King's Fund

Carers Impact: How do we know when we have got there?

Improving support to carers: Report of the first year's work of Carers Impact

October 1997

Introduction

"How do we know when we have got there?" was one of the first questions raised by the Carers Impact steering group* when discussing the new programme to improve support to carers.

In many ways this has become the key theme to the work across the country in which health and local authorities are reviewing their progress in supporting carers and the implementation of the Carers (Recognition and Services) Act 1995. The question throws open the whole debate about the clarity of policies to support carers and the ambiguous relationship of carers to the service system. It also presents challenges to authorities to develop ways of monitoring the effectiveness of their joint strategies and to obtain systematic feedback from carers about the impact of the service system on their lives and the person they care for.

Contents

This is a report of the first year's work of Carers Impact and describes first impressions of the national picture and our progress in answering the question posed.

The report includes:

- a brief description of the background to the Carers Impact programme and its work to date
- a summary of the key messages from carers on the first Carers Impact sites and their feedback on how far their local areas "have got there" in supporting them
- how sites are trying to achieve change and what appears to be helping and hindering them

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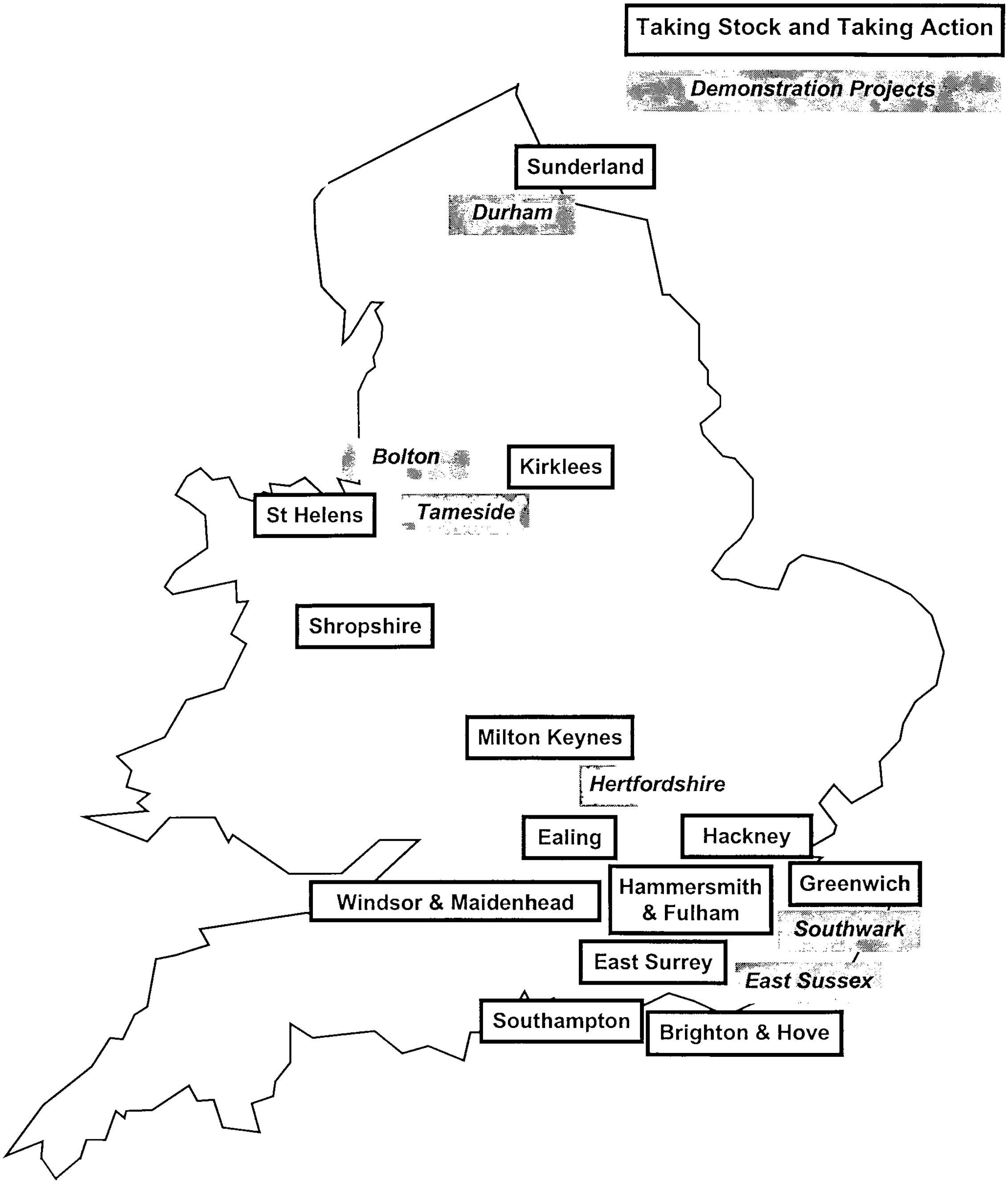
* Appendix 1 Membership

Carers Impact Development Sites



1 The New Carers Impact Programme

1.1 Background

The new Carers Impact programme was initiated in 1996 to build on the lessons learnt from the first Carers Impact Project 1992-95.

The first project was set up to maintain the momentum in improving support to carers during the implementation of the NHS and Community Care Act. The project supported multi-agency task forces in 13 local areas working to improve services to carers.

An independent evaluation of that project (J Unell - The Carers Impact Experiment*) demonstrated the work achieved and a number of significant service developments. But it could only show limited change in mainstream services and few visible improved outcomes for carers during the relatively short period of development work in each of the areas.

However the work did clarify the pre-conditions necessary to effect concerted improvements for carers in mainstream services and the importance of:

- ***the ability of different agencies to work together effectively across boundaries***
- ***a shared and clearly defined strategy for supporting carers***
- ***effective ways of involving carers in developing services and evaluating outcomes***

The new programme thus faced three key challenges to bring about demonstrable improvements in support to carers:

i) To bring more local areas up to a point where they have an agreed plan of action to improve carers' support with implementation targets and timetable

ii) To demonstrate improvements in carers' lives through the *implementation* of strategies, i.e. to ensure strategies are not merely paper exercises

iii) To increase the profile of service developments taking place in order to inspire and inform a more concerted approach to carers' support throughout the country.

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* Strategies for Change : A Carers Impact resource book M.Powell P.Kocher

1.2 Carers Impact 1996-9: the three-point programme

The Department of Health and the Gatsby Charitable Foundation have funded the three year programme which is based at the King's Fund.

The new programme has three distinct strands which aim to address the challenges outlined above:

1. A short intensive programme for areas to ***"Take Stock and Take Action"***

2. Longer term ***demonstration projects*** to show how all parts of the health and community care system can work together to make a positive difference in carers' lives.

3. A ***Carers Impact Network*** to disseminate the lessons and exchange information and good practice.

1.3 Method of work

Building on the experience of the first Carers Impact project, there has been an emphasis on a well defined and agreed programme of work with each of the areas taking part. Agreements have been negotiated with each site on the scope of each project, the timescales, key milestones and the responsibilities of both the site and the Carers Impact team. The financial contribution from each site appears to have been a useful way of focusing minds on the tasks involved and an immediate indicator of the commitment of local partners!

Carers Impact has offered a staged programme for both the Taking Stock and the demonstration projects which has been tailored to the needs of each site. The Carers Impact team has worked alongside the local multi-agency groups, facilitating workshops and providing information and expertise in managing change and support to carers.

As before the Carers Impact team has brought in other development consultants to work on the sites, drawing on the national stock of experience and knowledge. Outside consultants have been paired with members of the core team based at the King's Fund. Selection has been based on the needs of the site and specific experience of the consultant, as well as proximity to save on travelling and overnight stays.

1.4 Carers Impact Network

Dissemination of the work and exchange of good practice has been through:

- ***distribution of a Carers Impact bulletin*** every four months to over 600 people who have joined the network, plus every Director of Social Services and Chief Executive of Health Authorities and NHS Trusts

- ***running workshops***, for example: for the development consultants (May 1997); for researchers to share findings on the implementation of the Carers Act (Sept 1997); for Carers Impact sites who are 'taking action' (Oct 1997).

- ***publicity*** such as the launch of the new programme and the breakfast debate at the King's Fund during National Carers Week

- ***participation in other networks***, for example: ADSS Carers Reference Group; Carers Alliance; Reference Group SSI Inspection of Local Authority Support for Carers

- ***speaking at conferences and seminars***

1.5 Taking Stock and Taking Action

The following sites have elected to use the Taking Stock and Taking Action programme: ***Hammersmith & Fulham, Ealing, Windsor & Maidenhead, Southampton, Sunderland, Greenwich, East Surrey, Brighton & Hove, Hackney, Shropshire, Kirklees, St Helens and Milton Keynes.***

These sites have been concerned to take stock of their work to date and to take a more strategic approach with partner agencies, both to co-ordinate a number of developments and to make better use of existing resources. For the new unitary authorities it has been an opportunity to look afresh at carers needs, to kick-start joint work and to develop new working relationships with partner agencies. The majority of sites have looked at carers issues across the board but one site has concentrated on carers of people with mental health problems.

Each site has set up a ***multi-agency planning group*** to co-ordinate the two day workshops which form the core of the programme. The planning groups play a key role in taking the work forward and in some places have now ***become permanent structures for progressing joint strategic work to support carers.***

Carer involvement throughout has been an essential requirement and in some areas special sessions have been facilitated by a member of the Carers Impact team to ensure carers are properly supported to take part. *"I thought I had nothing to say - I ran out of time saying it!"* remarked one carer after the workshop.

In some areas preparatory sessions have been held with carers from black and minority ethnic communities to ensure their full involvement.

Working with carers has evidently been a new experience for a number of senior managers, particularly from the health authorities. Several managers have expressed concerns that expectations would be raised which could not be met and that strategic work could get bogged down with individual concerns. However, their experience of the work together with carers altered their views: *"This is the first time I have worked with people who really know about the quality of the services I buy.."*

The Senior Development Consultant (*Colin Cheeseman*) and one outside consultant facilitate the two day workshops in each site. A process for achieving a considerable agenda of focused joint work has now been developed. Immediate feedback from the workshop participants has been very positive as the workshops have:

- ***acted as a catalyst for joint action***
- ***brought together a wide range of perspectives and experience***
- ***ensured carers are centre stage in bringing about change***
- ***quickly identified the local key issues to be addressed***
- ***achieved some consensus on local priorities***
- ***developed realistic action plans within local resources***

The success of this approach will be tested when the Carers Impact team return to each site to review progress in achieving their action plans.

1.6 Demonstration Projects

In September 1996 all health and local authorities were invited to apply to run Carers Impact demonstration projects. The steering group was looking for areas which had gone some way in developing support to carers and where there was senior level commitment to the work, evidence of joint working between health and social services and local carer participation.

The Carers Impact steering group selected the following six sites: ***Bolton, Durham, East Sussex, Hertfordshire, Southwark and Tameside***. These sites include county and metropolitan authorities and offer a geographical spread. They also have taken differing approaches, with either separate carer strategies or action to support carers built into each care group strategy.

The projects aim to show how health and community care services can be developed to achieve benefits in the lives of carers by:

- assessing the effectiveness of each sites current carer support strategy and its impact on carers' lives
- finding ways of improving outcomes for carers which engage all levels of the service system - policy, planning, commissioning, practice and service provision
- using the information gained from carers' experience to revise strategies and influence strategic and local commissioning
- developing feedback systems and ways of monitoring the implementation of local strategies

As with the Taking Stock sites ***a multi-agency steering group*** including carers has been set up in each of the areas to lead the local project. Some of these groups have been newly formed, others are joint planning or development groups already in place. In the latter it has been an opportunity to review membership of the group and to ensure participation from all the key partners.

There has been considerable concern to avoid tokenistic ***carer involvement*** and to ensure carers are supported and have ongoing dialogue with local carers and carer networks in the area. Each of the sites have supported the carers and facilitated this dialogue through the help of local carer organisations, carer centres or development workers.

Carers experience

The work on the sites has started by asking carers about their experience of getting help, assessments and the services provided and the impact of this on their lives and the person they care for. **The aim has been to get a qualitative picture of carers' experience of the local service system** and in particular to find out what helps and hinders them in achieving the outcomes they desire.

Approximately 50 carers have been recruited in each of the sites to take part in either focus groups or semi-structured interviews conducted by Carers Impact researchers, Judith Unell and Hilary Bagshaw.

Recruitment of Carers

Recruitment has been undertaken by the sites using both known statutory and voluntary sector networks as well as trying to tap into the much larger numbers of carers whose only contact with services tends to be the GP. This has been a significant undertaking for the sites as it has not only involved extensive mailshots to carers known to voluntary and statutory agencies but has also included:

- briefing staff such as sheltered housing wardens, district nurses and homecarers to encourage people to participate
- liaising with outreach development work in black and minority ethnic communities and as one area remarked "literally knocking on doors"
- spending time with general practices to raise awareness of carers issues and to ask GPs and other practice staff to encourage carers to take part
- publicising the project widely using the local press and radio
- distributing leaflets to outlets other than health and social services, such as pharmacies, libraries, churches and mosques
- using other local public consultation exercises to publicise the project

Although there has been some evidence of consultation fatigue and some initial cynicism at the outcome of the exercise there have been very positive outcomes:

- some success in reaching out to hidden carers, particularly where agencies have worked together to do this and have explicitly aimed to extend the dialogue beyond the familiar circles
- positive feedback from carers who took part and who valued the experience and are keen to continue being involved; for example a meeting with Asian carers is moving on to becoming a regular support group
- a strong reminder that many users and carers do not readily complain or make comments directly to services and value voicing their concerns to a totally independent body
- raised carer awareness from the publicity drive
- in-depth feedback from carers enabling sites to assess and revise their current strategies and to take action on specific issues.

2 Where are we now? Key messages from carers

The overall picture from both the Taking Stock sites and the demonstration projects shows little evidence of "having got there" in supporting carers. Indeed it is shocking to listen to the experiences of many carers who have been at the receiving end of poor practice and unreliable services and to hear so many familiar concerns which continue to leave people isolated and vulnerable.

To date over 150 carers taking part in the first three demonstration projects have identified what has helped them locally to achieve the following outcomes which are important to them:

- being fully informed
- emotional support
- control of your own life
- time off
- financial security
- confidence in service quality ,reliability and ethnic sensitivity
- opportunities for the person cared for to have a good quality of life
- better public attitudes towards disabled people

Whilst the carers have identified and praised a number of local services and good practice which positively helped in achieving these outcomes, there are a number of recurring problems. These are messages which have been reinforced by carers taking part in the Taking Stock and Taking Action workshops.

➡ *Being fully informed*

Getting the right information at the right time remains one of the major concerns of carers. One carer likened service information to a web which was complex and difficult to penetrate. Once inside the system, however, it is possible to feel swamped by the vast amount of written material.

Carers found some of the best help was given on a one-to-one basis, for example, through either a well informed worker or advocate, staff at carers centres or information from other carers in support groups.

Lack of information from medical staff about the personal and social consequences of medical conditions, the insensitive ways in which a diagnosis was given and poor co-ordination between services were frequently cited by carers as denying them good access to information.

➡ *More active listening by staff*

Being listened to with respect by professional staff is of primary importance to the carers but so often missing, particularly for carers of people with mental health problems. Carers felt that staff needed to be more active in seeking them out and investigating their needs, particularly their needs for health care. Carers found many staff wrongly assumed they were coping and black carers frequently found there was a stereotypical response that their own communities would support them.

➡ *Assessment of carers' needs*

The feedback on carers' experience of assessments is reinforced by a number of other recent pieces of research (for example: *Still Battling? The Carers Act one year on,* CNA) which show many carers are not being offered an assessment nor do they know of their right to ask for one. Many assessments remain strongly focused upon the person cared for and carers needs are marginalised. Carers from black and minority ethnic communities are even less likely to have their needs assessed.

There was positive feedback from some carers whose assessments had resulted in practical services and just as importantly they felt better informed and involved in negotiating services.

But many of the carers were unclear whether their needs had been assessed; assessments had been service-led; few carers had received a written copy of either the assessment or care plan; many carers had to repeat the same information time and time again to different services.

➡ *Confidence in service quality and reliability*

The need for more consistent quality mainstream services is a major issue for carers, particularly the homecare and district nursing services. Carers were concerned that staff from many of the homecare agencies appeared poorly trained and that the services coming into their home often lacked continuity of contact and frequently there was insufficient time allocated to do the job properly. Black carers were concerned that few services were ethnically sensitive.

➡ *Accessing support*

Three specific problems in accessing appropriate support were raised by carers:

- a back up service for emergencies
- regular contact, or at the least easily accessible contact, with someone who fully understood the condition and changing needs of the person cared-for. Short term, task focused assessment and care management did not meet these needs
- difficulties when needs may be episodic, rather than continuous, particularly relevant to carers of people with mental health problems.

➡ *Opportunities for a break*

Gaps in respite care provision are logged up consistently. They include more opportunities for a break for parent carers, particularly those caring for teenagers and young adults, and for carers of older people with difficult behaviours.

➡ *Links across the whole service system*

Carers underlined the importance of key services such as transport and access to public facilities which can have more impact on their lives than many other services. Indeed difficulties with these could negate the support offered by community care services.

Poor liaison between services has been a recurrent theme; as one carer in The Taking Stock workshop remarked: *"Do you realise just how many people come into our home..."*

The unfulfilled potential for GPs to act as signposters to other services was another consistent theme.

➡ *More stability in the services*

Carers have commented on the frequent changes in the organisation and delivery of services which have undermined their need for a consistent framework of support.

3 Taking action to improve support to carers

3.1 The groundwork

The first year of Carers Impact has aimed to lay the foundations for achieving change on all the sites taking part, both within the Taking Stock sites and the demonstration projects. ***Essential first steps have included***:

- ***establishing multi-agency groups, with an ongoing commitment:*** The current work appears to reinforce the findings of the first Carers Impact project that more progress is made where there is a joint working group devoted to carers issues and clearly linked to planning and budgetary processes.

- ***fully involving carers***: Many areas have developed good carer networks and the ability to consult with and involve carers in many different ways. However a number of agencies are at much earlier stages of working with people using their services and rely mainly on more formal methods of consultation. The experience of working with carers in the two-day workshops appears to have been a significant experience for a number of managers.

- ***tapping in to outreach work with black and minority ethnic communities***: For example in Tameside, the project has linked into the Black Communities Initiative and Asian carers were brought together for the first time by bilingual "co-workers" personally contacting them.

- ***communicating the work to staff, carer and public networks***

- ***mapping out current work to improve support to carers***

- ***identifying potential local blocks and drivers to taking action***

3.2 Good news, bad news

Maintaining the carer profile has been challenging given:

- the work is taking place in a number of areas at a time of significant organisational change following the local government review

- in all areas the pressures on budgets are acute which has not eased relationships between health and social services

- management cutbacks in all sectors over the last few years have left fewer people to lead or give substantial time to development work

- frontline staff are interpreting and putting into practice increasingly tight eligibility criteria.

This is not to ignore the considerable work taking place to raise awareness of carers issues, particularly within primary healthcare, nor the numerous initiatives to support, inform and involve carers, nor the training, guidance and publicity geared to the implementation of the Carers Act. On a political front the carers lobby has been particularly effective in keeping carers needs on the political agenda.

However from the evidence of many carers taking part in the projects there is very real frustration at what appears to be a significant gap between local carer charters and policies and carers' day to day experience. Many carers are exasperated by the length of time it has taken to see any positive changes only to find these are now threatened, both by local cutbacks in services and more generally by the increasing emphasis on private provision and family rather than state solutions to care. There is a danger that the emphasis on 'responsibilities' can slide into 'lack of choice' for example some carers have been left to carry out invasive medical procedures with little training.

3.3 Taking joint action

The Carers Impact sites are working hard to address the feedback from carers and to implement workshop action plans. Action on **assessments, work with primary healthcare** and **information needs** appear to be consistent themes within the action plans developed during this first year.

The sites are tackling these from very different starting points, particularly in developing their joint work. In some areas carers needs appear to be very low down the health services agenda.

Taking action across a wide range of departments and agencies inevitably requires time-consuming consultation and negotiation. Seeing this through relies on considerable commitment from all the partners as well as champions at sufficiently senior level who can network across the agency boundaries and progress chase.

In Tameside the carers action plan which developed out of the carers feedback was taken to a chief officers meeting. One of the action points agreed was to address carers' issues and general practice within a health and local authority urban renewal project . This will require considerable collaboration between a number of agencies and departments.

In Hammersmith & Fulham a multi-agency group is working to establish a Carers Centre as part of their action plan to improve support to carers.

3.4 Influencing mainstream services

Making the links with other work in progress has been another important part of the work on the sites. Many of the issues raised by carers concern core health and social services such as homecare or nursing services, and other activities such as assessment and care management or information provision. The sites are alerting ongoing developments to 'think carer' so that the work can move forward mainstream. The aim is for *every* member of staff to take responsibility to progress the carer agenda, not just the specialist carer support worker or carer centre staff

In Southwark, the homecare specification is being reviewed in response to the carer feedback and to better inform the tendering process. The district nursing service is also responding to the concerns raised by carers and working with staff to raise awareness of the needs of carers.

Workshops are planned in Southwark and Tameside with front-line staff, managers and carers to develop indicators of good practice in carer assessments

Getting ownership of the issues at every level of all the partner organisations has required considerable work.

In Tameside taking the carers agenda mainstream has involved

- *holding a joint workshop to agree an action plan*
- *consultation with carers on proposed new structures for involvement*
- *presentation to the senior joint planning group*
- *dissemination of the feedback from carers and resulting action plans to managers in all the partner organisations including all managers with training responsibilities*
- *holding a workshop for front-line staff, managers and carers*
- *briefing the independent provider forums*
- *informing the public through a local newspaper delivered to every home*
- *informing carers through the Carers Centre newsletter*

4 Years Two and Three

The first year has primarily been about 'taking stock' and laying the foundations for achieving change. The next year will concentrate on implementing the action plans and working with sites on ways of monitoring each action point. Finally, both parts of the programme will be moving on to evaluate the work, review progress in implementing the local action plans and, in the demonstration projects, to achieve an 'after' picture of the impact on carers. The learning from this, as well as a comparison with this picture of the first year, should help us in answering the question ***"how do we know when we have got there?"***

Appendix 1

Carers Impact Steering Group

Rosanne Corben	**Chair**
Peter Ackland	Alzheimer's Disease Society *from Oct '97*
Jean Bailey	Royal College of Nursing
Dorothy Blatcher	Local Government Association *from July '97*
Charlotte Bruton	Crossroads *July-Oct '97*
Helen Cava	Crossroads *July '96-July '97*
Andrew Cozens	ADSS *from April '97*
Amanda Edwards	Social Services Inspectorate
Brian Jones	Association of Metropolitan Authorities *July '96-Apr '97*
Stella Lowry	British Medical Association *to Oct '97*
Graham Lythe	Association of County Councils *July '96-Apr '97*
Harry Marsh	Contact-a-Family
Janet Morgan	Gatsby Foundation *July '96-Apr '97*
Jill Pitkeathley	Carers National Association
Janice Robinson	The King's Fund
Roy Taylor	ADSS *July '96-Apr '97*
Unwin Monica	Alzheimer's Disease Society
Chris Vellenoweth	NHS Confederation
Matthew Williams	Gatsby Charitable Foundation *from April '97*

The Carers Impact Team

Penny Banks	Project Manager
Colin Cheeseman	Senior Development Consultant
Sarah Maggs	Project Secretary

The King's Fund
11-13 Cavendish Square
London W1M 0AN

Tel: 0171 307 2648
Fax: 0171 307 2810
E-mail: s.maggs@kehf.org.uk

48572 020000 048