

## End of Life Papers

# Inter-organisation communication for end of life care

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### Key messages

- People who want to die at home often die in hospital because there is insufficient communication between those involved
- New mechanisms are needed to support good whole system communication

### Why this matters to me

As a general practitioner working in an out-of-hours service I often have no choice but to admit

someone to hospital when a crisis occurs, even when I am fairly sure the patient wants to die at home. Sometimes advance directives made by a patient are not clear to me. Sometimes the family is not prepared to watch and wait. Sometimes I am the first person to open out a discussion that conservative treatment is an option. I want to improve communication between in- and out-of-hours practitioners and also families, to help me take my part in helping people to die with dignity.

### ABSTRACT

**Background** Poor communication between in-hours and out-of-hours (OoH) general practitioners (GPs) causes unwanted admissions to hospital of patients who want to die at home

**Setting** A GP OoH service in West London (London Central and West Unscheduled Care Service) used by 159 general practices from four primary care trusts

**Question** What helps to avoid hospital admission of patients who want to die at home when a crisis occurs in the OoH period?

**Methods** Whole system participatory action research, with four stages: 1. engage stakeholders; 2. understand the initial situation; 3. re-design the system; 4. action for change

**Results** The following help to avoid undesirable hospital admission of a dying person who has a crisis in the OoH period: 1. a register of vulnerable adults; 2. records at home; 3. key worker(s); 4. home

interventions; 5. day-time practitioner communication; 6. a development and governance group; 7. speedy discharge from hospital; 8. decision support for OoH GPs.

**Discussion** This project revealed a useful set of policies to help avoid unnecessary OoH admission to hospital, especially improved communication between day-time GPs and OoH GPs. The approach combined *whole system participatory action research* with systems modelling and this helped the issues to be revealed quickly and cheaply. Furthermore, including leaders from partner organisations at each stage of the inquiry has encouraged shared purpose and produced champions to move forward the project recommendations. Some changes have already happened.

**Keywords:** communication, end of life, participatory action research, whole system

## Background

In 2007 a general practitioner (GP) out-of-hours (OoH) service in West London (London Central

and West Unscheduled Care Service – LCW UCC), thought that poor communication between in-hours

and OoH practitioners was causing unwanted admissions to hospital of patients who wanted to die at home. The OoH service conducted a six month project to examine the present communication system and what could be improved. It was done in partnership with Westminster and Kensington

## Methods

In order to understand all relevant perspectives we used *whole system participatory action research*.<sup>1</sup> This brings together people from different parts of the system at the beginning, middle and end of the inquiry to share insights and challenge each others' interpretations. They use a whole system diagram to visualise where communication can fail. They use role play to gain a deep understanding of the perspectives of others.

Guba calls this approach '*fourth generation evaluation*'.<sup>2</sup> This is less concerned with measuring (1st generation), describing (2nd generation) and judging (3rd generation), even though measurements, descriptions and judgements are made. Its main focus is to help everyone to co-construct a system that makes sense to everyone involved.

Guba explains that it involves:

Initial contracting, the identification of stakeholding groups and their several claims, concerns and issues, through a hermeneutic dialectic interchange in which the constructions of each group are exposed to critique and reaction from all other groups, through the development of an agenda for negotiation and the process for moving through that agenda, to final reporting.<sup>2</sup> (page18)

Our inquiry had four stages:

**Stage one: engage stakeholders.** Different stakeholders considered ways in which the inquiry might be valuable to them, and agreed to take part in the inquiry.

**Stage two: understand the initial situation.** Local initiatives and published literature were reviewed. At a stakeholder workshop (10/10/07) people from different parts of the system described the problems they experience with communication. A communications diagram was drawn and redrawn to represent the initial situation (Figure 1). The group examined the diagram to identify problems within it and ways to solve them.

After the workshop, different people from different parts of the system gathered data to illuminate problematic areas.

**Stage three: re-design the system.** Information requested at the first workshop was reviewed at project management group meetings. Debate at this group resulted in

agreement about what existing things in the communication system should be built upon and what new things were needed (Figure 2).

**Stage four: action for change.** At a final workshop (29/2/08) people who had not been involved reviewed the transferable lessons from the work.

## Results

### Stage one: engage stakeholders

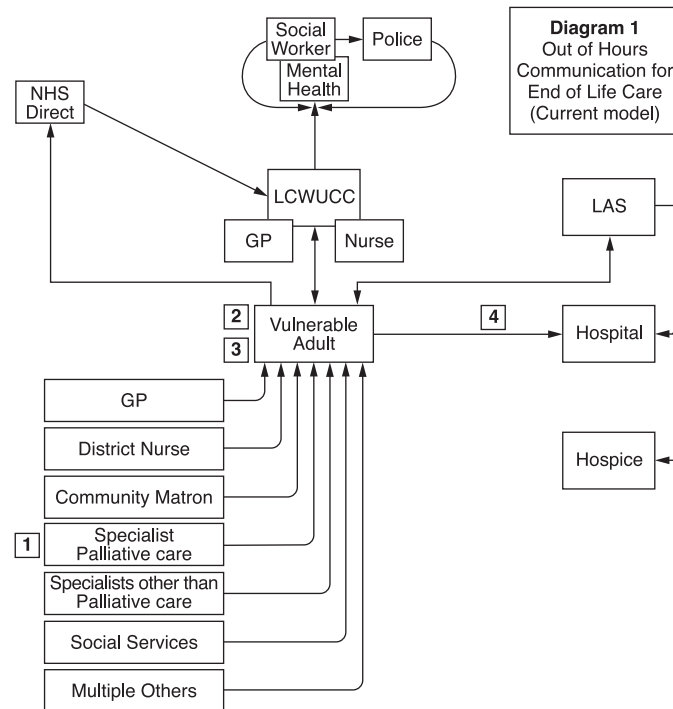
On 15 November 2006, West London Cancer Care held a workshop at which participants agreed that communication between various practitioners was poor. On 24 January 2007 LCW UCC held a workshop for its GPs to discuss the concerns raised at the first meeting. Participants similarly concluded that there is an important problem to be solved. Funding was gained to undertake this project. It started in October 2007 and finished on 14 March 2008. A Project Management Group met five times.

### Stage two: understand the initial situation

Using a snowball technique, local leaders in the field were identified and literature about end of life care was reviewed. A project management group of 22 was formed, including the project partners.

On 10 October 2007, a stakeholder workshop included 20 practitioners, managers and a patient. They undertook a role-play to identify communication problems. This revealed:

- **Patient's perspective.** Sometimes an OoH doctor can seem to be un-listening and unaware of previous consultations and decisions. They seem wary of conservative management, perhaps through fear of litigation.
- **OoH GP/LAS perspective.** Notes about patient do not always provide the information needed. Key contacts are rarely identified. There is a lack of overall planning of patient care, inadequate training of care home staff, and poor confidence of carers/families.
- **In-hours GP perspective.** Volume of work prevents making special patient notes (a system to alert OoH GPs to the special needs of patients). They may not know how to post a special patient note.
- **Hospital perspective.** When a patient has been referred, doctors tend to aggressively treat to maintain life. There is no systematic way for hospitals to feedback information about problems with the system.



1. Multiple in-hours attendants relate directly to a vulnerable adult without an agreed mechanism to communicate with each other. This makes it unclear who holds the most up-to-date and authentic information about patient preferences. The general practitioner is often expected to be the key authority, but this is not always realistic.
2. When a 'crisis' occurs, a vulnerable adult calls LCW or LAS. Without permission to do anything different, practitioners are obliged to do all they can to save a person's life, including 'heroic' procedures and emergency admission to hospital.
3. When a 'crisis' occurs, even when a vulnerable adult has previously stated they would prefer conservative management at home, the family/carers/attendants are likely to over-rule this if they themselves have not been prepared to do otherwise.
4. When a decision to admit to hospital has been made, it is often difficult to undo

**Figure 1** The whole system relevant to OoH care of vulnerable adults

### Still in role

Discussions between the four perspectives revealed that all are dissatisfied with the *status quo* except hospitals – they do not consider it their role to reverse a decision to admit. The hospital concern is to understand the best way for dying patients to return home. There was little agreement about whose role it is to oversee the development of the whole system, and to maintain it. Most thought that it should be the commissioners

### Out of role

Whole room discussion arrived at agreement between all participants that three important obstacles to good communication affect everyone.

- Human nature avoids the emotional difficulties involved with preparing for conservative management at the end of life.

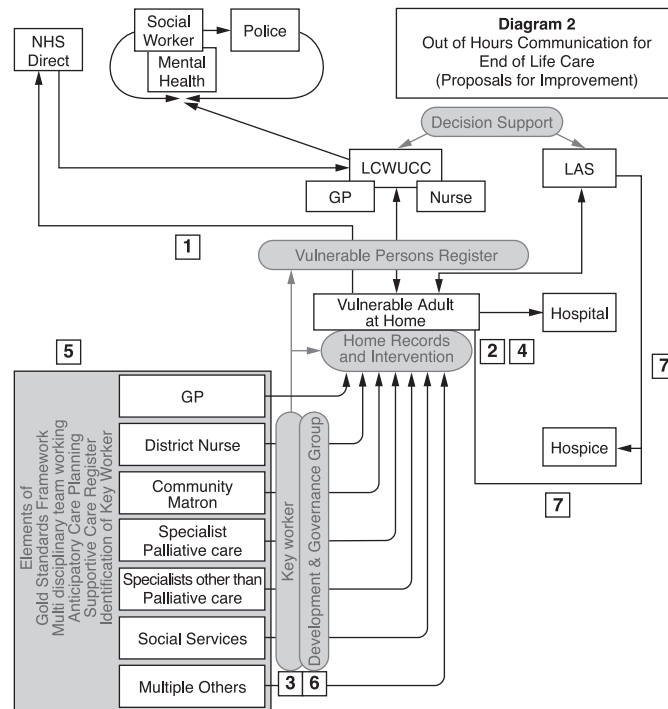
- Enabling integrated care is too complex for any one group to achieve.
- Patients have to consent to have their details on a database and this may be difficult.

Figure 1 displays the insights from this exercise.

### Stage three: re-design the system

Figure 2 includes the conclusions of the participants at the whole system events about solutions to the problems described in Figure 1. This reveals that many things have to be in place at the same time to help an OoH GP to confidently choose conservative treatment. These are beyond the ability of any one agency to provide.

The following inquiries were undertaken to understand the feasibility of Figure 2.



1. **A register of vulnerable adults** helps OoH practitioners to prepare their thoughts, and identify at an early stage where to find personal plans. The existing LCW 'special patient notes' system can do this.
2. **Records at home** are needed to quickly access the most up to date information. The existing 'message in a bottle' system can do this.
3. **A key worker** updates home records and vulnerable adult registers. Palliative care nurses and community matrons have a case manager (key worker) role, but most vulnerable patients do not have a named key worker.
4. **Home interventions** Existing models such as Gold Standards Framework and Liverpool Care Pathways can prepare family and Care Homes for crises.
5. **Practitioner communication systems** help practitioners and managers to pass information to each other and consider ongoing data about performance. There is no established way to systematically do this throughout primary care.
6. **A development and governance group** oversees the whole system, including interventions for good team-working. This group could operate alongside practice-based commissioning to facilitate system redesign, leadership development and ongoing quality improvements. Kensington & Chelsea has an existing vulnerable patients group that could do this.
7. **Speedy discharge from hospital**

**Figure 2** Interventions within the system that might overcome the problems identified in Figure 1

### *Do general practitioners use the special patient notes system?*

Between 1 September and 30 November 2007:  
 Practices that submitted, or updated  
 at least one note 56/159 (35%)  
 Largest number of new notes made  
 by a practice 9  
 Largest number of old and new  
 notes from one practice 19  
 Average number of notes per  
 practice per month 1

### *Do general practitioners use electronic communication with LCW?*

In 2007 electronic links were established between general practice and LCW; 26/159 (16%) of practices were registered to use electronic links in November 2007.

### *Why don't general practitioners use the system more often?*

Seventy-one practice managers were surveyed by email. Twenty-four replied (34%) – 22 from K&C PCT and two from Westminster PCT

- 23/24 said they used fax rather than electronic links to register Special Patient notes
- 22/24 said they had a protocol for patients nearing the end of life

The following reasons were given for low level of use of electronic links:

Pressure of work, time taken, faxing is easier	14
Few patient's on palliative care	3
Can't access the website	2
Forget about the OoH impact on care	1
Question not answered	4

### *What do community nurses think about the special patient notes system?*

Forty-two community nurses in K&C and W were surveyed by email.

In K&C 8/16 nurses replied (50%). Only two knew the register existed. None had tried to use it, but several said that they would like to. Two said that they thought that district nurses should be responsible for maintaining the register (at present only GPs are allowed to post notes). One suggested that the quarterly vulnerable adult liaison group for high users was well placed to oversee the system as a whole.

In Westminster 7/26 replied (27%). None were aware of the system but all thought it was a good idea and asked how they could access it.

### *How can we routinely monitor the number of people who die at home, care home, hospice and hospital, and cost the services?*

The public health departments of Westminster and K&C and W area, broadly in line with the national profile. It also reveals a marked difference between W and K&C in the number of people dying in hospices and care homes.

They agreed that it would be helpful and feasible to gather data every six months, using a one year rolling average to iron out blips. Data from the past two years shows a fairly stable pattern.

They also agreed that it would be feasible to interrogate the SUS database to quantify hospital stay of patients at the end of their lives. This could lead to an analysis of cost.

There is presently no equivalent way to quantify the cost of community care.

### **Stage four: action for change**

The project management group agreed that the proposed changes were needed and feasible. Recommendations for policy were made for PCTs, GPs, LAS and LCW UCC.

On 29 February 2008 these recommendations were endorsed by 39 people from partner agencies at a final dissemination workshop.

The following progress was made in the following within 12 months:

- eight training sessions for 54 practice managers, GPs and community nurses from 39 different practices to learn how to use electronic links to post special patient notes
- decision support for OoH doctors when visiting patients who are dying
- a mutual referral protocol between LCW UCC and London Ambulance Service
- expert palliative care advice service for OoH doctors.

## **Discussion**

This study showed that it is not easy to avoid hospital admission for someone who wants to die at home. Several links in a communication chain must work and others (e.g. families and care homes) must be ready to do their bit when a crisis happens. This project distilled the issues and gained agreement from the relevant organisations to act on the project recommendations. There is evidence of subsequent action on these recommendations.

When participants in this study stood back and looked at the whole system they quickly recognised the importance of the communication links – links that already exist but are poorly used. The shock for everyone was that no-one seems to have a role to maintain and develop them, nor to feedback information about their performance. Consequently these system-wide links are little valued and not monitored.

Perhaps the lack of attention to these connections is because healthcare managers and practitioners are not trained in whole systems thinking, and complex interventions that include a set of equally important interventions led by different organisations. Instead we learn about discrete project management and centralised approaches to change. Even the idea that a whole system of care can be conceptualised and evaluated was new to our informants. So perhaps the most important contribution of this project is to show that it is possible – cheaply and quickly – to conceptualise, analyse and pilot redesign of a whole system of care.

In this issue of *LJPC* other papers show how a multifaceted whole system approach is needed. Addicott's paper shows that a centralised approach to administration reduces the need for form-filling – but it also reduces opportunities for various professionals to learn and act in concert. Law's paper argues that opportunities for primary and secondary care professionals to learn and act in concert are essential, as well as flexible bed capacity and incentives for hospitals to keep patients in the community.

The model we have used aims for short-term clarity about the issues with modest movements towards the long-term aim. This contrasts with previous whole system models that have tried to do too much. Previous models of whole system change have taken large numbers of people on a collective journey. The Kings Fund model of whole system change<sup>3</sup> used a variety of large groups interventions<sup>4,5</sup> including *Real-time strategic change*, *Future Search*<sup>6</sup> and *Open Space Technology*.<sup>7</sup> They are powerful and effective – but they did not catch on and the health service continued with a direct, instrumental approach to change. A 'business process re-engineering' approach was used to facilitate whole system change in Leicester Royal

**Table 1** Place of death for residents (2003–2006). In 2006 the resident population of K&C was 165 000, and of Westminster was 211 000

Setting	K&C	Westminster	England (2005 data)
Hospital	1549 (57%)	2359 (61%)	75% (incl. care homes)
Hospice	175 (6%)	400 (10%)	5%
Care Home	422 (16%)	240 (6%)	See hospital (above)
Home	531 (20%)	786 (20%)	19%
Elsewhere	39 (1%)	85 (2%)	2%
<b>Total</b>	2716	3870	–

Infirmery – but leaders finally concluded that it was too ambitious, concluding that ‘*incremental revolution*’ is a more realistic aim.<sup>8</sup> The tortoise is faster than the hare.

There is something of a plodding tortoise in our intervention. We did not seek dramatic changes. Instead we sought to get people to stand back from their own preoccupations and look together at what already existed and how to make small improvements. We did not expect to achieve the changes within the project. Instead we wanted to set up a creative dynamic between different agencies and stimulate a network of deeply engaged leaders who wanted the whole system to work. We believed that this had a chance of resulting in future collaboration to act on the project recommendations. This is a non-linear belief about the process of change.

Evidence supports the view that sustainable change happens through non-linear routes. Innovation often happens through networks of deeply engaged participants, below the radar of formal scrutiny.<sup>9</sup> Multi-disciplinary facilitation teams,<sup>10</sup> professional mediation,<sup>11</sup> shared leadership<sup>12</sup> and distributed leadership<sup>13</sup> can harness motivation and creativity across organisational boundaries where hierarchal approaches fail.

If the health service is serious about its claim to want integrated services, whole system action inquiries like this are needed as part of routine activity. We need to find ways to embed this kind of collaborative inquiry within everyday PCT activity. Training courses need to teach the theory and leaders need to learn the skills. We also need to work out the best governance of this kind of inquiry that is neither research nor audit.

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#### ETHICAL APPROVAL

This was a service improvement project so did not need ethical committee approval. Instead the Clinical Governance Group of London Central & West Unscheduled Care Service approved and monitored the project.

#### CONFLICTS OF INTEREST

None.

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