

# Mapping Unpaid Carer Involvement in Hospital Discharge

Survey Analysis Report

January 2022

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## Purpose of this report

This report explores the results of a survey designed to capture the extent and nature of activity to involve carers when a cared-for person is discharged from hospital. Details are included on the different approaches being delivered across local health boards, how the impact of these approaches is being assessed, the factors that are enabling success and opportunities for further improvement.

This analysis will be of interest to staff working to support carers in all health and care settings and is designed to generate discussion around improvement in local areas. We are interested in continuing to support improvement around carer involvement in hospital discharge and are keen to hear feedback and ideas generated from this report.

## Summary of findings

### Extent of involvement of carers in hospital discharge

- The involvement of carers in hospital discharge varies considerably, across hospital settings and between NHS board areas.
- The majority of third sector staff describe this as happening to a lesser extent than staff that responded from the NHS and Health and Social Care Partnerships.

### Activities in place to support involvement across health boards

- 49% of respondents did not provide a description of activity.
- Where activities were described these included having a dedicated role to support carer involvement, awareness raising and signposting and involving carers in discharge meetings.

### The impact of activities to involve carers

- Many respondents were not aware of how the impact of current activities to support involvement of carers is being assessed.
- Some descriptions were given for assessing impact on carer experience e.g. surveys, Care Opinion, however measures to assess impact of involving carers on staff experience or on the hospital system were not identified.

### Factors that can enable success and support further improvement

- Good communication, team work and having dedicated resources to support carers were described as factors that enable successful involvement in discharge.
- Factors that would support improvement focus on:
  - systems and processes e.g. identification of carers and earlier discharge planning
  - staff awareness and understanding e.g. staff training
  - carer awareness and understanding e.g. information and support for carers

## Background to survey

[The Carers \(Scotland\) Act 2016](#) includes the duty that each health board must ensure that, before a cared-for person is discharged from hospital, it involves any carer of that person in the discharge. In this survey, Healthcare Improvement Scotland explored the current extent and nature of activity to involve carers in hospital discharge from the perspective of staff across the NHS, Health and Social Care Partnerships (HSCPs) and the third sector.

The aim of the survey was to describe staff perception on activity to support carer involvement in hospital discharge:

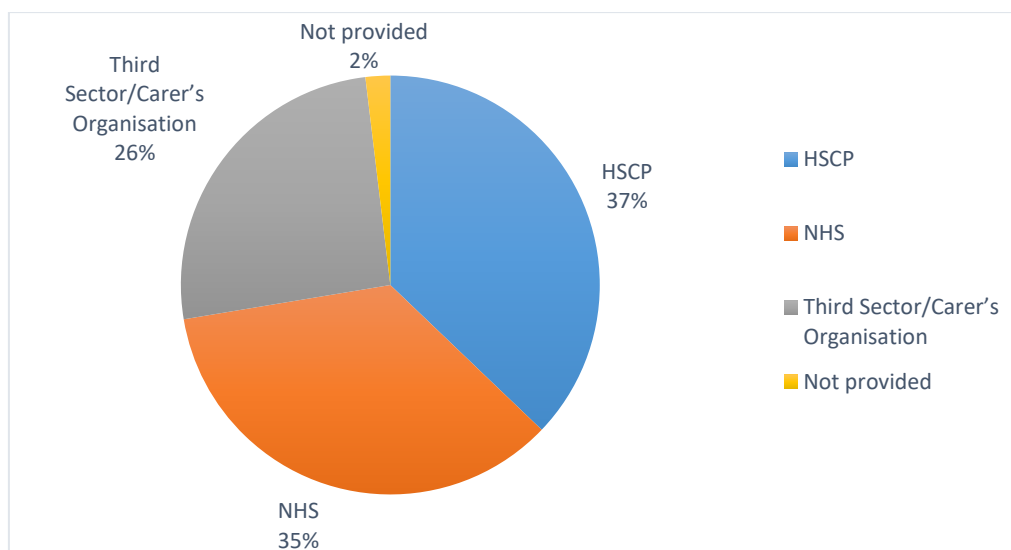
- the extent and nature of local activity
- the impact of these activities
- the factors that enable success and what is needed to support further improvement

The survey was distributed to staff for completion online. The survey questions were informed by a previous design developed to map activity prior to implementation of the Act.

### *Survey responses*

At the close of the survey there were 106 responses, covering all 14 health boards with the majority of respondents representing HSCPs and then NHS boards (Figure 1).

**Figure 1: Respondents by organisation**



# Overview of survey results

## Extent of involvement of carers in hospital discharge

Respondents were asked for their views on the extent to which involvement of carers in hospital discharge, as set out in the Carers (Scotland) Act is happening in their local area. A majority from third sector/carers organisations described this happening to slight extent compared with a majority from the NHS and HSCPs describing this as considerable.

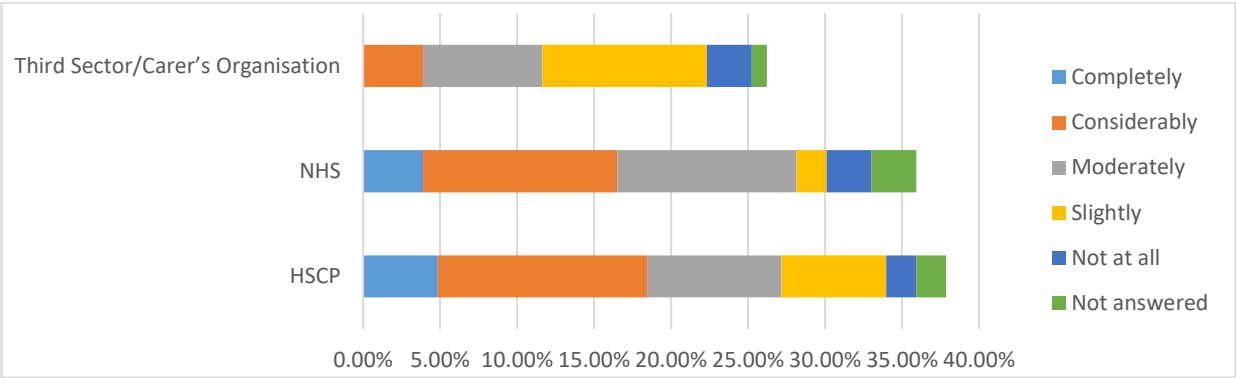
“Carers are not encouraged to share their views/concerns enough. They often feel unable to challenge views of medical staff. Forward planning is needed. Carers should always be advised re services/supports. Whilst they initially may feel able to cope without supports they should also be made aware of options should the situation change.”

(Third sector/carers organisation staff member)

“I believe this is something we do well in my area as discharges are strongly led by OT/PT etc. If medically fit following surgery. I think early discharge planning is beneficial for all, ensuring we are aware of the criteria for discharge and what is required for the carer and patient at home”

(NHS staff member)

**Figure 2. Extent to which involvement of carers in hospital discharge is happening by organisation perspective**



## Description of activities to support carer involvement in hospital discharge

Respondents were asked to describe the activities taking place within hospital settings to support carer involvement in hospital discharge. Many respondents didn't provide a description or indicated that there were no or limited activities taking place (49%). Where responses provided a description of activities taking place, table 1 illustrates the range provided.

Descriptions commonly mentioned the involvement of carers in discharge planning meetings. There were also descriptions of where specific activities had been put in place including the recruitment of dedicated roles to support carer involvement, staff training and activity around raising awareness aimed at both carers and staff.

Further details of these local approaches will be published in upcoming case studies on the ihub website: <https://ihub.scot/improvement-programmes/people-led-care/recognising-the-value-of-unpaid-carers/>

**Table 1. Examples of activities in place within hospital settings to support involvement of carers in hospital discharge**

<b>Recruitment of dedicated carer support worker</b>	Carers Trust Hospital Liaison worker attends the Complex Discharge Huddle daily and referrals are completed to Carers Trust for carers from all wards and areas such as Palliative Nurses, Chaplaincy, Mental Health Older Adults Team and Physiotherapy
	New post created for a Family Wellbeing Worker (Hospital Care Support) to work directly with carers when the cared for is admitted to hospital, supporting them to stay involved in the development and delivery of care and preparations for discharge
	Carers Facilitator has been employed. This post has made good progress and it's positive to be able to link in with this person around individual cases. Also has been able to implement some new processes re paperwork identifying carers on admission and carers leads on wards etc. Unfortunately it is a seconded post and not permanent and we are not sure if this will be continued when it is greatly needed.
<b>Carer involvement in discharge planning meetings</b>	Discharge planning is done with carer involvement and takes into consideration carers' needs and views.
	Daily MDT meetings to ensure OT/PT are liaising with carer/family regards home environment, essential equipment etc. We have also held MDT meetings with carer to ensure they are aware of the care needs and ensure we can facilitate the discharge safely. We have also been able to use hospital to home to support the carer on discharge to support with personal care etc.
	Discharge planning meetings involving carers and other stakeholders. Discussions throughout hospital stay with regards to situation at home. Weekly MDT meetings with situation being discussed for each patient and feedback to carer given
<b>Raising awareness with staff and carers</b>	Pilot programme underway in three hospitals to review ward staff awareness of carers and their rights in relation to cared-for hospital admission and discharge.
	There is a dedicated carers information board at the front of hospital reception areas. There has been training of staff when The Carers Act was implemented and there is a dedicated training section for staff on the intranet, this is currently under review and looking at best practice in other health board areas
	Carer Advice and Information Teams offer carer briefings for acute staff and GPs to identify carers. Acute setting have support and information services which offer information and advice to carers.

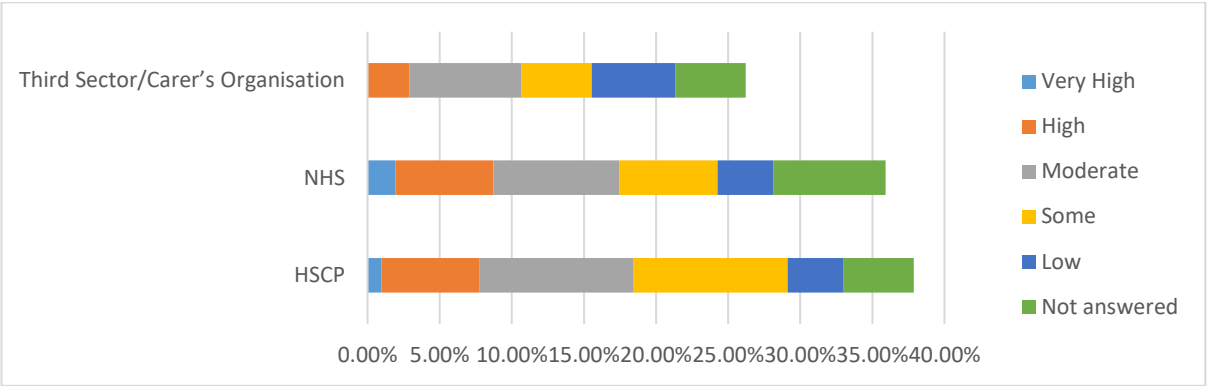
Some descriptions also included examples of perceived barriers to activities including pressures during the COVID-19 pandemic and sustainability of activities given the funding arrangements for roles such as the carer support worker.

“During the pandemic referrals have slowed as the hospital link worker could not be based in the hospital during this time. Staff turn-over and other pressures have meant that carer inclusion or referrals for support in discharge have not been actioned as often as before”  
(Third sector/carers organisation staff member)

*Proportion of hospitals included in current activity*

Respondents were also asked to rate the proportion of hospitals/departments incorporated in current activity to support carer involvement in hospital discharge. A majority of respondents across NHS, HSCPs and third sector described this proportion as some or moderate (Figure 4).

**Figure 4. Proportion of hospitals/departments incorporated in current provision**



## **Box 1. Carer experiences of involvement in discharge**

Some staff members who responded to the survey shared personal experiences of being a carer or from working closely with carers across a number of the free-text boxes. While these experiences tended to be negative in nature they highlight potential opportunities for improvement. These have been summarised under three broad themes:

### ***Involvement in decision making***

There were descriptions of missed opportunities to involve and value the views of carers in decision making.

We were never consulted or included in the discussions around discharge despite (mum) giving consent for us to know the medical information and be involved in decisions. We routinely had to phone multiple times to speak to a doctor to get any information

I often have carers tell me their cared for is being discharged without any prior discussion with them. On a recent occasion - after the carer expressed significant concern about this - her mother remained on the ward and was thereafter admitted into a care home. In some situations people are readmitted very shortly after discharge - despite the carers concerns re the likelihood of this happening.

### ***Expectations of the caring role***

There were examples of where carers are expected to take on the caring role without there being a realistic conversation about the support required at home and whether they can cope.

When a person is being discharged when they still need help, they assume the carer can fix it. Not the best outcome for patient and carer. The carer is left feeling very hopeless to support the patient.

Better communication is needed. I think carers need to be more informed throughout their cared for's journey. Not just to be told tomorrow is discharge day. I appreciate the demands within the hospital setting but carers have other things going on in their lives too - family, work, health issues of their own. Enabling/preparing carers for their caring role can be a vital part of a successful discharge.

### ***The importance of ongoing care needs***

There were descriptions of how planning for ongoing care needs should be improved to ensure that appropriate services are in place by the time of discharge.

People are often discharged without the appropriate support resulting in community workers having to go out and reassess the person and increase support, this can sometimes take weeks and a person is left with inappropriate support at home.



## Measuring the impact of activity to support carer involvement in hospital discharge

To develop better understanding regarding the outcome of different approaches to support carer involvement in hospital discharge respondents were asked to identify the measures in place to assess the impact of activity on:

- carer experience,
- staff experience and the
- hospital system (delayed discharge, readmission rate).

### *Impact on carer experience*

The majority of respondents did not know or were unsure if any measures are in place in their area to assess the impact of activity on carer experience. Where descriptions were given this mainly involved different types of feedback being collected through local approaches including surveys and phone calls or through standardised sources of routine feedback such as Care Opinion.

### *Impact on staff experience and the hospital system*

It is also not clear from responses what measures are in place across local areas to assess the impact of activity to involve carers in hospital discharge on staff experience or the hospital system. The majority of respondents described that they did not know or were not aware of any activity.

### *What has enabled successful involvement of carers in hospital discharge?*

Respondents shared a number of views around the elements that have enabled successful carer involvement in hospital discharge. The most common themes identified included:

- **Partnership working:** several mentions of the importance of a multidisciplinary team approach in the hospital setting and in addition partnership working with community services and with the third sector
- **Communication:** the importance of open and honest communication with carers
- **Dedicated staff roles:** several respondents shared the value of having dedicated staff to support carers, whether employed by the public or third sector

“The activity rates of involvement of carers in hospital discharge vary and are dependant on a presence from the hospital carers support worker, staff training, awareness, relationships between staff and hospital support worker”

(Third sector/carers organisation staff member)

### *What could improve carer involvement in hospital discharge?*

There were wide ranging descriptions by respondents of what could improve carer involvement in hospital discharge that have been summarised in three categories:

#### *Organisation: improving systems and processes*

The opportunity for carers to be consistently identified during the admission process was raised in addition to having a mechanism to record this in the patient file. Several responses highlighted the current challenges around electronic sharing of information between community and hospital systems with improvement in this area enabling the early identification of carers in hospital when carers are known by community services.

The importance of early discharge planning was commonly raised by respondents and the importance of involving carers throughout this process. There were also suggestions around improving accountability for involving carers in discharge, the importance of having a system in place to record involvement and how this aligns to local and national auditing and inspection.

“There needs to be more emphasis on measuring carer involvement in hospital discharge within documentation audits and inspection”  
(NHS staff member)

“Sharing of QI work that HIS is involved in with all areas so that planning can commence if areas are interesting in adopting ideas (staffing, system change etc.)”  
(NHS staff member)

#### *Staff: Raising awareness and sharing learning*

Raising awareness and understanding of hospital staff through provision of staff training and support was identified as a key improvement opportunity. There were suggestions of mandatory training and for a coordinated approach across Scotland. The importance of introducing and sustaining dedicated staff roles for supporting and involving carers in discharge was also described and ensuring increased opportunities for networking across Scotland to share learning and good practice.

“Once for Scotland approach for training, this should be mandatory”  
(NHS staff member)

“Access to completion rates of EPIC at a board level to allow areas to monitor the use of these resources. If carers are truly to be seen as equal partners then they should feature in training material.”  
(NHS staff member)

### *Carers: Raising awareness and understanding*

There were responses describing the importance of improving carer awareness of their right to be involved in hospital discharge and building their confidence to be involved in decision making. This included being encouraged to ask questions and to understand their own role in successful hospital discharge. There was also additional perspectives shared about carer expectation and improving understanding when carer views differ from those of patients and decisions need to be 'negotiated while respecting people's right to choice'.

"Encourage carers to ask questions as and when they arise and not to wait till a discharge date is set. For staff to encourage and ask questions of issues or concerns regarding discharge as carers may need prompting with this"  
(NHS staff member)

## Summary

A wide range of activity has been implemented within hospital settings to support the involvement of carers in hospital discharge however descriptions of these activities in this survey suggest there is vast inconsistency in practice between and within health boards. There are limited methods in place to understand and measure the impact of this activity and therefore it is challenging to draw conclusions on what approaches are proving successful.

Good communication, partnership working and having dedicated staff resources to support carers were identified as factors that enable carer involvement. Several factors that were suggested to enable improvement are related to the identification of carers whether through raising staff awareness or implementing a change in hospital processes. The role for national organisations in promoting consistency and sharing learning was also highlighted.

## Next steps

The Unpaid Carers Improvement Programme within the ihub are currently carrying out follow up interviews with local areas to capture and share further details and learning from local approaches. There is an opportunity to explore additional ihub support around measuring impact of activity to support carer involvement.

The ihub will also be working in partnership with NHS Education for Scotland to capture wider examples of good practice in identifying, involving and supporting unpaid carers across health settings. Evidence and learning from these local examples will be shared across national networks to engage with the wider health workforce and promote improvement activity.

Read our latest good practice case studies here: <https://ihub.scot/improvement-programmes/people-led-care/recognising-the-value-of-unpaid-carers/>

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