



REACH-ASD
T R I A L

BASELINE RESEARCHER BOOKLET

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|--------------------|--|
| PPT ID | |
| Visit Date | |
| Name of Researcher | |

Participant Information

REGISTRATION FORM

| | | |
|---|--|---|
| 1 | Index adult initials (up to 3 alpha) | |
| 2 | Index adult date of birth (DD/MM/YYYY) | |
| 3 | Date of consent (DD/MM/YYYY) | |
| 4 | Index adult gender | 1 Male 2 Female 3 Non-binary/third gender 4 Prefer to self-describe 5 Prefer not to say |

ELIGIBILITY

| INCLUSION CRITERIA | | |
|---------------------------|---|----------|
| 1 | At consent, child aged between 2 years 0 months and 15 years 11 months | Yes / No |
| 2 | At referral, child with a diagnosis of ASD from an NHS professional within the last 12 months. This is the age-range typically seen by ASD diagnostic teams. | Yes / No |
| 3 | One 'index' adult (child's parent/primary caregiver; must be aged 18 years or over) per child, nominated by family on 'intention to participate' basis | Yes / No |
| 4 | Child with ASD is a patient of one of the trial collaborating centres | Yes / No |

| EXCLUSION CRITERIA | | |
|---------------------------|--|----------|
| 1 | Adult with insufficient English to preclude participation | Yes / No |
| 2 | Adult with significant learning disability or significant hearing/visual impairment to preclude participation | Yes / No |
| 3 | Adult with current severe psychiatric condition to preclude participation | Yes / No |
| 4 | Significant current safeguarding concerns within family, identified by referring clinician | Yes / No |

Service Use Interview

Please be extremely careful to avoid unblinding. We do not require any information about EMPOWER-ASD or any groups you have attended to learn about autism. This will be collected separately and placed in a confidential envelope to prevent researcher unblinding.

Instructions

The interview covers parent's use of health and social care services for the **six** months preceding the interview, as well as time off work during the same period. Unless specified each section should contain details of all attended healthcare services (physical and mental health).

Note that this carer service use schedule should be completed in accordance with the adverse events form.

Missing codes

777 = not applicable, 888 = not done, 999 = unknown

Please enter a response, a zero or a missing code into every box.

Please do not leave any box blank.

SECTION A: USE OF HOSPITAL SERVICES

Use of hospital inpatient services

| | | | |
|----------|---|---|------------|
| 1 | Have you had an overnight stay in hospital in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you have had a hospital overnight stay, please tell us about each stay you have had in the last 6 months using the table below.

| 2 | 3 | 4 | 5 | 6 |
|--|--|-----------------------------------|--|---|
| Reason for admission <i>Give details</i> | Speciality <i>Select code from list below.</i> | <i>If 'other', please specify</i> | Planned or unplanned? <i>1. planned 2. unplanned</i> | Number of nights spent in hospital <i>in whole days</i> |
| | | | | |
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Speciality codes list

| | | |
|-------------------------------------|--|----------------------------|
| 1. Anaesthetics | 11. General psychiatry | 21. Trauma & Orthopaedics |
| 2. Cardiology | 12. Gynaecology | 22. Perinatal psychiatry |
| 3. Critical care | 13. Haematology | 23. Physiotherapy |
| 4. Clinical psychology | 14. Liaison psychiatry | 24. Psychotherapy |
| 5. Dermatology | 15. Maternity/obstetrics | 25. Radiotherapy |
| 6. Diagnostic imaging (X-ray/Scans) | 16. Nephrology/renal unit | 26. Rheumatology |
| 7. Ear nose and throat (ENT) | 17. Neurology (including stroke services) | 27. Urology |
| 8. Forensic psychiatry | 18. Nutrition and dietetics | 28. Other (please specify) |
| 9. Gastroenterology | 19. Oncology | |
| 10. General surgery | 20. Ophthalmology | |

Use of hospital outpatient and day appointments

| | | | |
|----------|--|---|------------|
| 7 | Have you had any planned hospital outpatient appointments (lasting 4 hours or less) or day appointments (lasting more than 4 hours) in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you have had a hospital appointment, please tell us about each visit you have had in the last 6 months using the table below.

| 8 | Reason for visit <i>Give details</i> | 9 | Speciality <i>Select code from list below</i> | 10 | <i>If 'other', please specify</i> | 11 | Outpatient or Day? <i>1. Outpatient 2. Day</i> | 12 | Number of visits |
|----------|--|----------|---|-----------|-----------------------------------|-----------|--|-----------|-------------------------|
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| Speciality codes list | | | |
|------------------------------|-------------------------------------|-----|--|
| 1. | Anaesthetics | 11. | General psychiatry |
| 2. | Cardiology | 12. | Gynaecology |
| 3. | Critical care | 13. | Haematology |
| 4. | Clinical psychology | 14. | Liaison psychiatry |
| 5. | Dermatology | 15. | Maternity/obstetrics |
| 6. | Diagnostic imaging (X-ray/Scans) | 16. | Nephrology/renal unit |
| 7. | Ear nose and throat (ENT) | 17. | Neurology (including stroke services) |
| 8. | Forensic psychiatry | 18. | Nutrition and dietetics |
| 9. | Gastroenterology | 19. | Oncology |
| 10. | General surgery | 20. | Ophthalmology |
| | | 21. | Trauma & Orthopaedics |
| | | 22. | Perinatal psychiatry |
| | | 23. | Physiotherapy |
| | | 24. | Psychotherapy |
| | | 25. | Radiotherapy |
| | | 26. | Rheumatology |
| | | 27. | Urology |
| | | 28. | Other (please specify) |

Use of A&E departments

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|-----------|---|---|------------|
| 13 | Have you attended an accident and emergency (A and E) department in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| 14 | Reason for visit <i>Give details</i> | 15 | Admitted as an inpatient or not admitted? <i>1. Admitted 2. Not admitted 0. No A&E</i> | 16 | Ambulance or no ambulance? <i>1. Ambulance 2. No ambulance</i> | 17 | Number of visits |
|-----------|--|-----------|--|-----------|--|-----------|-------------------------|
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SECTION B: USE OF PRIMARY AND COMMUNITY-BASED HEALTH, SOCIAL AND COMPLEMENTARY SERVICES

Use of primary, community, social and complementary care health services

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| 18 | Have you used any primary, community, social and complementary care health services in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| | Primary health care service | Number of contacts |
|-----------|---|--------------------|
| 19 | GP (at the surgery/practice) | |
| 20 | GP (at your home) | |
| 21 | Practice nurse (at the surgery/practice) | |
| 22 | Practice nurse (at your home) | |
| 23 | District nurse, health visitor, midwife | |
| 24 | NHS walk-in clinic | |
| 25 | Community psychiatric nurse | |
| 26 | Psychiatrist in the community | |
| 27 | Clinical Psychologist | |
| 28 | Other Mental Health Practitioner/Therapist e.g. IAPT, CBT Therapist | |
| 29 | Psychotherapist/Counsellor | |
| 30 | Social worker | |
| 31 | Advice service e.g. Citizen's Advice Bureau, housing association | |
| 32 | Helpline e.g. Samaritans, MIND | |
| 33 | Complementary therapy e.g. homeopathy, acupuncture etc | |
| 34 | Self-help groups e.g. AA | |

| | | | |
|-----------|---|-----------|---|
| 35 | Have any other primary health care services been stated? | 1 | Yes |
| | | 0 | No |
| 36 | Other <i>Give details</i> | 37 | Is this a privately funded mental health service? <i>1. Yes</i> <i>0. No</i> |
| | | 38 | Number of contacts |
| | | | |
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SECTION C: MEDICATION – PSYCHOTROPIC ONLY

Use of medication for mental health problems only (plus sleeping tablets)

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|-----------|--|---|------------|
| 39 | Have you used any medication for mental health problems and/or sleeping tablets in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| 40 | Medication <i>Select code from list below</i> | 41 | <i>If other medication, please state</i> | 42 | Goal of treatment <i>Select code from list below</i> | 43 | Weeks in the last 6 months | 44 | Continuing treatment? <i>1. Yes 0. No</i> |
|----|---|----|--|----|--|----|-----------------------------------|----|---|
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Medication list

- | | | |
|---|--|--|
| <ul style="list-style-type: none"> 1. Alprazolam 2. Amitriptyline (Triptafen) 3. Amoxapine (Asendis) 4. Buspirone (Buspar) 5. Chlorazepate (Tranxene) 6. Chlordiazepoxide 7. Citalopram (Cipramil) 8. Clomipramine (Anatranil) 9. Diazepam 10. Dosulepin (Dothiepin) 11. Escitalopram (Cipralext) 12. Fluoxetine (Prozac) 13. Flupentixol (Fluanxol) 14. Flurazepam (Dalmane) | <ul style="list-style-type: none"> 15. Fluvoxamine (Faverin) 16. Imipramine (Tofranil) 17. Isocarboxazid 18. Lofepramine (Gamanil) 19. Loprazolam 20. Lorazepam 21. Lormetazepam 22. Maprotiline (Ludiomil) 23. Meprobamate 24. Mianserin 25. Mirtazepine (Zispin) 26. Moclobemide (Manerix) 27. Nitrazepam 28. Nortriptyline (Allegron/Motival) | <ul style="list-style-type: none"> 29. Oxazepam 30. Paroxetine (Seroxat) 31. Phenelzine (Nardil) 32. Reboxetine (Edronax) 33. Sertraline (Lustral) 34. Temazepam 35. Tranylcypromine 36. Trazodone (Molipaxin) 37. Trimipramine (Surmontil) 38. Zapelon (Sonata) 39. Zolpidem (Stilnoct) 40. Zopiclone (Zimovane) 41. Other 0. No medications stated |
|---|--|--|

Goal of treatment list

- 1. Alcohol or substance use disorder
- 2. Generalized anxiety disorder
- 3. Adult Attention Deficit/Hyperactivity
- 4. Bipolar disorder
- 5. Depression
- 6. Eating disorder
- 7. Schizophrenia
- 8. Obsessive-compulsive disorder
- 9. Posttraumatic stress disorder
- 10. Other

SECTION D: TIME OFF WORK

Time off work due to unanticipated childcare and/or health reasons

| | | | |
|-----------|---|---|------------|
| 45 | Have you needed to take time off work in the last 6 months, either to take your child to health and social care appointments, or due to your own health? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| | | |
|-----------|---|--|
| 46 | Absent from work due to child's Autism (any appointments, behaviour/wellbeing) <i>Time missed (days, including half days)</i> | |
|-----------|---|--|

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| 47 | Absent from work due to child's health and social care (excluding the above) <i>Time missed (days, including half days)</i> | |
|-----------|---|--|

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| 48 | Absent from work due to own physical health <i>Time missed (days, including half days)</i> | |
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|-----------|--|--|
| 49 | Absent from work due to own mental health <i>Time missed (days, including half days)</i> | |
|-----------|--|--|

CHILD SERVICE USE INTERVIEW

Instructions

The interview covers child's use of health and social care services for the **six** months preceding the interview. Please remind carers that this should include services they have attended with the child, as well as services that the child has attended alone (if applicable).

Note that school-based services should not be captured in this form as they are excluded from data collection.

Missing codes

777 = not applicable, 888 = not done, 999 = unknown

Please enter a response, a zero or a missing code into every box.

Please do not leave any box blank.

SECTION A: USE OF HOSPITAL SERVICES

Use of hospital inpatient services

| | | | |
|-----------|---|---|------------|
| 50 | Has your child had an overnight stay in hospital in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If your child has had a hospital overnight stay, please tell us about each stay they have had in the last 6 months using the table below.

| 51 | Reason for admission <i>Give details</i> | 52 | Speciality <i>Select code from list below.</i> | 53 | If 'other', <i>please specify</i> | 54 | Planned or unplanned? <i>1. planned 2. unplanned</i> | 55 | Number of nights spent in hospital <i>in whole days</i> |
|----|---|----|---|----|--------------------------------------|----|---|----|--|
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| 5. Dermatology | 15. Maternity/obstetrics | 25. Radiotherapy |
| 6. Diagnostic imaging (X-ray/Scans) | 16. Nephrology/renal unit | 26. Rheumatology |
| 7. Ear nose and throat (ENT) | 17. Neurology (including stroke services) | 27. Urology |
| 8. Forensic psychiatry | 18. Nutrition and dietetics | 28. Other (please specify) |
| 9. Gastroenterology | 19. Oncology | |
| 10. General surgery | 20. Ophthalmology | |

Use of hospital outpatient and day appointments

| | | | |
|-----------|--|---|------------|
| 56 | Has your child had any planned hospital outpatient appointments (lasting 4 hours or less) or day appointments (lasting more than 4 hours) in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If your child has had a hospital appointment, please tell us about each visit they have had in the last 6 months

| 57 | Reason for visit <i>Give details</i> | 58 | Speciality <i>Select code from list below</i> | 59 | <i>If 'other', please specify</i> | 60 | Outpatient or Day? <i>1. Outpatient 2. Day</i> | 61 | Number of visits |
|-----------|--|-----------|---|-----------|-----------------------------------|-----------|--|-----------|-------------------------|
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Speciality codes list

| | | |
|-------------------------------------|---|----------------------------|
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| 7. Ear nose and throat (ENT) | 17. Neurology (including stroke services) | 27. Urology |
| 8. Forensic psychiatry | 18. Nutrition and dietetics | 28. Other (please specify) |
| 9. Gastroenterology | 19. Oncology | |
| 10. General surgery | 20. Ophthalmology | |

Use of A&E departments

| | | | |
|-----------|---|---|------------|
| 62 | Has your child attended an accident and emergency (A and E) department in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| 63 | Reason for visit <i>Give details</i> | 64 | Admitted as an inpatient or not admitted? <i>1. Admitted 2. Not admitted 0. No A&E</i> | 65 | Ambulance or no ambulance? <i>1. Ambulance 2. No ambulance</i> | 66 | Number of visits |
|-----------|--|-----------|--|-----------|--|-----------|-------------------------|
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**SECTION B: USE OF PRIMARY AND COMMUNITY-BASED HEALTH,
SOCIAL AND COMPLEMENTARY SERVICES**

*(DO NOT INCLUDE PRIVATELY FUNDED INTERVENTIONS OR THERAPISTS E.G., SALT OR
ABA THERAPIST)*

Use of primary, community, social and complementary care health services

| | | | |
|-----------|--|---|------------|
| 67 | Has your child used any primary or community care health services in the last 6 months? | 1 | Yes |
| | | 0 | No |
| | | 2 | Don't know |

If you answered yes, please tell us more

| | Primary health care service | Number of contacts |
|-----------|--|---------------------------|
| 68 | GP (at the surgery/practice) | |
| 69 | GP (at your home) | |
| 70 | Practice nurse (at the surgery/practice) | |
| 71 | Practice nurse (at your home) | |
| 72 | District nurse, health visitor, midwife | |
| 73 | NHS walk-in clinic | |
| 74 | Educational Psychologist | |
| 75 | Clinical Psychologist | |
| 76 | Child Psychiatrist | |
| 77 | Other CAMHS Professionals | |
| 78 | Speech and Language Therapist | |
| 79 | Occupational Therapist | |
| 80 | Art/Music/Drama Therapist | |
| 81 | Portage worker/Play Therapist | |
| 82 | Social worker | |
| 83 | Community Paediatrician | |
| 84 | Dietitian | |
| 85 | Nutritionist | |
| 86 | Gastroenterology | |
| 87 | Neuro-Disability Nurse | |
| 88 | Neurologist | |
| 89 | Audiologist | |
| 90 | Ophthalmologist | |

| | | |
|----|---------------------------------|--|
| 91 | Geneticist | |
| 92 | Ear, Nose and Throat Specialist | |
| 93 | Podiatrist | |
| 94 | Physiotherapist | |
| 95 | Urologist | |
| 96 | Counsellor | |

| | | | |
|----|--|--------|---------------------------|
| 97 | Have any other primary health care services been stated? | 1 0 | Yes No |
| 98 | Other <i>Give details</i> | 99 | Number of contacts |
| | | | |
| | | | |
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SECTION C: ACCOMMODATION & RESPITE CARE

Use of out of home placements

| | | | |
|-----|---|-------------|-------------------------|
| 100 | Has your child had any overnight out of home placements in the last 6 months? | 1 0 2 | Yes No Don't know |
|-----|---|-------------|-------------------------|

If you answered yes, please tell us more

| | Out of home placement | Number of days in the last 6 months |
|-----|--------------------------------------|-------------------------------------|
| 101 | Foster care | |
| 102 | Residential care | |
| 103 | Short break/respice care OVERNIGHT | |
| 104 | Other service provided accommodation | |