we can change) which contribute to autism
<input type="text"/>	What is the chance that I will have a second child with autism if I already have one
<input type="text"/>	What is the chance that I will have an autistic child if I have autism

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55. What should be the direct benefits for people who take part in early autism research studies?

Please rank the options in order of importance, where 1 = most important

You can rank options by selecting the number in the menu on the left or dragging them up and down into the right place.

<input type="text"/>	Information about autism generally
<input type="text"/>	Information about themselves and their family
<input type="text"/>	Insight into the research process
<input type="text"/>	Detailed profiles of their child with autism (e.g. strengths and difficulties, ability level)
<input type="text"/>	Detailed profiles of their other children (e.g. strengths and difficulties, ability level)
<input type="text"/>	Access to new intervention techniques
<input type="text"/>	Attention from an expert clinical and research team

Involvement

Please think about if you were considering being part of an early autism research study, as a participating family.

56. How would you prefer to be contacted about involvement in a new research study?

Please tick all that apply

- Personal phone call
- Personal email
- A personal letter
- By subscription to a research newsletter
- Personal referral from a clinician

Other (please specify)

57. How would you like to receive more information about it, after the initial approach?

- Information on a website
- Face to face with a researcher
- Face to face with a clinician
- A letter from the research team
- A letter from a clinician
- A phone call from the research team
- A phone call from a clinician
- Email from the research team
- Email from a clinician

Other (please specify)

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58. What information is most important in making your decision to become involved or not?

Please rank the statements where 1 = most important.

You can assign rankings by using the menus on the left or dragging statements up and down.

<input type="text"/>	The science behind the research
<input type="text"/>	Time commitment for participants in the study
<input type="text"/>	What it will involve for you
<input type="text"/>	What it will involve for your child
<input type="text"/>	Details about the expertise of the research team
<input type="text"/>	The long-term goals of the research
<input type="text"/>	Whether there is an intervention component

Measurements

These questions are about the type of information that researchers might collect in early autism studies. If you are not, please imagine that you are the parent of an autistic child.

59. Which types of information would you allow to be collected from your child?

Please tick all that apply

	Definitely not	Probably not	Probably yes	Definitely yes	I don't know what this is
Blood samples	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA samples (cheek swab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain scans (MRI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recording where they are looking (non-invasive eye-tracking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Film of your child playing with you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Film of your child playing with a researcher	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Copies of medical records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnostic assessments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability tests (i.e. mental age tests)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other play-based tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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60. Which types of information would you allow to be collected from you?

Please tick all that apply

	Definitely not	Probably not	Probably yes	Definitely yes	I don't know what this is
Blood samples	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA samples (cheek swab)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain scans (MRI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recording where I am looking (non-invasive eye-tracking)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Film of you playing with your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Questionnaires about you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Questionnaires about your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family medical history report form	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Copies of medical records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnostic assessments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Measures of autism characteristics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability tests (i.e. IQ tests)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other puzzle-based tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

61. Where and how would you agree to assessments taking place?

	Definitely not	Probably not	Probably yes	Definitely yes
Home visits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visits to a university	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visits to a hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
By post	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

62. After data has been collected, what information should be disclosed to the parent?

Please tick all that apply

- Full disclosure of child's scores on everything
- Only inform parent if there is cause for concern
- Pass on any concerns to the child's GP rather than parents directly
- Don't tell parents anything
- General study findings

Other (please specify)

63. Do you have any other comments on measurement issues in autism research?

Intervention

64. Some early autism studies have an intervention component. How do you feel about this?

- Essential part of involvement
- Not essential for involvement to be worthwhile
- Would prefer studies not to involve intervention

65. Should an intervention be offered if it is not yet proven to be effective?

- Yes
- No

66. If provided, who should an intervention be provided for?

Please order in terms of priority where 1 = highest priority.

You can assign rankings by using the menus on the left or dragging statements up and down.

<input type="text"/>	Infants and young children who are more likely to develop autism
<input type="text"/>	Infants and young children who display early signs of autism
<input type="text"/>	Infants and young children who have a confirmed diagnosis
<input type="text"/>	Infants and young children who are experiencing difficulties associated with autism
<input type="text"/>	Infants and young children whose parents have raised concerns

67. What sort of interventions would be preferred?

Please rank the statements where 1 = most preferred.

You can assign rankings by using the menus on the left or dragging statements up and down.

<input type="text"/>	One-to-one therapy at home
<input type="text"/>	One-to-one therapy in a clinic
<input type="text"/>	Parent-training
<input type="text"/>	Technology-based intervention (e.g. online advice, therapeutic iPad apps)
<input type="text"/>	Nursery staff training
<input type="text"/>	Medical (drugs) intervention

At-risk Language

68. Academic papers in this research area often use the phrase “at risk” to describe babies who are more likely to receive a diagnosis of autism later, because they have an older sibling with autism or because of another factor (e.g. being born very pre-term).

What other language could we use instead?

Please rank phrases from the one you like best (1) to the one you like least (7).

<input type="text"/>	Special infant groups
<input type="text"/>	Infants with high autism likelihood
<input type="text"/>	Infants susceptible to autism
<input type="text"/>	Pre-autistic infants
<input type="text"/>	Infants with higher chance of developing autism
<input type="text"/>	Infants with increased susceptibility for autism
<input type="text"/>	Infants at risk of autism

69. Any other suggestions?

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Statements

70. Before creating this survey we ran some group discussions with members of the autism community. How much do you agree or disagree with the statements below, which we collected from these focus groups?

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Sharing information between researchers and participating parents is essential	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in an early autism study might influence parenting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autism diagnosis is not necessarily a negative outcome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents don't necessarily realise that autism is influenced by genetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
'at-risk' language makes parents feel that they are to blame for their child's autism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early autism studies ignore the older sibling who already has a diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents want to work with clinicians not researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early autism studies should include an intervention, not just observation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting earlier diagnosis of autism is important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Early autism researchers assume that autism diagnosis is a negative outcome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents in a long-running study might change their mind about what they want to agree to as the study goes on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-running studies should be responsive to families' needs and opinions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Final Comments

Thank you very much for completing this survey!

71. Is there anything else you would like to tell us?

72. Once all responses have been collected we will be writing a short report. If you would like to receive a copy of this please leave your email address below. It will not be used for any other purpose.