

# **A Review of Methods of Evaluation and Outcome Measurement of a Complex Intervention in Social Care: the Case of Assistance Dogs**

## **SSCR Internal Report**

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# **A Review of Methods of Evaluation and Outcome Measurement of a Complex Intervention in Social Care: the Case of Assistance Dogs**

## **Introduction**

The aim of this project was to conduct a small scale review of published quantitative and qualitative evaluations of assistance dogs to inform an application to SSCR for funding for an evaluation of Hearing Dogs for Deaf People. The budget was made available by SSCR to support the development of research funding applications. The review took place between January and April 2016.

An academic paper focussing on design and methods issues associated with evaluating complex and non-traditional interventions in social care, using evaluations of assistance dogs as an example, was also proposed as an additional output.

This is an SSCR internal report not for wider circulation. The report is arranged as follows: methods; findings in six sections (overview of included papers, hearing dogs for deaf or deafened people, guide dogs for blind or visually impaired people, mobility dogs for people with physical impairments, seizure alert and seizure response dogs and the costs of assistance dogs) and a brief conclusion.

## **Methods**

The following eight databases were searched in December 2015: ASSIA; CINAHL; MEDLINE; OT Seeker; PSYCHINFO; REHABDATA; Social Care Online; and Social Services Abstracts. Searches were limited to English language but there were no date limits. The databases included published and grey literature. Appendix 1 gives the search strategy used for Ovid MEDLINE as an example.

The initial search identified 3268 references. After de-duplication, titles and abstracts of 2906 references were screened for eligibility. References were excluded if they were *any* of the following:

- a.** not relevant – for example, about dog health/illness; other animal health/illness; other animal-assisted interventions/therapies (not dogs); drug testing on animals
- b.** written in a foreign language
- c.** about therapy dogs, companion dogs, pet dogs, not assistance or services dogs
- d.** a discussion, opinion piece or legislation, not an evaluation/empirical research
- e.** primarily about children not adults
- f.** duplications.

KB screened all references. BB screened a sample of 250. Differences of opinion discussed and agreed.

After screening, the full texts of 129 references were assessed for eligibility. The eligibility exclusion criteria given above were applied again, and references were included only if they fulfilled *all* of the following inclusion criteria:

- a.** primarily about assistance or service dogs (defined as dogs trained and placed permanently with individuals, for example, as guide dogs, hearing dogs, dogs to assist with physical impairments, to alert or respond to medical events, such as seizures, to support people with autism or mental health issues)
- b.** primarily about adults not children (to ensure outcome measures relevant to an adult population)
- c.** primary empirical research (or reviews of empirical research)
- d.** an evaluation – quantitative or qualitative, and of any design.

KB assessed all references. BB assessed a sample including those KB found difficult to categorise.

Fifty-four studies were eligible for inclusion. Nine of these were review articles that were used for background reading and checking that all their included studies had been identified. Findings from the remaining 45 references are reported here.

A data extraction form was designed to gather information on (a) the interventions and their active ingredients and (b) the methods adopted in the evaluations to measure the impact of interventions. Data were extracted onto a spreadsheet under the following headings:

- Author, year, reference ID number
- Country of study
- Study aims
- Service dog type (hearing, guide, mobility, seizure alert)
- Research type (quantitative, qualitative, both)
- Brief description of study design
- Recruitment methods and timescales
- Data collection methods
- Follow-up period
- Sample and baseline characteristics
- Description of intervention (including user engagement and active ingredients if described)
- Outcome measures used
- Primary outcome, duration and profile of effects
- Secondary outcomes, duration and profile of effects
- Measurement of resource use and costs
- Wider costs and outcomes, including on families and other sectors
- Other.

The references were not formally assessed for quality although relevant limitations were included in the ‘other’ category in the data extraction sheet.

## **Findings**

### **Overview of included papers**

#### *Quantitative Studies*

Thirty-six papers described studies that used quantitative methods. Twenty papers evaluated service dogs that assisted physically disabled people with mobility (three also included some dogs that assisted with hearing or seizure alerts, not mobility). Eight papers reported evaluations of guide dogs for blind or visually impaired people, three were about hearing dogs, two about hearing dogs and dogs that assisted with mobility, and three were about seizure alert dogs.

Studies took place in Australia (1); Canada (4 papers described 3 studies); France (1); Japan (3); UK (5 papers); USA and Canada together (2); and the USA alone (20 papers described 14 studies).

The majority of quantitative studies comprised cross-sectional designs but included some controlled studies (including one RCT) and some longitudinal. In addition, one study used quantitative observations (Eddy *et al.*, 1988); one modelled costs (Wirth & Rein, 2008); one described developing an assessment tool (Zapf & Rough, 2002) and another involved a concept mapping exercise (Glenn, 2013).

### *Qualitative studies*

Nine papers described qualitative evaluations. Six were about guide dogs for blind or visually impaired people, one was about guide dogs and mobility dogs, one about mobility dogs only and one about seizure alert dogs.

Two studies took place in Canada, two in the USA and one in both the USA and Canada; two took place in the UK, one in multiple European countries and one in South Africa.

Methods comprised interviews and observations; one study used a combination of open and closed interview questions and then converted open ended responses into Likert-type scales (Kirton *et al.*, 2008).

### **Hearing dogs for deaf or deafened people**

Three quantitative papers focussed on hearing dogs alone. They evaluated whether psychological, social and health changes were attributed to having a hearing dog (Guest *et al.*, 2006); compared actual and expected experiences of owners and prospective owners (Hart *et al.*, 1995); and explored the social consequences of hearing dog ownership (Hart *et al.*, 1996).

For the Guest study, interviews were conducted (in BSL if appropriate) at five time points over three years by a researcher member of the Hearing Dogs staff. The time points were a mean of 9.5 months prior to receiving the dog to 20 months after. Fifty-one interviews were conducted. Guest *et al.* used two validated questionnaires – the Profile of Mood State (POMS) and the General Health Questionnaire (GHQ) – plus a Hearing Dog Questionnaire

designed specifically for the study. The latter questionnaire asked participants to rate on a 5-point scale (from 'never' to 'always') how often they experienced known everyday problems for deaf people, such as fearfulness or dependency on others (the full questionnaire is given in the paper's appendix).

Both Hart papers appear to be based on the same study which used a one-off postal questionnaire. The sample comprised 38 hearing dog owners and 23 prospective owners. Hart *et al.* (1995) describes respondents being asked to list three answers each to questions on what they expect to enjoy most about having a hearing dog and what problems they expect. In Hart *et al.* (1996), respondents rated experiences of feeling lonely, feeling safe when alone, and being aware of doorbells/smoke alarms, and so on, on a 4-point scale of 'rarely' to 'almost always'. They were also asked how the dog had changed community interactions, how upsetting they rated 19 life events (for example, marriage, job change) in the last year, and to rank their top three 'enjoyments' and 'problems' with their hearing dog from a list of eight.

None of the studies stated a primary outcome. Guest showed significant differences in means over time for all subscales and the overall mood score on the POMS, suggesting the onset of living with the dog was associated with improvements in well-being. The GHQ showed significant differences in all four subscales and the overall score, but some increases in difficulties with social functioning between the post-dog times 4 and 5 (although both times scored better than pre-dog scores). The Hearing Dog Questionnaire suggested reductions in difficulty over time in responding to sounds, and reductions in fearfulness and social isolation across most time comparisons.

Hart (1995) showed the most frequent actual or anticipated pleasures to be companionship and hearing assistance. Other pleasures included feeling physically and emotionally better, getting more exercise, and watching the dog perform. Simply having a dog and achieving more personal independence were only mentioned as pleasures by prospective owners. Fifty per cent of dog owners said that dog behaviour (including aggression, barking and destructiveness) was a problem compared to only 13 per cent of prospective owners who anticipated unpleasant behaviour. The authors suggest that more targeted training prior to receiving a hearing dog might give prospective owners a better understanding of potential negative impacts.

Hart (1996) found no significant differences in responses from people deaf from birth and people deafened. Hearing dogs owners were significantly less lonely than before receiving the dog as well as compared to prospective owners. Three quarters of hearing dog owners reported a change in interactions with the hearing community; only 29 per cent of prospective owners anticipated this. Findings were similar for interactions with the local community and neighbours; participants felt this was because there was greater awareness of them in the community. There were no differences in the prospective and current owners in the number of life events over the last year, but hearing dog owners were significantly less stressed by the events. The highest ranked reasons for getting a hearing dog were alerting to sounds, protection, and companionship; the highest ranked problems were behaviour, tasks like training or travel arrangements, access to businesses, and failure to provide alerts. Prospective owners expected similar problems to current owners. Hearing dog owners were, as expected, more aware of alarms, and so on, than prospective owners. In the discussion, the authors note that the decision to get a hearing dog requires a person to have the strength to acknowledge to the world that they have a hearing loss – they can no longer try to hide it.

We found no qualitative evaluations of hearing dogs.

### **Guide dogs for blind or visually impaired people**

Eight quantitative and seven qualitative papers described evaluations of guide dogs for blind or visually impaired people. There were no RCTs and only two studies made any kind of comparison: Matsunaka and Koda (2008) compared stress levels between guide dog owners and non-dog owners when out and about in shops, restaurants, and so on, in Japan; and Yamamoto *et al.* (2015) compared walking activity of guide dog owners with pet dog owners in the USA. The remainder of the quantitative studies were one-off surveys or structured interviews. The qualitative studies used face to face or telephone, one-off interviews; one used ethnography.

#### *Quantitative studies*

Matsunaka and Koda's (2008) main aim was to investigate how well assistance dogs were accepted in public buildings since the passing of a recent law on public access.

Questionnaires were distributed to guide dog users and non-dog users through the president of a dog guide organisation and a teacher at a school for blind and visually impaired people, respectively. The questionnaire had three sections; non-dog users completed only one section

– their level of stress on a 5-point scale from ‘not at all’ to ‘very stressful’ on a ‘Stress Checklist for People with Visual Impairment’. The checklist was developed by the authors in an earlier study; it comprised 24 questions in three sections on situations relevant to mobility, conflicts and interactions with sighted people (for example, stress when in an unfamiliar place). Guide dog users also answered questions on their experiences of the acceptance of dog guides in 16 different facilities, such as shops, restaurants, and so on, on a 3-point scale of ‘rejected’, ‘conditionally accepted’ and ‘accepted’; and on main factors that would increase acceptance (they were asked to select three from a list of eight). Thirty guide dog users and 50 non-dog users responded. Facilities least accepting of dogs were restaurants, taxis and specific types of hotels (ryokans). The highest acceptance rates were from hotels other than ryokans, supermarkets, railways and buses. The main reasons for rejection were being a nuisance to other customers and hygiene issues. The main factors the guide dog group felt would improve access were public education, improvements in dog users’ manners and government resources for each facility. In comparing the groups, the mean ages of the groups were different (guide dog group mean age 49 years v. non-dog group 19 years) but tests showed no significant correlation between stress levels and age. Stress levels were significantly higher on situations relevant to mobility in the guide dog group than the non-dog group, but there were no significant differences in the conflicts and interactions with sighted people categories. The individual questions that were significantly different within the mobility category were: rainy days; lavatories when out alone with the dog; and going to distant places.

Yamamoto *et al.* (2015) undertook a web-based survey in the USA of people living with a guide dog and people living with a pet dog, the latter being used as a form of control group to assess physical activity. People were recruited through online social networks and mailing lists, plus snowballing. The survey comprised closed questions with space at the end for comments. Two hundred and thirty guide dog owners, 366 owners of large pet dogs and 263 owners of small pet dogs responded. Ages in the three groups were significantly different, with guide dog owners being the oldest and small pet dog owners the youngest. The questionnaire included demographics; participant's walking activity and interaction with dog; affection for the dog and whether the dog lessened discomfort in public; the dog's physical activity; and interaction with other people/dogs. The full questionnaire is given in the paper's appendix. Results showed the median time each day spent walking with their dog was significantly more for guide dog owners than pet dog owners, but the median overall daily

walking time was less for guide dog owners. All respondents had lived with their dogs for a median of five to seven years and affection for the dogs was very high in all groups. Guide dogs were reported to lessen discomfort in public ('frequently' or 'often') more than pet dogs but the effect size was not large.

Two quantitative studies used questionnaires to explore life/satisfaction with guide dogs and guide dog programmes (McAllister & Brown, 1999, Koda *et al.*, 2011) and one very short report (Milligan, 1999) surveyed dog guide schools to determine their admissions criteria in relation to occupation and mobility training. All had small sample sizes: McAllister and Brown recruited 43; Koda *et al.* had a sample size of 55 split into three groups (first time guide dog users, experienced users and former users) and Milligan did not give numbers. McAllister and Brown showed overall satisfaction with the guide dog service (in Australia), that half the respondents would have liked to talk to an experienced guide dog owner before deciding to apply for a dog, and that immediate local help with any problems is important. All reported a positive impact on quality of life, especially mobility/independence. Koda *et al.* focussed on ways to improve dog guide training but also showed 90 per cent of owners played/relaxed with their guide dog which potentially aided bonding. Milligan, from the perspective of guide dog organisations, found important criteria in assessing potential guide dog users included problem solving skills, responsibility, motivation, attitude and home environment.

Another very short report of half a page (Gaunet, 2012) described a survey to shed light on why few people have guide dogs in France and the UK. It showed most guide dog owners were recently blind whereas most non-owners were blind from birth. The main reasons to get a guide dog were for: support for orientation, mobility, sharing affection and interactions. Guide dog owners see the dog as having social integration role but non-owners view guide dogs as limiting activities and requiring care. Most owners see their dog as a working dog and a pet but non-owners see this combination as problematic.

### *Qualitative studies*

Qualitative studies explored how guide dog users felt and understood themselves (Sanders, 2000), guide dogs' impact on perceptions of leisure participation (Hicks & Weisman, 2015), attitudes to using communication and mobility devices (including guide dogs) (Hersh, 2013),

adjusting to life with a guide dog (Wiggett-Barnard & Steel, 2008), and the impact of dog attacks on guide dog owners (Marques-Brocksopp, 2015).

Sanders (2000) used ethnography and published accounts in other papers to present data in four *a priori* themes: personal, collective and social identity, and person/dog team identity. Personal identity was impacted by greater feelings of control, fewer feelings of helplessness and enhanced self-worth. In the collective identity theme, some people felt ambivalence towards getting a guide dog as the dog was seen as an ‘identifying creature’ making it obvious the person was blind, but after getting the dog they felt no stigma. (Hart (1996) also raised the issue of no longer being able to hide an impairment in relation to hearing dogs.) However, some felt pressure in public to foster a positive image of people with guide dogs/visually impaired people, despite some frustrating situations, such as not being allowed in restaurants or people talking to the dog. For social identity, all respondents expressed concern that the dog made them conspicuous and generated unwelcome attention (making them an ‘open person’ who complete strangers could approach) but also redefined them as competent people less deserving of pity. People felt identified as a social unit or partnership and sometimes this meant the loss of individuality (for example people would know the dog’s name but not the guide dog user’s). However, the positives of joint identity far outweighed the negatives and people felt bound together in a cooperative and communicative relationship.

Hicks and Weisman’s (2015) study of 10 North Americans’ participation in leisure activities with their guide dogs showed some similar findings to Sanders (2000), for example, feelings of interdependence and mutual benefit plus a lifelong emotional connection. They also explored how the owner considered the dog’s needs as well as whether the dog would help or hinder participation or add to stress.

The issue of stigma, highlighted already in findings by Sanders (2000) and Hart (1996) was the main focus of Hersh’s (2013) study of deafblind people’s use of communication and mobility devices. Only three of 28 interviewees used guide dogs. Of these three, none spoke of the stigmatising potential of dogs that were expressed about canes. Across the whole sample, family attitudes to guide dogs varied from trying to persuade a reluctant, allergic deafblind person to get a dog, to threatening to leave if a spouse got a dog. The author

speculates on whether the threat to leave may be associated with ‘courtesy stigma’ – concern about being associated with a person who has a guide dog.

The consequences of getting a guide dog for the first time were reported by Wiggett-Barnard and Steel (2008) in their study of six new owners in South Africa. Some are familiar from other studies (improvements in mobility, companionship, responsibility, cost implications, the dog is a social magnet, a source of pride, the general public have little awareness of how to treat a working dog). An additional theme not noted elsewhere was personal growth resulting from the necessity to be firm in handling the dog – this could give people more confidence to be firm with family and to be more independent.

While the above studies reported mainly positive consequences of owning a guide dog, Marques-Brocksopp (2015) considered the consequences for guide dog owners’ well-being of their dog being attacked by another dog. Four overarching themes emerged: physical health; emotional well-being; social connectedness and spiritual well-being. Within these were 10 sub-themes on which the dog attack had an impact: personal injury, physical symptoms of emotional trauma, exacerbation of existing physical conditions, reduced mobility and functionality, negatively perceived emotions, empowerment and resilience, changes in routine to avoid a further attack), relationships with others, financial situation, and meaning and purpose in life.

#### *End of a guide dog partnership*

Most studies covered quite different topic areas, however three papers described studies that had explored the end of a guide dog partnership (Nicholson, 1993, Nicholson *et al.*, 1995, Kwong & Bartholomew, 2011) and this was also touched upon by McAllister (1999).

Both Nicholson papers reported on the same study. The quantitative paper (Nicholson *et al.*, 1995) reported on the GHQ-28, a specially designed Grief Rating Scale (GRS) (a list of 15 bereavement symptoms associated with human loss), level of social support and comparison with other losses for 59 people undertaking retraining for a replacement guide dog. Stress levels were compared across reasons for the end of the partnership – dog retirement, death or withdrawal. Stress measured by the GHQ and GRS were high, but significantly higher if the dog had died or been withdrawn. Responses to loss were similar to those for the loss of a human. In the associated qualitative paper, the authors also reported the loss of the dog was

considered equal to the loss of sight. While one in four showed sufficient distress to make clinical illness a possibility, some showed no response, possible because they had learned coping skills or the relative importance of the dog to them was low. If the end of the partnership was due to a mismatch and so withdrawal, people felt they had failed/let down the dogs and trainers; repeated failures led people to question their suitability for a guide dog. Being involved in re-homing a retired dog was important; people wanted to know the dog would be well cared for. Some were worried about keeping a retired dog as a pet while also getting a new working dog – they were concerned that the retired dog would struggle to cope with affection being transferred to the new dog. Kwong and Bartholomew's (2011) paper conducted qualitative interviews with 25 people who had experience of loss of at least one guide (n=22) or mobility (n=3) dog. They were interested in attachment as well as loss. They categorised findings into *a priori* themes of safe haven, a secure base, separation anxiety, caregiving and grief. In the grief theme they found people felt the loss due to death or retirement as one would the loss of a close relationship/significant other, an intense loss, with a wish to soothe the dog (if loss due to retirement), and feelings of guilt and helplessness. McAllister (1999) touched briefly on the end of partnerships and found respondents had very mixed scores on how well prepared they felt for the retirement of the dog and the usefulness of peer emotional support.

### **Mobility dogs for people with physical impairments**

Twenty quantitative and one qualitative paper evaluated mobility dogs. The quantitative papers were mainly cross-sectional and/or collected retrospective data; some had a form of comparison group. The only RCT was Allen and Blascovich (1996).

The main limitations of the study designs, as given by the authors, were: small sample sizes; no control/comparison groups; missed data collection points due to poor communication between researchers and training/recruitment centres; non-standardised outcome measures; possible selection bias due to individuals motivated to take part in the study, convenience samples or samples selected with help of training centres; non-randomised groups; and self-reported data. Lane *et al.* (1998) also considered it important to note whether or not it was the disabled person's own decision to get a mobility dog or someone else's as this might affect satisfaction scores.

The qualitative paper (Camp, 2001) reported findings from interviews and some observations with five participants. The purpose was to understand the experience of owning a service dog in order to help occupational therapists consider whether to recommend a dog. The findings suggest participants used their dogs as ‘adaptive strategies’ to compensate for physical issues, such as motor control or endurance; assistance with daily tasks increased participation. They also identified the following benefits: companionship, independence, increased self-esteem, security, increased social contact, skill development and fun. Participants did not talk about drawback, but labelled difficulties as responsibilities, adjustment periods and challenges.

Table 1 shows the validated outcome measures used in the quantitative studies of mobility dogs. Many authors also developed their own questionnaires based on previous work and/or areas of specific interest. These typically included sections of functional assistance, such as help with ADL work or leisure activities; emotional assistance for example safety, stress, confidence; social functions, such as new networks, getting out, being approached by strangers; and economic functions, such as costs and un/paid help. Eddy *et al.* (1988) observed 20 wheelchair users (10 with and 10 without a mobility dog) in public places, such as shopping malls to assess responses of passers-by. They noted responses to a pre-defined list of behaviours: smiles, conversations, touch, gaze aversion, path avoidance, no response. If participant had a dog, passers-by responses to the dog were recorded separately.

One paper (Zapf & Rough, 2002) was specifically designed to develop an assessment tool questionnaire to evaluate the need for service dogs as a form of assistive technology. Some also included tests of mobility, such as time to complete walking tasks or to transfer from a sitting to standing position and back.

**Table 1: Validated outcome measures used in evaluations of mobility dogs**

Outcome measure	Studies using outcome measure
Rosenberg self-esteem scale	(Rintala <i>et al.</i> , 2002, Frost <i>et al.</i> , 2001, Allen & Blascovich, 1996, Collins <i>et al.</i> , 2006)
Wheelchair User's Shoulder Pain Index (WUSPI) - 15 items assessing pain during transfers, self-care, wheelchair mobility, and general activities on a 10 cm visual analogue scale.	(Vincent <i>et al.</i> , 2015b, Vincent <i>et al.</i> , 2015a, Hubert <i>et al.</i> , 2013)
Canadian Occupational performance measure (COPM)	(Vincent <i>et al.</i> , 2015b, Vincent <i>et al.</i> , 2015a)
Reintegration to Normal Life Index (RNLI)	(Vincent <i>et al.</i> , 2015b, Vincent <i>et al.</i> , 2015a)
Psychosocial Impact of Assistive Device Scale (PIADS)	(Vincent <i>et al.</i> , 2015b, Vincent <i>et al.</i> , 2015a)
Positive and Negative Affect Scale (PANAS)	(Frost <i>et al.</i> , 2001, Collins <i>et al.</i> , 2006)
Assessment of Life Habits (LIFE-H) questionnaire for social participation using the abbreviated version (version 3.1) - includes 77 items from the LIFE-H and covers 12 categories of life habits. Developed in 1990s in French, validated for spinal cord injury.	(Hubert <i>et al.</i> , 2013)
Quality of Life Index (QLI) - measures satisfaction with 37 aspects of life and the importance of those same aspects. Results interpreted in four dimensions: (1) health and functioning, (2) social and economic status, (3) psychological and spiritual aspects, and (4) family.	(Hubert <i>et al.</i> , 2013)
Reintegration to Normal Living Index (RNLI) - self-administered, assesses reintegration into normal social activities. Includes mobility, personal care, ADLs, leisure, and social roles.	(Hubert <i>et al.</i> , 2013)
SF-36v2 (Medical Outcomes Study Short-Form 36 Item	(Shintani <i>et al.</i> , 2010)

Health Survey version 2) composed of 8 subscales and 2 summary scores. The subscales are referred to as physical functioning (PF), role physical (RP), bodily pain (BP), general health perceptions (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH). The 2 summary scores consolidate the 8 subscales into a physical component summary (PCS) and a mental component summary (MCS). The subscales of PF, RP, and BP contribute to PCS; MH, RE, and SF contribute to MCS; while SF, VT, and GH contribute to both summary scores	
Social Provisions Scale	(Frost <i>et al.</i> , 2001)
Craig Hospital Assessment and Reporting Technique (CHART)	(Frost <i>et al.</i> , 2001)
Social Integration domain only	(Collins <i>et al.</i> , 2006)
Physical independence and mobility scores only	(Collins <i>et al.</i> , 2004)
Spheres of Control Scale	(Allen & Blascovich, 1996)
Affect Balance Scale	(Allen & Blascovich, 1996)
Community Integration Questionnaire	(Allen & Blascovich, 1996)
Centre for Epidemiologic Studies - Depression (CES-D) Scale.	(Collins <i>et al.</i> , 2006)
UCLA Loneliness Scale - version 3 (UCLA-3)	(Collins <i>et al.</i> , 2006)

None of the papers gave detailed descriptions of the interventions; typically the intervention was the acquisition of a mobility dog. Some details were given in some papers about the length of training the dog received and the length of time the potential new owners spent at the training centre receiving training in handling the dog.

In general, findings showed owning a mobility dog had positive impacts on physical and social functioning and on emotions and quality of life. There were, however, some negative

effects, such as the inconvenience and expense of caring for a dog, and some people's negative reactions.

One issue that stands out as having positive and negative impacts is the attention that service dogs attract from strangers. Mobility dog owners welcomed feeling more independent and being able to go out with the dog, but also reported feeling invisible when out with the dog as most conversations were centred around the dog; some also reported feeling invisible when alone because they received fewer approaches from the public. Some people reported locals knowing the name of the dog but not the dog owner. A further problem was the public petting the dog when the dog was working.

### **Seizure alert and seizure response dogs**

Two studies investigated the accuracy of diabetes alert dogs (Gonder-Frederick *et al.*, 2013, Rooney *et al.*, 2013) and one studied epilepsy alert dogs (Strong *et al.*, 2002). One study explored subjective changes in quality of life for people with seizure response dogs (Kirton *et al.*, 2008); seizure response dogs are different to alert dogs in that they do not warn people of impending attacks but instead demonstrate specific behaviours after an event. Two related papers looked at workplace issues for seizure alert dogs and mobility dogs (Glenn, 2013, Glenn, 2015).

Gonder-Frederick *et al.* (2013, Rooney *et al.*, 2013) and (Strong *et al.*, 2002) all investigated the accuracy of dog alerting by measuring the frequency of seizures before and after getting the alert dog. Gonder-Frederick *et al.* (2013) found that 61 per cent of 36 respondents were less worried about episodes after getting the dog; 75 per cent felt their quality of life had improved and 75 per cent felt more able to participate in physical activities. The findings were based on a retrospective survey. Rooney *et al.* (2013) interviewed 17 people about their experiences with an alert dog. Respondents were asked to rate 10 statements about the impact of the dog on their life on a 5-point scale. Findings show strong positive responses to: increased independence; enhanced quality of life; and being totally satisfied. There was strong disagreement with the statement that they would not get a dog again. There was a high level of trust in alert dogs but mixed responses to dogs being a big commitment and the dog's 'charity coat' receiving attention from other people. Strong *et al.* (2002) did not report on any issues other than accuracy of the dog.

Kirton *et al.* (2008) undertook retrospective semi-structured interviews with 22 people who had received a seizure assistance dog from one named organisation. The interview data were then transformed into Likert scale scores by the researchers. All people reported improved quality of life since getting their dog; these benefits were in the following areas: interpersonal relationships, self-confidence, work and education, safety and security, mood and depression, anxiety, and independence. On the downside, 12 of the 22 interviewees had occasional difficulties accessing public facilities with their dog.

### *Workplace issues*

The two Glenn papers related to the same study (Glenn, 2013, Glenn, 2015). The study used an online (single question) questionnaire, brainstorming and ‘concept mapping’. The single open-ended question was ‘What elements are important to a successful service dog partnership in the workplace?’ The question and brainstorming produced 68 suggestions which were categorised into six clusters. The seizure alert dog group ranked the clusters as follows: (1) dog preparation, (2) monitoring, (3) employee competence, (4) legal knowledge, (5) information and education, and (6) co-worker preparation. The mobility dog group ranked co-worker preparation third and employee competence last, but the remaining categories in the same order. One reason why co-worker preparation was ranked higher by the mobility dog group, according to the author, may be that mobility dogs are by definition large and so harder to accommodate in offices/under tables.

### **The costs of assistance dogs**

Eight papers included data on costs (Wirth & Rein, 2008, Rintala *et al.*, 2008, Rintala *et al.*, 2002, Allen & Blascovich, 1996, Collins *et al.*, 2002, Milan *et al.*, 2006, Fuhrman *et al.*, 2004, Fairman & Huebner, 2001), although only four presented much detail. Six papers were about mobility dogs, one about hearing dogs and one about guide dogs. There was one RCT (Allen & Blascovich, 1996), one pre-post wait list-controlled pilot study (Rintala *et al.*, 2008), one uncontrolled pre-post evaluation (Rintala *et al.*, 2002), one modelling exercise (Wirth & Rein, 2008) and the remainder were cross-sectional studies.

For the modelling paper, data on costs were collected by email from 11 dog guide training schools, the American equivalent of the RSPCA and published papers. Six of the evaluation papers collected data from telephone, email or face to face interviews with study participant and one used data collected for previous studies.

Four studies had follow-up periods of up to two years but only Collins *et al.* (2002) explicitly reported collecting data at more than one time point (baseline, 3 and 9 months from enrolment, but it is not clear whether this is enrolment into the study or the assistance dog programme). None reported using validated data collection forms for resource use or the period of time for which data were collected (for example, the previous month, three months, and so on). Data collected included the number of hours of paid and unpaid (human) assistance, and the annual costs and outside assistance to pay for the dog. Wirth and Rein's (2008) modelling paper collected data on the costs of dog acquisition and care by the training schools, annual dog care, and the annual costs of formal and informal care with and without an assistance dog.

Of the four papers that gave some detail, Rintala (2008) reported that the mean out of pocket costs from the time a hearing dog was placed with a recipient to the time of the post-placement interview six months later was an average of \$785 (sd \$606, median \$780, range \$100 to \$1800). The sample size was, however, very small – from 14 people in the pilot study, six received a dog, four did not and four dropped out.

Allen and Blascovich's (1996) RCT of mobility dogs showed a decrease in the number of paid and unpaid hours of assistance at 12 months for the intervention v. wait list control group (28 v. 84 hours of paid assistance and 15 v. 40 hours of unpaid assistance). They also modelled costs using assumptions of training costs, lost investment income on the costs of training, annual animal maintenance costs, expected dog service of eight years, and costs per hour of human assistance. Actual savings according to this model began to accrue after year two, and were a total of \$60,000 after eight years. They undertook sensitivity analysis on the hourly costs of human assistance.

Collins *et al.* (2002) showed no significant changes in the hours of human assistance over the nine month study period but claimed two non-significant trends. First, the hours of human assistance with IADL for the dog group remained stable over time whereas for the control group the hours increased at nine months. Second, the hours of transport to medical appointments peaked for the dog group at three months but fell at nine months despite the number of appointments per month being 2.6 times higher than the control group at both times. This suggests the dog group found accessing appointments less time consuming.

Wirth and Rein (Wirth & Rein, 2008) give a very detailed account of their modelling exercise. They calculated the net cost per year of a dog guide by adjusting the total cost of dog acquisition and subsequent care downwards to account for the reduced cost of formal and informal care. They considered using QALYs as an estimate of benefit but could not find a reliable estimate of the utility provided by guide dogs. They undertook sensitivity analysis on: the cost per dog/person team trained (doubled and halved the cost); the working life of dog (8 years +/- 2 years); excluded the cost reductions of formal and informal care, separately, and also reduced these costs by 50 per cent, and finally varied the discount rate from 0 per cent to 5 per cent. Their estimates showed the total discounted cost of breeding, training & caring for a guide dog over its eight year working life was \$40,598. The majority of this cost (\$34,972) was incurred by the training school. Lost wages for the person receiving the guide dog whilst at training school accounted for \$564. The remaining \$5,061 was for routine dog care over animal's working life, paid for by the guide dog user. Net savings on formal care were \$16,324 and on informal care \$5,244. The cost per year of a dog guide service was therefore \$2,379 over an eight year working life at a discount rate of 3 per cent. The authors also presented a threshold analysis to see what change in utility was required (no dog v dog) for an incremental cost-effectiveness ratio of less than \$50,000/QALY. Assuming the guide dog improves utility by 0.055 QALYs/year, the cost would be \$48,000/QALY saved.

Of those papers that gave limited detail, Milan *et al.* (2006) and Fuhrman *et al.* (2004) were both short papers from conference proceedings; some co-authors appeared on both papers and also on Collins *et al.* (2002). Both papers measured the number of hours of paid and unpaid care but gave no details on how data were collected other than by questionnaire, and they gave no definitions of paid and unpaid care. Milan *et al.* (2006) reported that people who had mobility service dogs for more than two years used (non-significantly) less informal caregiver hours (12.7 hours) for help with ADL than the non-dog group (17 hours). It is not clear whether these are measured as hours per week or some other time period. Fuhrman *et al.* (2004) investigated the effect of service dog ownership on paid assistance for people with spinal cord injury. Compared to people with spinal cord injury and no service dogs, service dog ownership was significantly associated with individuals who used more hours of paid care. The conclusion was that people with more limited mobility may be more likely to use mobility dogs.

Fairman and Huebner's (2001) postal survey in the USA and Canada collected data on, amongst other things, the economic effects of service (mainly mobility) dogs on disabled people. The survey asked about the annual cost of paying for the dog, any outside financial assistance, and hours of paid and unpaid care. The range of annual costs reported was from \$1 to \$10,000 but 75 per cent reported spending a maximum of \$1000 per year on care and feeding. A third received financial assistance from state funds or donations. Hours of paid assistance dropped by two hours a week after getting the dog, and hours of unpaid assistance dropped by six hours a week (both were statistically significant). The cost of human assistance was estimated to have dropped by \$600 a year.

The final paper (Rintala *et al.*, 2002) gave no specific data but reported that participants in their before and after study felt that family members spent less time caring and had more time to do their own things after participants received a service dog.

## **Conclusion**

The purpose of this review was to inform the design of the proposed evaluation of Hearing Dogs for Deaf People. As anticipated, there was a wide range of study designs but few randomised controlled trials. We therefore used narrative synthesis to draw together the findings and identify evidence to support wider work by the research team in developing the application to evaluate Hearing Dogs.

Although limited to English language papers, the studies identified took place in many countries. They included a wide range of designs and many types of assistance dogs. There were, however, only three studies focussing on hearing dogs.

This review aimed specifically to identify information about the active ingredients of assistance dog interventions, but none of the papers reporting quantitative studies gave sufficient detail about, or tested the effectiveness of, particular elements of being supported by an assistance dog. However, some of the qualitative studies identified issues, such as identity, personal growth and the visibility of impairment, that shed light on some of the changes assistance dog ownership can bring about in addition to the physical assistance the dogs are trained to provide.

The review also aimed to identify relevant outcome measures and methods of evaluation. In general, the studies had small sample sizes and short follow up periods. Samples (for both quantitative and qualitative studies) were often convenience samples. There was only one RCT; most quantitative studies employed cross-sectional designs, although some studies had comparison groups. The studies used a wide range of outcome measures. Validated measures were the Profile of Mood State (POMS), General Health Questionnaire (GHQ) and those reported in Table 1. Many used non-validated questionnaires and scales designed specifically for the study in question which makes meaningful comparison across studies very difficult.

Few studies reported data on resource use or costs. Those that provided detailed data and analysis of costs reported on the costs of training assistance dogs and off-set this against actual or potential changes in, for example, formal and informal care or earnings. One paper reported trying to find data on the utility of assistance dogs measured in QALYs, to include in a modelling exercise, but could find none.

In summary, there is a wide range of papers reporting evaluations of assistance dogs. However, there are few controlled trials, few large studies and no quantitative measures of the effectiveness of the different active ingredients of being supported by an assistance dog. The articles included in this review cover such a wide range of interventions with varying degrees of detail that writing an academic paper on design and methods issues associated with evaluating complex and non-traditional interventions in social care, as originally proposed, may be unrealistic.

The proposed evaluation of hearing dogs for deaf people which this review was designed to inform, entitled '*Partnerships between deaf people and hearing dogs: a mixed methods realist evaluation*', has recently been submitted by Bryony Beresford to SSCR for consideration for funding.

## Appendix 1 – Example search strategy

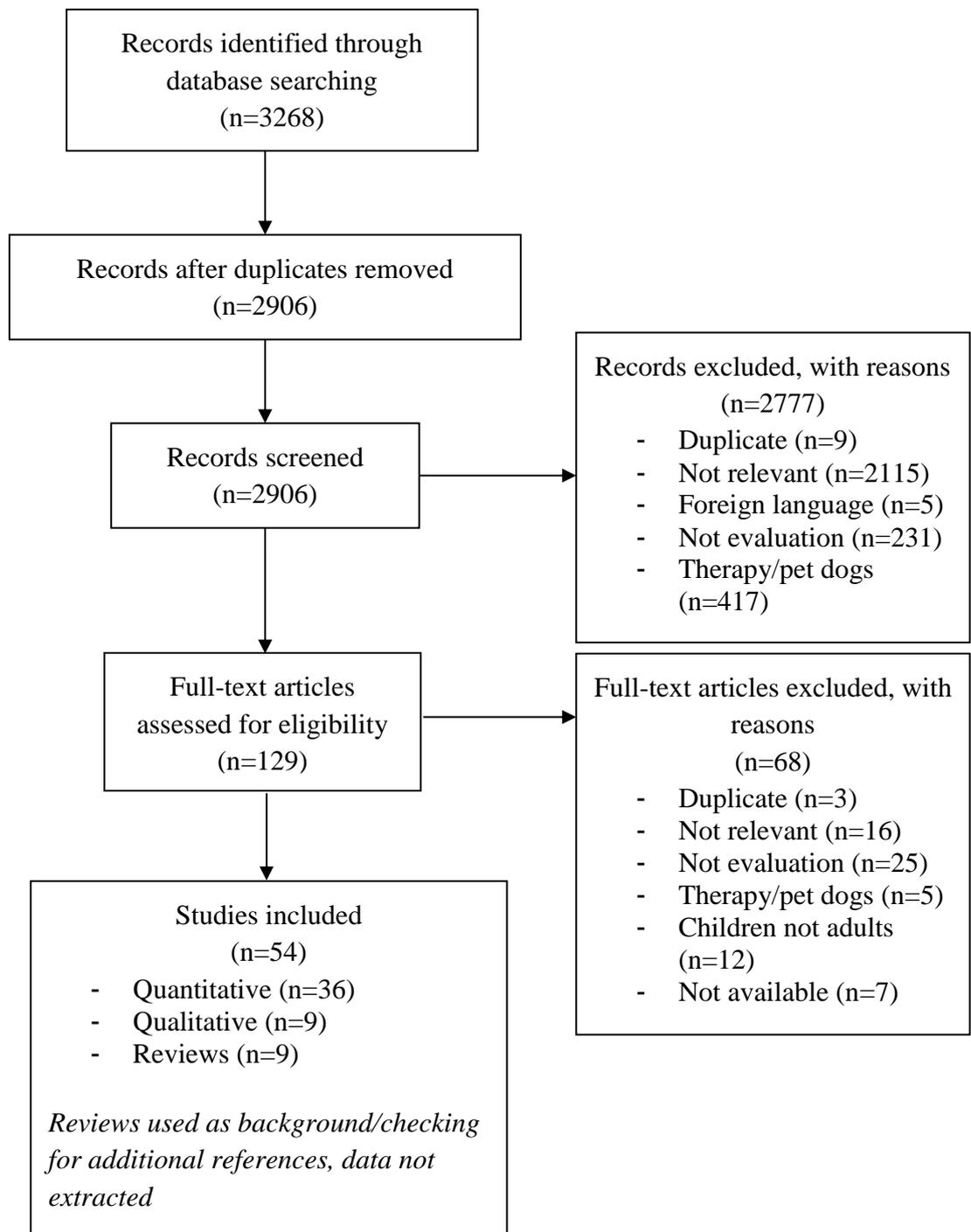
### MEDLINE OVID

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

- 
1. Animal Assisted Therapy/ (166)
  2. (assist\$ adj2 (dog or dogs)).ti,ab. (89)
  3. (service adj2 (dog or dogs)).ti,ab. (81)
  4. (rehabilitat\$ adj2 (dog or dogs)).ti,ab. (6)
  5. (guide adj2 (dog or dogs)).ti,ab. (93)
  6. (sight adj2 (dog or dogs)).ti,ab. (3)
  7. (seeing adj2 (dog or dogs)).ti,ab. (12)
  8. (blind\$ adj3 (dog or dogs)).ti,ab. (174)
  9. (hearing adj2 (dog or dogs)).ti,ab. (29)
  10. (deaf\$ adj2 (dog or dogs)).ti,ab. (42)
  11. (mobility adj3 (dog or dogs)).ti,ab. (33)
  12. ((disability or disabl\$) adj3 (dog or dogs)).ti,ab. (18)
  13. (handicap\$ adj3 (dog or dogs)).ti,ab. (3)
  14. (impair\$ adj3 (dog or dogs)).ti,ab. (177)
  15. (alert\$ adj3 (dog or dogs)).ti,ab. (64)
  16. (seizure adj3 (dog or dogs)).ti,ab. (73)
  17. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (814)
  18. ((autism or autistic) adj4 (dog or dogs)).ti,ab. (8)
  19. (dementia adj4 (dog or dogs)).ti,ab. (8)
  20. (stroke adj4 (dog or dogs)).ti,ab. (92)
  21. ((mental\$ or psychiatric\$) adj4 (dog or dogs)).ti,ab. (40)
  22. 18 or 19 or 20 or 21 (148)
  23. 1 or 17 or 22 (1092)
  24. limit 23 to English language (989)

**Appendix 2 – Flow chart of references identified and included**  
**(based on PRISMA 2009<sup>1</sup>)**



<sup>1</sup> See <http://prisma-statement.org/PRISMAStatement/FlowDiagram.aspx>

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