NHS Greater Glasgow and Clyde’s preparation for the Carers (Scotland) Act, 2016

Identifying, Involving and Supporting carers in discussions and decisions about the person they care for, before they are discharged from hospital.

Brenda Friel
Health Improvement Senior
March 2017
1. Introduction
The Carers (Scotland) Act (2016), introduced a number of provisions that will ensure carers and young carers are recognised and supported to continue caring. The focus of this paper is to support NHSGGC’s duty to involve carers in the hospital discharge of the person they care for. A task group was established and a number of areas for improvement were agreed that will aim to identify, involve and support carers within the Acute Directorate. Six elements were agreed, this includes carer engagement, which is the focus of this research. The Patient Experience Public involvement and Quality team currently undertake a programme of Carers’ Audits within agreed wards, learning and opportunities for improvement are identified through analysis. In addition, it was agreed to engage with carers within the community setting. The purpose of this is to ascertain from carers what they believe to be good information provision, involvement in care and involvement in hospital discharge decisions for the person they care for. Findings from this are the focus of this paper. Insight was obtained from 132 carers across five Health and Social Care Partnership carer services within NHS Greater Glasgow and Clyde (NHSGGC) area. In addition one third sector carer service conducted a focus group, involving six carers, using the same questionnaire. Findings and recommendations are presented. This information will assist NHSGGC in identifying, valuing, involving and supporting carers within the Acute Directorate and ensuring they meet their duties set within the Carers (Scotland) Act, 2016.¹

2. Background

2.1 Definition of a carer
A carer can be defined as an individual who provides unpaid practical, physical and emotional support to relatives, friends or neighbours due to physical or mental illness, addiction, frailty or disability, this includes young carers, parent carers and individuals who care for each other. They may or may not live with the person.

2.2 Who are carers

According to the Scottish CENSUS, 2011 there are 118,264 carers within the NHSGGC health board area, 9.7% of the Board’s population. In addition it is estimated that there are 2,368 young people under the age of 16 years, across NHSGGC Board area, who have a caring role, this is 2% of all carers. Carers can be very young to older age groups, can be male or female and from various ethnic groups. Carers can be in full time education, in paid employed, unemployed, retired and can be in a full time caring role. Levels of caring varies, 53% provide 1 – 19 hours of care per week, 10% 20 – 34 hours, 9% 35 – 49 hours and 29% more than 50 hours per week. The proportion of people who provide unpaid care within each Scottish Index of Multiple Deprivations (SIMD) category is comparable, however in relation to levels of caring there is an incremental increase in the proportion who provide more than 35 hours of care per week from the least deprived to the most deprived. 47% of carer from SIMD 1 (most deprived) provide more than 35 hours of care per week compared to 24% of SIMD 5 (least deprived). It is evident that people who care come from all backgrounds, however there are differences across some population groups. Women are more likely to care than men however levels of caring are comparable in older age groups. Carers, who provide more intense levels of caring, are more likely to be from areas of greater deprivation, this includes young carers. Caring responsibilities increase with age and those aged 65 years and over provide the greatest amount of care. There are more young carers from lone parent families and are more likely to provide higher levels of caring. Many carers find their caring role rewarding, however others experience poor mental and physical health as a result, in particular for those who provide greater levels of caring and are experiencing existing inequalities. In addition and as a consequence of their caring responsibilities, carers may experience financial hardship because they may need to reduce working hours or stop working all together, in addition there are financial burdens associated with caring. Analysis of NHSGGC Health and Wellbeing Survey data indicated that carers are more likely to be detrimentally affected by welfare reforms. This further confirms the importance of ensuring carers are identified,

1 CENSUS Scotland, 2011 http://www.scotlandscensus.gov.uk/
2 NHS Greater Glasgow and Clyde Carers Pathway Evaluation, 2017
assessed and supported so to optimise carers’ health and wellbeing and mitigate a significant cause of inequalities and inequalities in health.

2.3 The Carers (Scotland) Act
The Carers (Scotland) Act was passed on 4th February 2016 and gained Royal Assent on 9th March 2016. The intention of the act is to ensure carers (including young carers) are recognised and provided with support to enable them to continue in their caring role, if they wish to do so; to ensure they receive support to optimise their own health and wellbeing and to enable carers to achieve a good quality of life alongside their caring responsibilities. In order to achieve this and to ensure carers are better supported in a consistent way, the following provisions are included to that aim to identify, assess and support carers:

- Changing the definition of carer so that it encompasses a greater number of carers.
- Giving local authorities a duty to prepare an adult carer support plan (ACSP) and young carer statement (YCS) for anyone they identify as a carer, or for any carer who requests one.
- Giving local authorities a duty to provide support to carers that meet local eligibility criteria.
- Requiring local authorities to establish and maintain advice and information services for carers.
- Requiring local authorities and NHS boards to involve carers in carers’ services.
- Giving NHS boards a duty to involve carers in the discharge of the cared for person.
- Local authorities and health boards will be required to jointly produce local carers’ strategies.

Responsibilities cited within the Act, for NHS Greater Glasgow and Clyde’s Acute Directorate, is the involvement of carers in decision about hospital discharge of the person they care for.

2.4 Preparing for the Act
Work is underway across NHSGGC Health Board and all Health and Social Care Partnerships to ensure the requirements of the Act are in place by April, 2018. To support this, a partnership group, Corporate Carers group, has been re-established. The purpose of the group is to jointly plan, agree and work to support carers of all ages across NHSGGC area, to identify and share best practice, promote consistency, identifying and addressing gaps in evidence, influencing national and local policy and implementing the Carers (Scotland) Act, 2016. In addition an Acute Carers Task Group was formed to both scope the readiness of the Acute Division for specific provisions within the Act (duties) and ensure that Carers are appropriately involved in the care and decision making for the person they care for. The specific duty for the Acute Division is as follows:

*Inform the carer, as soon as is reasonably practical of the intention to discharge; invite the carer to give views about the discharge; take account of the views of the carer in making any decisions about the discharge of the cared-for person.*

2.5 Carer engagement
The focus of this research was to undertake further engagement with carers, within the community setting, to ascertain, from carers, when the person they care for was admitted to hospital, what they believe to be good information provision while the person they care for was in hospital; what they believe is good involvement in day to day care for the person they care for and; what they believe is good involvement in decisions about hospital discharge of the person they care for. This was undertaken in partnership with third sector carer services. This information will be directed back to the Acute Division and the Acute Carers Task Group. This will also inform training for staff so they can effectively identify, involve and support carers within NHSGGC Acute Division. In addition the findings will be fed back to carers who participated.

3. Methods
Carers were recruited through local third sector carer service contacts across NHSGGC Health Board area. Arrangements were made to engage with carers through existing training and information sessions, carer meetings and carer support
groups. Questionnaires were developed and agreed. One version, which included prompts, was used as a topic guide to facilitate group discussion and feedback (see appendix 1) the second version did not include prompts (appendix 2) and participants were able to self complete if preferred. The questionnaire included an introduction and background and three specific questions, as follows:

**Question 1:** While the person you care for is in hospital, what is it you would like to know from our staff that will make you feel you are being kept informed?

**Question 2:** While the person you care for is in hospital, what does being involved in their care mean to you?

**Question 3:** When the person you care for is being discharged from hospital, what does ‘good’ involvement in decisions mean to you?

Participants had the option to either self complete the questionnaire or provide collective, verbal feedback which was recorded on a flipchart. Literacy issues were considered by ensuring participants were not put under pressure to self complete the questionnaire. In addition post it notes were available if anyone wanted to provide additional thoughts or feedback. Written consent was not required as this was anonymised verbal feedback from carers. No personal, identifiable information was collected and used within this report. Information about where the groups were hosted was removed from the report and stored separately from this report and each group was numbered 1 – 9. Advice was obtained from an NHSGGC Senior Public Health Researcher who confirmed that written consent was not required as this was a service feedback and evaluation.

The majority of feedback was through group discussion, four questionnaires were self completed at one group and no one used the post it notes. Carer services obtained verbal agreement from the carer groups to participate. Time available for discussion varied from 10 to 90 minutes. There was insufficient time at two groups to obtain feedback for question three. 132 carers participated from nine carer support or training groups. Discussion groups ranged from 3 to 52 participants. The majority
were female, four groups were carers from mixed caring roles, three groups care for someone with dementia, one group cares for someone with Parkinson’s disease and one group was a BME carer support group. See table 1 for an overview of type of group, numbers attended, gender of participants and duration of the group.

**Table 1: Participant profile**

<table>
<thead>
<tr>
<th>Carer group</th>
<th>No</th>
<th>Gender</th>
<th>Group duration - minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Group 1: mixed</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Group 2: dementia</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Group 3: dementia</td>
<td>7</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Group 4: mixed *</td>
<td>13</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Group 5: mixed</td>
<td>52</td>
<td>17</td>
<td>35</td>
</tr>
<tr>
<td>Group 6: Parkinson’s Group</td>
<td>16</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Group 7: BME group</td>
<td>9</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Group 8: Mixed</td>
<td>24</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Group 9: dementia *</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
<td>36</td>
<td>96</td>
</tr>
</tbody>
</table>

* Unable to obtain responses to question three*

In addition, one third sector carers’ service conducted a focus group using the same questionnaire. Six carers participated from mixed caring roles, one carer was 49 years the rest ranged from 59 to 73 years, all participants had experience of the person they care for being admitted to hospital. The focus group discussion lasted 2 hours, one carer support worker asked the questions, the other recorded carer feedback on a flip chart. Insight from this will be reported separately within this report. It was difficult to fully contextualise, analyse and understand some of the feedback. An overview of comparable findings and any new insight identified will be presented.

Notes from flip charts and questionnaires were transcribed into a single word document. Participant responses was collated and organised under each question heading. An overview of each discussion group was recorded including the location
of the group; number of participants; duration of the session; characteristics of participants such as age and gender; type of group, for example if the group was a condition specific or mixed caring role and; any reflections about the group, such as experiences of hospital admission of the person they care for. Transcript was then collated into a single word document for each question. Thematic analysis was conducted and responses were grouped into identified themes and were collated under each theme within an additional word document. The methodology does not allow quantitative analysis at individual level, as feedback was through group discussion. Quantitative presentation of feedback, in terms of frequency of comment, will relate to the number of groups where this information was highlighted and discussed.

This was a particularly emotive topic for the majority of carers and resulted in considerable dialogue about participant’s own experiences and the experiences of the person they care for when they were engaged with NHSGGC hospitals. These experiences have also been collated and fed back to the Acute Carers Group. Information that does not relate to the specific focus for this research will not be included in this report.

4. Findings
Finding will be presented and organised under each individual question and subdivided under identified themes. It is worth noting that there is no time specification about when carers experienced specific situations while the person they care for was in hospital. Some experiences may be recent while others may be some time ago. Approximately two thirds of all participants had experiences of the person they care for being admitted to hospital. Feedback from a focus group conducted by a third sector carers’ service will be included in a separate paragraph for each question, presenting similar findings and any additional insight highlighted.

4.1 Being informed
The purpose of this section is to identify from carers, the information they require so they feel sufficiently informed. This will support the carer, where appropriate and where consent has been obtained from the person they care for, to make informed decisions about the person they care for. This may include decisions about
treatment, care, discharge planning and planning for care at home. There is some evidence of good communication experiences when the person they care for is in hospital. One carer cited that the reason for this is that hospital staff provided regular and honest updates about the person they care for. However the majority of participants did not have good experiences. What is evident is that carers want information from hospital staff about the person they care for and what is equally important is that staff should listen to what the carer has to say about the person they care for. In analysing carer feedback, three themes were identified, this includes information carers require to feel informed; how information is provided to feel informed; and the impact towards the carer when they are not sufficiently informed.

4.1.1 Information carers require to feel informed

Almost all carer groups wanted to obtain regular updates about the person they care for. They want to be kept informed about improvements and outcomes from investigations, diagnosis, treatment and prognosis. One carer group cited that they wanted staff to give them condition specific information and advice in particular if the person they care for has been newly diagnosed with cancer or a long term condition.

Just under half of carer groups, when asked what information they want to receive from staff to feel informed, said they want to know when the person they care for is going home. In preparation for this they want to know about any changes in medication and if there are any side effects; if there will be any changes in the behaviour of the person they care for; is the person they care for able to look after themselves; are there any changes in support needs for the person they care for, so the carer can be prepared for this and consider how they will manage; they want to know if any support package, that is required, will be in place before the person they care for is discharged from hospital; and they want information and advice about any specific support needs for the cared for, for example incontinence products. There is further insight relating to hospital discharge later in this paper.

Four carer groups out of nine say they are looking for day to day information about the person they care for, for example, have they slept well; are they eating and drinking enough; how are they coping while in hospital, in particular when the cared for is dependent on the carer; and they want to know if the cared for is happy and
being looked after. For example, a carer who looks after someone with dementia wants to be informed if the person they cared for has been unsettled and required sedation. This information is important to them as it may explain any changes in their behaviour and or appearance. The carers’ experience is that this information was not always shared.

Other less frequently cited feedback include carers being informed about care they can provide for the person they care for while they are in hospital; to know about their care plan; and knowing the allocated name nurse for the person they care for.

4.1.2 How information is provided to feel informed

One participant had good experiences of being informed while the person they care for was in hospital. The reason for this is that they were given regular honest updates. However the majority, six out of nine carer groups who participated, cited that they wanted hospital staff to be more proactive in providing progress reports about the person they care for. Many carers say they have to seek out a member of staff so they can receive information and when the carer does find someone they are not always able to provide an update or the carer has to wait for a specialist nurse to become available.

Over half of participating carer groups said they want to be better involved in communication and decision making with hospital staff about the person they care for. They believe the role of the carer, in relation to communication, should have greater importance. Three carer groups believe this should happen when the person they care for has capacity issues such as recollection and comprehension. An example was given in a situation where the person they care for has dementia and they were given an update from medical staff earlier in the day, by the time the carer came to visit, the cared for had forgotten what was said. The carer requested an update however the doctor was no longer available. In addition, four carer groups want to be involved in communication with staff because they believe they have a good understanding of the person they care for’s needs, their preferences and one carer cited that they know how to keep the person they care for calm when required. Three carer groups believe that being listened to and listening to the needs of the
cared for is really important. One carer cited that they prefer open, frank discussions about the person they care for.

Carer involvement in communication was a particular focus of discussion at the Parkinson’s disease carer support group. Cited reasons are that people with Parkinson’s disease have slower communication abilities in terms of comprehension, processing and responding. In addition they have specific medication routines and any deviations from their normal routine can detrimentally affect their condition. Carers believe they have an important role in communication between nursing staff and the person they care for. In addition, carers cited that people who have Parkinson’s disease can become particularly distressed if the timing between information provision and treatment is prolonged. For this reason the carer wants to be present when new information or updates are communicated to the person they care for. This will allow the carer to provide reassurance and support and reduce distress.

A third of participating carer groups want information to be communicated in a format that is simple and easily understood. They ask that time is taken to ensure information provision is simple and ensuring no specialist language or medical jargon is used. This is applicable for face to face and telephone conversations. In addition, one carer does not want staff to say that the person they care for is stable as they do not understand what this means. In addition consideration is needed for the communication needs of carers whose first language is not English. It was cited at a BME carers’ support group that often they do not have the knowledge and understanding about the person they care for’s hospital treatment because of language barriers.

Just under half of carers highlighted difficulties in connecting to and obtaining updates when contacting the hospital ward by telephone. The phone is often engaged, information provision is too vague and not understood and hospital staff are not always available to provide information. Carers suggest that there should be more phone lines, that there is a designated person to answer telephone enquiries and that information provision is easily understood.
A third of carer groups highlighted that the ‘what matters to me’ white board that is situated next to the patient’s bed is not used. Their observations are that this is rarely completed and when it is completed this information is not used by staff. Carers believe this is a good resource to highlight the specific preferences of the person they care for and should be used.

There were other individual communication suggestions from carers, these include: a condition specific proforma that could be used to record individual preferences and specific treatment needs for the person they care for to ensure continuity of normal care; information could be recorded on their bedside chart to provide an update for the carer without them having to seek information from ward staff; a suggestion that the carer is given a copy of the hospital discharge paperwork so they would know about treatment and outcomes for the person they care for while they were in hospital. According to the carer they did not receive this information while the person they care for was in hospital and did not obtain this information until they visited their GP four weeks later; better joining up of information provision between hospital and community services; there could be better signposting to information leaflets, they believe that these are not fully utilised; and suggest that hospitals could better utilise information technology to update carers for example text messages, email and apps.

4.1.3 Impact if not sufficiently informed
Three carers highlighted that insufficient information provision can have a detrimental impact for them. One carer said they can feel distressed if they are not sufficiently informed, in particular when they already lack confidence in their caring abilities. Having the required information and knowing what to expect when the person they care for goes home will enhance the carers’ confidence to continue caring.

Two carers highlighted situations when they were not sufficiently informed when the person they care was discharged from hospital or was moved to another ward. Coming to the ward and finding someone else in their hospital bed was distressing for the carer. Another carer was not sufficiently informed that the person they care for had been discharged from the ward and returned to a care home. They came to visit them on the ward and were then informed that the person they care for had
been discharged back to the care home. The elderly carer then travelled to the care home, however they had not yet arrived. The carer returned to the hospital to be informed that they were in the hospital discharge lounge awaiting transfer. This resulted in time wasting for the carer who had to travel on public transport between the hospital and the care home.

4.1.4 Feedback from Carers Service focus group
Feedback from carers at the additional focus group in terms of being informed is comparable to what has already been highlighted. For example carers want honest communication between the carer and staff, they want to be informed about treatment; about medication changes; arrangements for hospital discharge; carer being involved in communication between hospital staff and the person they care for; and knowing what the carer can do for the person they care for while they are in hospital. A recurring theme is that carers want staff to be available to provide updates however they believe that staff shortages and staff being overstretched prevents this. Other cited information needs include carer training for staff so they can recognise carers and understand their role; and for staff to enquire how the carer is coping.

4.2 Being involved in care
The focus of this question is to identify, from carers, what being involved in the care of the person they look after, while they are in hospital, means to them. This is a specific focus of NHSGGC Welcoming Ward ethos where family members and or carers are seen as partners in care. Analysis of carer feedback identified three themes. This includes carer opinions about being involved in the care of the person they look after; the identified benefits of being involved for the carer and the cared for; and some barriers that might get in the way for carers to be involved.

4.2.1 Carers’ opinion: being involved in care
Carers being involved in the care of the person they look after while they are in hospital varies. Participants were asked if they would like to provide care for the person they care for while they are in hospital. In order to gain an open and honest opinion and to ensure carers do not feel guilty, it was verbally acknowledged that there is no expectation for them to provide care, that it was their choice and if they
chose not to provide care, that is reasonable. Across all groups collectively, approximately one third of carers said they would like to involved in care, the majority were either unsure or hesitant to respond. It appears that for some this would be a break from caring. There may be differences in relation to the long term condition of the person they care for. All participants from the Parkinson’s disease carers’ support group indicated they wanted to be involved in care were as carers from the three Dementia support groups were less likely to say they would want to be involved. The largest participating carers’ group (52 attended), approximately 10% indicated they would like to be involved, caring roles varied within this group.

A small number of carers say they are already involved in providing care and are happy to do so, another indicated they has been asked by ward staff to be involved. Some would like to be involved however are happy if this is not possible as long as staff communicate this with the carer. Others indicated that being involved in care would depend on capacity and the needs of the person they care for, for example if it is an end of life situation. A small number of carers openly said they did not want to provide care. They believe that staff on the ward should provide this, that is their job, however if support from the carer is required they would like staff to ask them. One participant believed strongly that nursing staff are better placed and would provide better care. Another is happy that the person they care for is in hospital, that they are safe and looked after.

Almost all carer groups indicated that it is important for them to choose whether they want to be involved in care. A concern was raised by one carer, where the person they care for has challenging behaviours, that there is an expectation that they should stay with and look after them. The carer is willing to do this however they do not want to be under pressure from staff to do this. The carers’ circumstances can change each day, one day they might be able to stay with the person they care for the next day they might not.

The majority of carers indicated they want to be involved in care planning. They know the person they care for and know their likes and dislikes. They believe that staff should listen and include the carer in any assessment of care needs. One carer, who carers for someone with Dementia, would like to share their getting to know you
sheet with ward staff. In addition, many carers highlighted the benefits of the getting to know you boards that are situated beside the patient’s hospital bed, however they believe the boards are not being used.

**4.2.2 Benefits of being involved in care**

Benefits in providing care for the person they look after while they are in hospital were articulated. One carer group highlighted that their involvement in care provision while the person they care for is in hospital to be beneficial. This would facilitate continuity of care and in turn will provide insight of future care needs of the person they care for. In addition, they know the person they care for and know their individual needs and how to keep them comfortable. There are particular benefits for those caring for someone with Parkinson’s disease while they are in hospital, as the cared for does not respond well to changes in routine. The carer will act as a constant presence and safeguard, support the person they care for through any changes and in turn reduce anxiety and distress. Many carers indicated they would like to help at meal times and supply food that the person they care for enjoys. Some carers believe the person they care for can be lonely, in particular if they are in a single room. Therefore being with them and being able to stay overnight, if the carer and the cared for want to do this, will alleviate loneliness. In addition one carer believes that if the carer provides care this might prevent the person they care for acquiring hospital infections.

**4.2.3 Barriers to being involved in care**

Three out of nine participating carer groups say they do not feel confident in providing care. They can lack confidence when the person they care for is particularly unwell or if they are at an end of life stage. One carer said that because of this, they would find it difficult to make decision about their care.

Carers would like to be more involved in helping the person they care for at meals times. However approximately half of all participating carer groups cited that visiting restrictions, at meal times, which is displayed within the wards, is a barrier. Carers feel they are well placed to assist the person they care for at meal times and believe, at times, there are insufficient staff to assist patients at meal times.
Three carer groups believe that the hospital environment does not facilitate their involvement in care. They can feel that they are in the way or do not feel welcome on the ward. They believe that staff do not always acknowledge or value their caring contribution on the ward and would like staff to recognize and understand their role.

4.2.4 Feedback from Carers Service focus group
The responses listed for this question were more aligned to being informed and is difficult to understand how this relates to the specific question.

4.3 Being involved in hospital discharge arrangements
Carer involvement in decision about hospital discharge is a specific duty for the Acute Division cited within the Carers’ Act. This section will provide feedback, from carers, about what they believe to be good involvement. Seven out of nine carer groups provided feedback as there was insufficient time to discuss this at two carer groups. Seven themes were identified: do carers want to be involved; when do cares want to be involved; being involved in pre-discharge discussions; preventing delayed discharge; what needs to be in place before discharge; care, support and follow up needs following discharge; and other practical information. The following is feedback from one carer, this comment resonates feedback from other participating carers. They believe that person centeredness should be core to this, that carers should be asked about the needs of the person they care for and that this information should be remembered. They believe that their involvement should not be lip service and that the information they provide should be used in discharge planning, otherwise their involvement is a waste of carers’ time, which is precious.

4.3.1 Do carers want to be involved?
All participating carer groups indicated that they want to be involved in decisions relating to the hospital discharge of the person they care for and this should happen as soon as possible. One carer indicated that they did not want to be involved however, they want sufficient information about the support needs for the person they care for and that this is in place before they go home. Another carer is happy for hospital staff to make decisions and then inform them about what has been arranged. They have an expectation that staff will make the right decisions for the person they care for.
4.3.2 When to be involved
The majority of carers want to be involved in discussions as soon as possible. Carers believe they should be central to decisions relating to hospital discharge. Around half of carer groups want to know the expected date of discharge, ensuring there is sufficient notice, so they can put arrangements in place, whether the person they care for is going home or on to a care home. This was particularly important for carers who are working.

4.3.3 Involvement in pre-discharge discussions
Five out of seven carer groups would like the opportunity to be involved in any pre-discharge discussions for example multi-disciplinary team meetings (MDT), however many say this does not happen. Reasons why carers want to be involved in MDT meetings is that they know the person they care for, they know their care needs, they want the opportunity to share this knowledge with hospital staff and be involved in decision making. One carer group thought that the MDT meeting might be intimidating and language and jargon can be used that might be difficult to understand. They suggested that the role of a Carer Support Worker might support the carer at a MDT meeting.

4.3.4 Preventing delayed discharge
Carers do not want to experience any unnecessary delays when they have been informed of a date and time when the person they care for can be discharged. This was a focus of discussion at three carer groups who were delayed because they had to wait for discharge medication to arrive from pharmacy. This type of delay can be challenging for patients and carers. One parent carer who cares for a child who is on the autistic spectrum, said that having to wait for medication to arrive without any idea of timescales can be difficult. Any delays can be particularly distressing for someone who has Parkinson’s disease.

4.3.5 What needs to be in place before discharge?
Five out of seven carer groups want everything to be in place before the person they care for is discharged from hospital. This includes new, existing and modified care packages, adaptations and equipment needs and who to contact for additional
supplies for example incontinence pads. One carer believes that if this is arranged in plenty of time, this will prevent delayed hospital discharge.

4.3.6 Care, support and follow up needs following discharge
In addition, many carers say they want to know about any follow up treatment, any changes in medication and any dietary requirements for the person they care for. Three carer groups highlighted that they would want to know what to expect when the person they care for is at home. This includes level of care that is required from the carer, in particular if this is new or if there are changes in the level of care required. Carers believe that good communication is important to ensure they receive this information.

4.3.7 Other practical information
Other practical suggestions include information about how the person they care for will be discharged home, are there any transportation arrangements in place and want staff to ensure that someone is at home, for the cared for, if support is needed. Carers also want to ensure the person they care for has plenty of medication when going home. The carer who cited this has had good experiences of this. One carer suggested that they receive a copy of the hospital discharge letter as this would give the carer a summary of care and treatment while the person they care for was in hospital. Another carer would like to be informed about local carer support services that they can connect with following hospital discharge.

4.3.8 Feedback from Carers Service focus group
Feedback findings from carers at the additional focus group, in relation to hospital discharge involvement, are comparable to what has already been highlighted. For example being kept informed; being listened to as the carer knows the person they care for; involvement in MDT decision and not lip service; and informed of levels of care that is required at home. Additional feedback not already mentioned includes: improved systems and procedures relating to discharge, for example, not using the hospital discharge lounge when the person they care for is still unwell; being less explicit about bed management pressures from staff; being clearer about roles and responsibilities of the family, the carer and paid staff as well as transportation arrangements and medication needs; believing that there is too much red tape, if
consent has been obtained to share information with the carer, why is this still an issue; and improved joining up of health and social care services, pressures for targets to be met appear to be visible. Additional support needs were highlighted, this includes ensuring the main carer has sufficient support to be able to carry out day to day activities such as shopping and paying bills as a result, without this, the carer has to leave the person they care for on their own, resulting in additional stress for the carer; carer assessment of need to also be carried out during the hospital discharge process; for staff to recognise that the carer can also have health issues; and for staff to recognise the impact, towards the carer, of what happens next (assuming discharge from hospital).

5. Conclusions

5.1 Being informed
It is evident that carers do want to be kept informed when the person they care for is admitted to hospital. They want day to day information about the person they care for in relation to treatment progress and outcomes; have they slept well; are they eating and drinking enough; are they comfortable. They also want to ensure they have sufficient information in preparation for the person they care for being discharged from hospital. Carers want hospital staff to be proactive in providing information and they want this information to be easily understood. Carers believe their role in terms of communication between hospital staff and the person they care for should have greater importance. Equally carers want to be listened to, they know the person they care for and have a good understanding of their needs and preferences. Their role is particularly relevant when there are capacity issues with the person they care for. Using other methods of communication should be considered, in particular the ‘what matters to me’ board that is in place across all hospital sites. Sufficient and relevant information provision, that is easily understood, and being sufficiently listened to will acknowledge and value their role as a carer and increase their confidence to continue caring.

5.2 Being involved in care
There are mixed responses from carers about being involved in the care of the person they look after while they are in hospital. Approximately one third of
participating carers indicated they would like to be supported to be able to provide care for the person they look after. The majority were either hesitant or unsure if they want to be involved in providing care, this would depend on the situation or if hospital staff asked them to provide care. Being able to choose if they want to be involved is important for the carer, that there is no pressure exerted from staff and for staff to understand that the availability of the carer to provide care varies. A small proportion indicated they would not want to be involved and believe that this is the role of ward staff. There are benefits in providing care for the carer and the cared for were recognised. Carer benefits include better insight of caring needs in preparation for going home and provide continuity of care for the cared for. Barriers in providing care include insufficient confidence to care when the person they look after is unwell and feeling that they are in the way of ward routines.

5.3 Being involved in hospital discharge arrangements

Carers clearly want to be involved in decisions about hospital discharge arrangements for the person they care for. This involvement should be as soon as possible by informing them of the expected date of discharge. This will allow carers plenty of time to put in place any arrangements that are required, in particular if the carer works. Carers want to be central to any discussions about discharge planning, for example MDT meetings, carers believe that staff should take account of what they know about the person they care for. Taking account of the amount of care the carer can provide will then influence any required packages of care. Any required support arrangements should be in place before they are discharged from hospital, for example, care package, adaptations and medication requirements. This should be arranged in place in plenty of time to prevent delayed discharge. Once a date and time has been agreed for discharge this should not be unnecessarily delayed, for example awaiting medication to arrive from pharmacy.

6. Recommendations

The following are high level recommendations to be considered to effectively identify, involve and support carers. This will support NHSGGC Acute Division to meet their duties cited within the Carers (Scotland) Act, 2016.

6.1 Being informed
1. In order to effectively inform and involve carers, there is a need to be able to effectively identify and involve carers, to understand their needs and signpost carers to appropriate support. Therefore carer awareness training should be developed and delivered across the Acute Directorate. Carer feedback cited within this report should be used within the training. This should include a monitoring and evaluation framework to assess reach and impact.

2. To consider reviewing communication protocols within the Acute Directorate that will ensure information provision meets the communication needs of carers so they feel sufficiently informed. This will include information that is understood and ensuring the Clear to All Policy and the Interpreting and Communication Support Policy are used. To explore communication methods such as the ‘teach back’ method, this confirms if information provided has been understood.

6.2 Being involved in care
3. Implement NHSGGC’s Welcoming Ward: Partners in Care vision where patients, family members or carers and hospital staff are partners in care, by facilitating carers’ involvement in looking after the person they care for, while they are in hospital. Ensuring carers want to be involved and no pressure is exerted for them to do so. Where appropriate, being involved in care may prepare carers to provide care when the person they care for is discharged from hospital.

6.3 Being involved in hospital discharge arrangements.
4. Hospital discharge protocols and procedures should be revisited to ensure carers are routinely involved in hospital discharge discussions and decisions for the person they care for. Indicative discharge period should be discussed indicating short, medium or longer term discharge period is likely. Agreed measures to monitor carer involvement for example written documentation and audit to ascertain carer satisfaction.

5. Support requirements, that are required at home, should be in place before the cared for is discharged home, for example, care packages, adaptations and equipment.
7. Good practice points
If addition the following are good practice points for consideration. These will contribute towards the identification, involving and supporting carers.

7.1 Being informed
1. To proactively and regularly inform and update carers about the person they care for. This will include updates and progress about their treatment and day to day information, for example have they slept well, eating well, are they comfortable.

2. To acknowledge and value the carers’ role and listen to what they know about the person they care for.

3. To have greater awareness of the specific support and communication needs of people with specific conditions, for example Parkinson’s disease.

4. To consider how telephone contact with hospital wards can be improved.

5. To work with carers to complete the ‘what matters to me’ board, ensuring the preferences for the person they care for are recorded and used.

6. To consider other forms of communication that could be used to ensure carers are informed for example text messages, email, hospital discharge summary letter.

7.2 Being involved in care
7. Hospital staff should ask carers, while the person they care for is in hospital, if they would like to be involved in their care planning.

7.3 Being involved in hospital discharge arrangements.
8. Where possible carers should be involved in multi-disciplinary discharge discussions or any local arrangement for hospital discharge discussions about the person they care for.

9. To ensure discharge medication is available for agreed day and time of hospital discharge to prevent avoidable delays.
10. Acknowledgements

Thank you to all carers who participated and shared their experiences which informed this paper. In addition thank you to West Glasgow Carers Centre, Glasgow South East Carers Centre, Glasgow South West Carers Centre, Renfrewshire Carers Centre, East Renfrewshire Carers Centre, Carers Link East Dunbartonshire Carers Centre, Carers of West Dunbartonshire and Inverclyde Carers Centre for facilitating this engagement with carers.
Appendix 1: Carer informed and involved while the person you care for is in hospital

**Adult carers**

<table>
<thead>
<tr>
<th>Why are we asking you these questions?</th>
</tr>
</thead>
<tbody>
<tr>
<td>From work we have already done, carers want to be kept informed and be involved in decisions for the person they care for. This is while the person you care for is in hospital and when they are ready to be discharged from hospital. We want to know what this means to you and what is important to you. What does ‘good’ look like to you?</td>
</tr>
<tr>
<td>The information you give us will help us ensure you are better informed and involved. We want to ensure we meet your needs and the needs of the person you care for. This is what we want to do to ensure we identify and involve carers in decisions around the discharge from hospital of the person they care for; this is an important part of the new Carers’ Act.</td>
</tr>
</tbody>
</table>

1. While the person you care for is in hospital, what is it you would like to know from our staff that will make you feel you are being kept informed?

2. While the person you care for is in hospital, what does being involved in their care mean to you?

3. When the person you care for is being discharged from hospital, what does ‘good’ involvement in decisions mean to you?
## Appendix 2: Carer informed and involved while the person you care for is in hospital

### Adult carers – with prompts

**Why are we asking you these questions?**

From work we have already done, carers want to be kept informed and be involved in decisions for the person they care for. This is while the person you care for is in hospital and when they are ready to be discharged from hospital. We want to know what this means to you and what is important to you. What does ‘good’ look like to you?

The information you give us will help us ensure you are better informed and involved. We want to ensure we meet your needs and the needs of the person you care for. This is what we want to do to ensure we identify and involve carers in decisions around the discharge from hospital of the person they care for; this is an important part of the new Carers’ Act.

### 1. While the person you care for is in hospital, what is it you would like to know from our staff that will make you feel you are being kept informed?

**Possible prompts**

- How they are
- Any changes
- Progress
- When they are getting home
- What support would you need
- POA

### 2. While the person you care for is in hospital, what does being involved in their care mean to you?

**Possible prompts**

- Do you want to be involved in care
- Help with eating/drinking
- Washing/dressing
- Any support you need
- Has POA been discussed, are you involved in legal decisions
- Jointly agreeing care plans with nursing staff
- Jointly agree about non-medical decisions
- Does the person you care for have a ACP and were you involved?

### 3. When the person you care for is being discharged from hospital, what does ‘good’ involvement in decisions mean to you?

**Possible prompts**

- Would you want to be involved
- When should you be involved
- Attend planned meeting to discuss the person you care for (multi-disciplinary meetings)
- Know about changes in treatment/medication/rehabilitation/adaptions
- Any changes to care package
- Any changes in level of care expected from you
- What if they are not going home – nursing home, hospice – what is important
- Time of discharge
- What needs to happen to ensure you are prepared for them leaving hospital discharge?