



Involving unpaid carers in hospital discharge

Summary

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Improvement Hub
Enabling health and
social care improvement



1. Introduction

The Carers (Scotland) Act 2016 aims to improve the support that unpaid carers receive.

"It is the intention of the Scottish Government that Scotland's estimated 788,000 carers including 44,000 young carers are better supported on a more consistent basis so that they can continue to care, if they so wish, in good health and wellbeing, allowing them to have a life alongside caring."

(Scottish Government, 2018, page 13)¹.

The Act includes a legal duty for health boards to involve unpaid carers in the hospital discharge process¹. This evidence summary will explore what we already know about involving carers in hospital discharge.

What is an unpaid carer?

We use the term carer to describe people who provide **unpaid care**. An unpaid carer **provides care and support to family members, friends or neighbours**. The people they care for may be affected by disability, physical or mental ill-health, frailty or substance misuse². Unlike paid care workers, carers receive no wage for the support they provide.

Carers can support a variety of tasks. Some examples include:

- personal care
- helping to manage finances
- undertaking practical tasks including shopping, cooking or providing transport
- emotional support
- managing medication, and
- ensuring that the person can maintain their interests and friendships.

Carers do not have to live with or be related to the person they care for. They also do not need to be their only carer².

What is a young carer?

Young carers are **unpaid carers who are under 18 years old.** They often look after a parent, brother or sister. They may care for someone with a disability, illness, mental health condition, or drug or alcohol problem. Their caring tasks may include cooking, cleaning or helping someone get dressed and move around³.



Overview

In this document, we set out some of the reasons why involving carers in hospital discharge is beneficial for staff, patients and carers. We also set out some key learning from different approaches to date.

We consider:

- an introduction to carers and young carers
- an <u>overview of unpaid carers in Scotland</u>
- an <u>overview of published literature</u> about the involvement of unpaid carers in hospital discharge
- analysis of <u>carer feedback from the Care Opinion website</u>
- findings from an <u>evaluation of pilot projects</u> involving unpaid carers in hospital discharge, and
- a <u>case study</u> on hospital discharge carer support workers in Fife.

2. Context

The <u>Carers (Scotland) Act 2016</u> estimates that there are 788,000 carers in Scotland. This includes an estimated 44,000 young carers¹. More recently in 2020, <u>Carers UK</u> estimated that there may be as many as 1.1 million carers in Scotland⁴.

It is very difficult to provide an exact total of the number of carers. This is partly because **many carers do not recognise their role as a carer**. Research by <u>Carers UK</u>⁵ in 2016 found that more than one in two carers (54%) took over a year to recognise they were a carer. Nearly one in four (24%) carers took over five years to recognise they were a carer⁵.

Profile of carers

We know that anyone can be a carer, and carers and caring situations can be diverse and varied. For example:

- 61% of Scottish carers are women, and 39% are men (Carers UK, 2020)4.
- 58% of Scottish carers are in paid work (Carers UK, 2020)4.
- Analysis of the 2011 Census demonstrates that 41% of Scottish carers have a long-term health condition themselves (Scottish Government, 2015)⁶.
- There is evidence that the experience of caring may be different for people from minority ethnic backgrounds. They may start to care earlier, and they may care for longer (Carers UK, 2017)⁷.

Impact of COVID-19 on caring

There is evidence that the COVID-19 pandemic has increased the number of people who are unpaid carers. Analysis by <u>Carers UK</u> in 2020 estimates that there are now a **further 392,000 unpaid carers in Scotland** compared to at the beginning of the pandemic⁴.

The pandemic has also impacted on the amount of time that carers spend caring. Research by <u>Carers Trust Scotland</u> in 2021 found that 90% of the carers they spoke to were now spending more time caring⁸.

Overview in numbers



There may be as many as **1.1 million** carers in Scotland⁴.

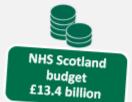


There are an estimated **44,000** young carers¹.



60% of the Scottish population will be carers during their lives (<u>Adult social care: independent review</u>, 2021)⁹.

The estimated value of unpaid care in Scotland is more than £36 billion per year. This compares to the NHS Scotland budget of £13.4 billion in 2019 (Adult social care: independent review, 2021)⁹.





3. Overview of published literature

3.1 Overview

There are a number of published articles and studies which explore involving carers in hospital discharge. A literature search was conducted by NHS Education for Scotland (NES) in August 2020 to consider:

- how health services can ensure that unpaid carers are appropriately involved in any decision to discharge a person they care for from hospital, and
- the views and experiences of hospital staff regarding the role of unpaid carers in hospital care.

The literature search identified **32 studies**. These studies considered interventions from a number of countries, primarily Europe and North America. The studies also spanned a number of settings and specialities including mental health, older people, dementia, intensive care and end of life.

In this overview, we highlight themes identified within the studies.

The value of involving unpaid carers in hospital discharge

Three studies provided analysis on the value of involving unpaid carers in hospital discharge.

- Rodakowski et al (2017) conducted a meta-analysis of 15 studies that considered involving carers in the discharge of older adults. A number of different interventions were considered in the analysis including:
 - o signposting and supporting carers to access services and resources in the community
 - o providing care plans
 - o assessing carers' needs, and
 - o support for carers to learn tasks related to providing care.

They found that the interventions considered within the studies together led to around 24% fewer readmissions within 180 days¹⁰.

- <u>Li et al (2018)</u> explored involving patients and carers in hospital rounds. This was found to provide patients and carers an opportunity to discuss hospital discharge in advance. This technique was associated with a reduction in readmission to the same hospital within 30 days¹¹.
- An approach involving a full time carer support worker based in a stroke unit reported a median reduction in length of stay of nine days, and potential savings of around £35,000 over the 19 month period of the study¹².

Policy and guidance

The literature search identified relevant guidance and policy documents. The search highlighted the <u>NICE Quality Standard</u> 136¹³ for the NHS in England which sets out a specific <u>quality statement to involve carers in discharge planning</u> 14. Other examples of discharge policies and initiatives that include carers are shared in the box on the right.



3. Overview of published literature

3.2 Activity to involve unpaid carers in hospital discharge

Here we consider how health services can ensure that unpaid carers are appropriately involved in any decision to discharge a person they care for from hospital. Themes identified within the literature search are listed below.

Theme	Recommendation	Examples of practice	
Recognising carers	 Staff should know how to recognise carers, gain permission to engage with them and how to capture their details. Some studies made recommendations on how to do this, for example: staff capturing patient consent for carer involvement soon after their admission¹⁹, and staff seeking carer information when a patient is admitted²⁰. 	A toolkit to support the implementation of legislation in New York highlights that patients should be asked to identify a carer, consent should be gained to share information with the carer and that this information should be recorded ²¹ . Some studies recommended methods to record this including: • Amendments to health records to allow carer information and interactions to be recorded ²² , and • using stickers on patient's charts to note where carers should be involved in discharge planning ²³ .	
Engaging carers early	Fitzgerald et al (2011) recommends carers should be involved early in the process for planning for discharge ²⁴ . Giacco et al (2017) recommends carer involvement should happen soon after admission to receive necessary information and participate in making decisions ²⁵ .	A toolkit to support the implementation of USA legislation in New York highlights that patients should be asked to identify a carer as early as practical after admission ²¹ .	
Involving carers	Two studies noted that carers wished to participate in discharge planning, and particularly to help resolve any issues that might arise ^{26,27} .	Schuster et al (2020) recommends that carer involvement should be a key part of shared-decision making processes ²⁰ .	
		Giacco et al (2017) recommended that staff should use the carer's knowledge of the patient's condition ²⁵ .	
Identifying carers' needs	Studies highlighted the importance of staff identifying the needs of carers ^{28,29} . Ewing et al (2018) highlights that by supporting their carers, readmission rates for patients can be reduced ²⁸ .	Ewing et al (2018) piloted a tool to identify and support carer needs ²⁸ . Lin et al (2018) reported on a six-step hospital discharge planning process which includes assessing carer needs ²⁹ .	
Supporting carers	The recommendations and examples considered supporting both carer wellbeing and in their practical tasks. The recommendations which supported carer wellbeing included providing:	A meta-analysis highlighted projects that involved techniques to support carers undertake their caring tasks. This included care tasks demonstations (5 studies) and using " teach back " techniques (7 studies) ¹⁰ .	
	 emotional support for carers^{25,} and counselling and referral services ahead of hospital discharge²⁹. 	Hendrix et al (2020) described a training and support programme for carers. Carers attended a training session and received two telephone checks after the patient was discharged ³⁰ .	

3. An overview of published literature

3.3 Staff perspectives

In this section, we **focus on the views and experiences of hospital staff in** involving unpaid carers in hospital care. Themes presented in these studies are summarised below.

Benefits, barriers and opportunities

Studies highlighted that staff felt that **involving carers was helpful**^{31,32}. For example, <u>Lewis et al (2017)</u> highlighted that nurses can feel that carers can contribute important information about a patient that they might not be aware of³³.

However, studies also noted that there could be some barriers or difficulties in involving carers^{31,33}. Walker and Dewer (2001) highlighted that staff are not always able to interact with carers in the way that they wish to, for example due to lack of time or availability³⁴. A study by Kydonaki (2020) found that staff and carers had different views on what it meant to involve carers. The study found that carers wished to be involved in making decisions however staff felt they were meeting carer's expectations by informing them of decisions³⁵.

Some barriers preventing helpful staff and carer interactions highlighted within the literature are listed below, as well as potential opportunities to improve these interactions.

Barriers

Impact of the hospital system and culture A study by Walker and Dewar (2001) identif

A study by <u>Walker and Dewar (2001)</u> identified potential barriers within one hospital. Example of barriers found include:

- staff did not always feel they had time to engage with carers
- no policies or procedure were in place to support carer interactions, and
- staff were unaware of the barriers that carers experience³⁴.

Difficult conversations and relationships

Studies reported that staff can find it difficult to interact with carers who might be upset, annoyed or frustrated^{31,34}. Another study suggested that staff can sometimes planning conversations with carers to be arduous³⁶.

Opportunities

Strategies which focus on hospital culture

As noted above, studies found that staff felt that involving carers was helpful. A study by Hoplock et al (2019) suggested that any planned improvements do not need to change staff viewpoints on involving carers. Instead, interventions should focus on making changes to the system to facilitate staff and carer interactions³².

Tools and training for staff

Training and education was considered to be valuable to support staff in their interactions with carers^{31, 32}. Koren et al (2018) suggested training on topics including communication and difficult conversations may be helpful³¹. Caswell et al (2015) suggest using a "concordance" model of communication to support conversations³⁷.



4. Carer perspectives

Analysis of Care Opinion stories

<u>Care Opinion</u> is a website where people can share their experiences of health and care in ways which are simple, safe and can lead to learning and change³⁸.

In this section, we review comments posted on the <u>Care</u> <u>Opinion website</u> that share experiences of carer involvement in hospital discharge. While this does not provide a sample of experiences that we can draw generalisable conclusions from, we have undertaken analysis to identify relevant insights from the comments.

Identification of stories for analysis

Comments were identified for analysis which met the following criteria.

- The post is tagged with "carer" or the text includes "carer" or a related word (eg refers to a partner or family member).
- The post is tagged with "discharge" or discharge is referred to in the text.
- The comment is linked to (at least) one **Scottish hospital**.
- The comment was posted between April 2017 and March 2020 (before the onset of the COVID-19 pandemic).

In total, 270 stories were identified. Each of these stories were read. Stories were removed if they did not refer to the experience of carers, or did not describe the experience of carers in sufficient detail to allow analysis. In total, **33 stories were identified for analysis**.

Thematic analysis was conducted to identify insights about carer experience from the available stories. Two themes have been identified from the thematic analysis.

1. Communication and involvement in planning for hospital discharge

Many of the stories highlight the importance of carer involvement and of communication between staff and carers when planning for hospital discharge.

Impact of good communication between staff and carers

There are positive stories describing where **staff have taken time to communicate with carers in ways that enabled involvement** in the process of hospital discharge. Stories describe how communication was supportive and offered guidance and explanation in what can be a difficult and uncertain time for carers.

Impact of lack of involvement and information on carer experience

There are also negative stories describing experiences of carers not being involved and informed in the discharge planning process and the consequences of this. There are descriptions of situations where information hasn't been provided, carer views and concerns have not been listened to and plans for discharge have been unclear. Carers shared the importance of staff taking the time to find out information from them during the planning process. Some experiences highlighted the impact of lack of carer involvement in **ensuring dignity and respect for the cared for person**. Stories also described situations where lack of involvement and being kept informed led to **discharge feeling unsafe for carers**.

"... he was treated with respect and dignity and the support advice and information received by the family at this time. The family were also contacted on his discharge from hospital and helpful advice support [sic] and guidance again offered which felt invaluable to a family struggling to manage a difficult situation."

"At each of these instances I stressed that I did not think he was fit for release and that he was liable to falls but was told that he was monitored and fine. ...Now he has been released then guess what? I have to call a GP or come to A&E with an 85 year old and isn't mobile and can't get out of a chair."

Care Opinion³⁹

Care Opinion⁴⁰

4. Carer perspectives

Analysis of Care Opinion stories

2. Preparing for ongoing care needs at home

Stories also highlight the importance of recognising ongoing care needs in discharge planning, whether this will be provided by carers or paid services, and how gaps can form between hospital and home.

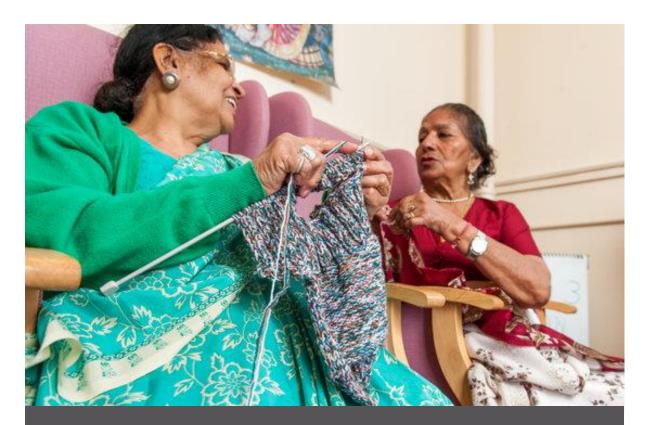
Expectations and support for carers

Some stories describe carer concerns about the appropriateness and safety of hospital discharge where there are ongoing care needs and uncertainty during discharge planning about how these would be managed at home. There were situations described where families were expected to take on new or additional caring responsibilities without the impact of this being discussed or agreed to with hospital staff. Some stories highlighted a lack of education for carers around how to care for a loved one after discharge and where to find support for their own wellbeing.

Planning and coordination of support in the community

Some stories highlight issues regarding how care ongoing from hospital is planned and coordinated and the impact that this can have from the perspective of carers. These include:

- · lack of planning for care needs in hospital,
- needs identified in hospital did not match the reality of needs at home, and
- plans were not implemented as agreed following discharge.



"There is no ongoing support. I asked my partner to ask what support there might be for family members - partner, children etc. She was told that there was nothing on offer and we would need to find our own support. They didn't offer any info/advice [sic]. We have been left floundering- struggling to come to terms with what happened. Struggling to deal with the impact. And no support is available."

Care Opinion⁴¹

"Elderly father...Sent home to his own home in the care of my elderly and extremely frail mother. We had been advised he would get home at least 24 hours later than he actually did so we were unprepared, the agencies who should have been involved were all closed for the evening. Totally unacceptable."

Care Opinion⁴²

5. Evaluation of local activity

Overview

To support implementation of the Carers (Scotland) Act 2016, the Scottish Government funded a number of local projects to learn more about involving unpaid carers in hospital discharge.

An evaluation of these local initiatives was completed in 2018 by Matter Of Focus Ltd in 2018. The evaluation aimed to consider the following points.

- "Improve understanding of the process of involving unpaid carers in decision making around hospital discharge and what can be put in place to help this to happen.
- Capture and share insights from the work in a form that can be used by others to improve practice in this area.
- Support the pilot teams to reflect on their work as it unfolded and to use these insights to inform."

(Matter of Focus 2019)

In this section, we look at an overview and the key learning points from the Scottish Government funded projects. The key points in this summary were drawn from the project evaluation report.



Pilot projects: an overview



Twelve projects within eight health board areas were funded for between six months and a year.



Seven projects informed staff about their duty to involve carers, and gave training to support.

Eight projects provided information, advice and support to carers.

Four projects provided carer support workers to provide advice and support.

Some examples of project activities included:



Information and educational resources including leaflets and posters



Awareness raising activities, including social media activities, and



Training for staff members



Recruitment of carer support workers to provide expert support.

There were two main target audiences for these projects:



Unpaid carers of people in hospital, and



Hospital staff.

Eight health board areas were involved:

- Greater Glasgow and Clyde (3 projects)
- Highland (2 projects)
- Lothian (2 projects)
- Ayrshire and Arran

- · Dumfries and Galloway
- Forth Valley
- · Lanarkshire, and
- Shetland.

5. Evaluation of local activity

Challenges and strategies

The evaluation found that improving the involvement of carers in hospital discharge takes time to achieve. Within the timeframe of the evaluation (January to October 2019), the evaluators identified that the projects had made:

"...good progress with their work to inform staff, inform and support carers and provide expert support in hospitals."

Matter of Focus

The evaluation found that the projects which had provided expert support to hospitals had made the greatest impact within the time frame. However, the evaluation highlighted that expert support should be undertaken in conjunction with work to inform staff and carers in order to have the greatest impact.

The table summarises some of the challenges experienced by carers, staff and within the hospital system and some of the strategies used to counteract these challenges. A number of key learning points are summarised in <u>our diagram</u>.



	Challenges	Strategies
Carers	Not all carers will identify as carers.	Use plain English and avoid technical terminology that a carer may not relate to.
	Not all carers will want to access support.	
	Limited visiting times can be a barrier for staff wishing to engage with carers.	Ensure the carer support worker visits each ward at different times.
Staff members	Staff may be focused on the patient rather than carers.	Ensure staff are clear about how engaging with carers can support
	Staff are unsure where or how to refer carers, and the process of referral can take time.	their work.
		Consider where and how to share information about engaging carers. For example, speak to staff in areas they feel more comfortable.
	Staff are unsure what information they can share with carers and other staff.	
		Include details of the carer centre
	Staff feel overwhelmed with their workload.	within information provided to staff
	It can be difficult to engage with staff due to their shift patterns.	
Within the hospital system	Identifying, informing and involving carers can be perceived to conflict	Ensure staff are clear how engaging with carers can support their work.
	with optimal patient flow.	Build relationships between carer
	The hospital culture does not always	support workers and other
_	recognise the value of carers.	stakeholders – carer workers should aim to be seen as approachable and familiar.

Carer support workers should be part of team meetings to support

referral of carers.

5. Evaluation of local activity

Learning points

- Support projects to involve carers to ensure they can be developed and sustained.
- Ensure that the process for referral is straightforward.
- Ensure that involving carers is seen as an essential part of person-centred care.

Change to practice and culture

Local projects

Learning and points to consider

 ...with staff to support their learning and development.

> ...with individual carers to help identify support needs.

 Develop and strengthen relationships with carer centres.

 Support a joined up approach between organisations.

Support Joint working

> Local partners working together

Building

relationships

- Consider:
 - Realistic
 Medicine
 - Excellence in Care
 - Carer Impact Assessments, and
 - Health and Social Care Standards.

Ensure a focus within strategic agenda

Culture

Embed a focus on carers

Raise staff awareness

- Raise staff awareness about:
 - the value of involving carers, and
 - that staff have a duty to work with carers.
- Working with carers as an equal partner should be highlighted within staff training.

Recognising inequalities

Recognising that carers and caring situations are diverse

- A "one size fits all approach" is not appropriate for all carers when considering how to engage and involve carers.
- Hospital staff who are carers should also be considered in policy and practice.

Resources for health boards

Adaptable resources

 A bank of practical resources available to health boards to adapt and use.

Support to share resources

 Opportunity for boards and areas to adapt or develop existing resources.

6. Case study

The role of the Hospital Carer Support Worker in Fife

In Fife, a dedicated carer support worker helps carers who are caring for someone in hospital to prepare for discharge. Fife Health & Social Care Partnership commission Fife Carers Centre to deliver this service. The service was piloted at the Victoria Hospital in Kirkcaldy. Following the success of the pilot, the service was expanded in the Victoria Hospital and extended to all hospitals within Fife. Currently there are four carer support workers based in both the acute and community hospitals covering all of Fife.

In this case study, we explore the role of the carer support worker in the Victoria Hospital in Fife.

Role of the Carer Support Worker

The carer support worker is co-located within the hospital discharge hub. They are an integral part of a multi-disciplinary team who set pathways for patients medically ready to leave hospital but who need further support. The carer support worker ensures that carers are involved in decision making and have all the information and support they need to prepare for discharge. The process diagram provides further information about how the carer support worker supports a carer during a hospital discharge.

The carer support worker also has a role in raising the awareness of staff to the role of carers and the importance of their involvement in a successful hospital discharge. This work includes giving presentations and providing resources and support for staff.

Next steps

The team are further developing the service in a number of ways:

- The service is expanding to reach and support more carers across all hospital settings in Fife.
- The team are considering how they can support carers living in Fife when the cared for person is admitted to hospital outside Fife.
- Finally, the team are exploring how they can measure the impact of their service.







Process for providing hospital discharge support to carers

Referral

Any hospital staff member can refer a carer. Carers can also self refer. A form for referrals is available which captures the carer's permission to share their information with the service.



Assessment

The carer meets with the carer support worker to discuss their current and future needs, and any issues they have.



Support after discharge

Once the patient is discharged from hospital, the carer can receive support from the community team based in their local area.



Support during discharge

Support is provided to promote carer involvement in discharge and to plan for ongoing needs after discharge. Examples of support given are shown below.

The support provided is person centred and based on the needs identified during assessment. Some examples of support provided during discharge planning include:



Help to understand discharge plans



Support to access benefits



Advocate



Linking to other support services



Emotional support, and



Identify respite opportunities.

6. Case study

The role of the Hospital Carer Support Worker in Fife

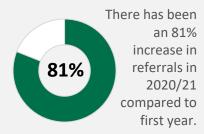
Impact of service

Since the pilot, the service has continued to grow.



In the first year of operation in 2017/18, the service received 252 referrals.

In 2020/21, they received 457 referrals.



66 99

"Thank-you for listening to us and our concerns about moving Mum to a nursing home. We had promised not to send her there. You explained the Discharge pathways and assessments clearly and made us think about what was really best for Mum, to keep her safe and prevent her being readmitted to Hospital again."

Service user

"Thanks for all your support whilst Dad was in Hospital and planning his discharge home with Carers. It has made a big difference to us all that we had not appreciated until we met with you."

Service user

Further reading

More information on the service can be found on the <u>Fife Health and Social</u> <u>Care webpages.</u> Fife Carers Centre have produced a <u>case study film</u> about the role of the carer support worker.

Success factors

1. Identifying a carers champion

A trusted person promoting the service has been important to help embed the role. During the pilot phase, the Patient Flow Co-ordinator in the discharge hub was very proactive in promoting the service and encouraging referrals.

2. Ongoing communication and promotion

Ongoing promotion of the service has been important due to recruitment and staff turnover at ward level. As well as the initial promotion of the service, the carer support worker has continued to identify opportunities to meet and present to staff members.

3. Continuity with community services

As well as the hospital-based service, Fife Carers Centre also provide community services. Once a patient is discharged from hospital, the carer can be referred to a support worker in their local community, ensuing that carers receive a **continuous support service.**

4. Links to speciality services

Fife Carers Centre have a good working relationship with a number of local specialist services including Deaf Blind Scotland and Support in Mind Scotland. This means the team can refer to specialist services where this would be beneficial.

5. Knowledge and skills of support worker

The support workers have a wide range of knowledge and skills so can provide support on a wide range of issues. The support workers also have strong interpersonal skills to develop good relationships with both carers and staff.

6. Established before Covid-19 pandemic

The service was already **well established before the Covid-19 pandemic**. This helped the service to continue to provide support during this challenging time.

7. Opportunities for improvement

This summary demonstrates the positive impact of involving carers in hospital discharge on carer experience, staff experience and the wider health system. It also highlights current challenges and learning from a number of different local approaches that have been implemented across Scotland.

Action points for frontline staff

The duty to involve carers in discharge applies to all hospital settings in Scotland. All staff should be encouraged to think about how this applies to their role. Hospital staff may wish to consider how well their ward or team engages with the family and friends who provide care and support for the patients who use your service. Some points to consider are listed below.

- In your own clinical practice, how effective are you at identifying, involving and informing adult carers and young carers?
- How effectively does your ward/team identify, involve and inform adult carers and young carers? How do you know? For example:
 - O How do you record carer information?
 - Can you give a recent example of your ward/team working well with a carer?
 - How do you seek feedback from carers? What impact does this have?
- What, if any, areas for improvement would you suggest? It might help to consider:
 - What makes it more likely that you/your team will identify, involve and inform carers and how can you do more of that?
 - What makes it challenging or less likely you/your team will identify, involve and inform carers and how can you address these things?



More information

Additional resources can be found in the <u>Carers section of TURAS learn</u>. This includes:

- Carer involvement in hospital discharge: Carers (Scotland) Act 2016: a
 resource to help make staff aware of their responsibilities in ensuring NHS
 boards meet the duty to involve carers in the discharge of the cared for person
 from hospital.
- Equal Partners in Care (EPIC): a learning resource for health and social care staff which will help you to have better conversations and interactions with carers.

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