

# Summary of Royal Hospital for Sick Children Carers Needs Assessment

2012

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## **Purpose**

The following paper has been compiled in order to determine the changing needs of Carers at the Royal Hospital for Sick Children (RHSC) and develop a work programme to help address these needs.

## **Background**

NHS GGC outcomes for carers have been outlined in two of the five priorities for NHS GGC within the Corporate Plan. In line with this, the Acute Division focus for carers is:

1. Improving identification of carers/young carers through ensuring critical staff understand the impact of caring and benefits of early intervention.
2. For staff to know how to signpost carers to sources of information and advice (Carers Pathway)

In order to progress this work, a Health Improvement Senior Acute Carers Information post was appointed in Dec 2012. The post holder is working with key staff to support services within the Acute Operating Division to embed carer identification and signposting to carer services with care pathways.

In June 2015, RHSC will transfer to the New Children's Hospital (NCH) campus and be co-located with the New South Glasgow Adult Hospital campus. As part of this relocation, the "On The Move" programme will realign Children's services as part of the Clinical Services Review. It is an opportune time to ensure that carers' needs are considered and embedded within the redesigned care pathways associated with "On The Move." Therefore it is essential that the needs of parent/guardian/kinship carers are addressed in advance of this move.

## **Carers Needs in RHSC**

The hospital has approximately 90,000 outpatients and 15,000 inpatients each year. Estimating the national picture of Carers as 2 in 5 people caring at some point in their life, as well as the potential under-reporting of Parent & Kinship carers, it is recognised that there must be a significant volume of Carers utilising the hospital.

In 2010 a Carers Needs Assessment was undertaken in the Outpatients department in order to explore what carers need whilst in this hospital setting. This resulted in a number of recommendations to support Carers using the hospital services. For example, identified at the time was a 1 year Financial Inclusion Pilot Project following the Healthier Wealthier Children Programme in August 2012. In the interim there has also been further work undertaken in RHSC to raise the profile of carers via health events as well as national awareness-raising of the support available for carers.

Given the developments undertaken since 2010, the identification of the Acute Divisions carers outcomes and the 'On The Move' programme, it was decided to replicate the Needs Assessment in 2013. This work aimed to assess the impact that the carers support programme is having in RHSC, revisiting identification of carers and young carers along with exploring the need for services required to support carers.

## **Method**

150 parents/guardians of children attending the Outpatient Department were interviewed using a structured questionnaire over three days during Carers Week 2013. Themes explored were similar to that of original Needs Assessment, such as: carer identification; carer's status; and usefulness of services provided via carer support. However due to the evolving priorities since 2010, some questions were different preventing a full comparison of both data sets.

## Results

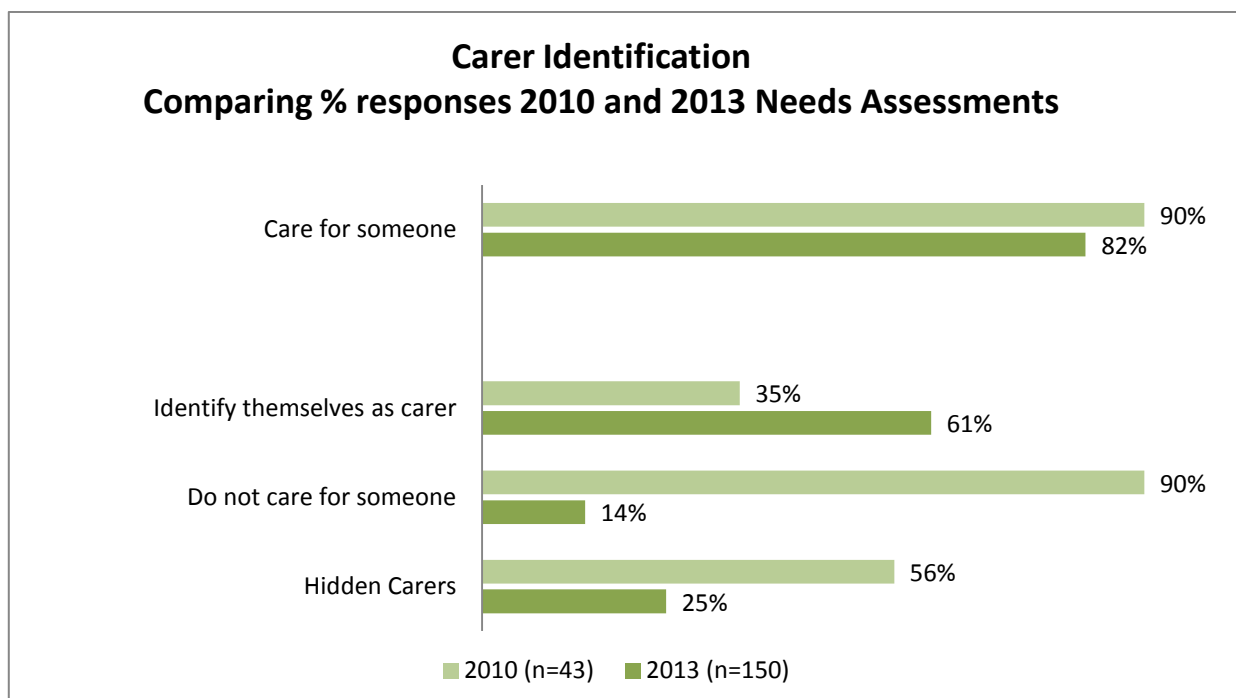
### Carer Identification:

The first two questions of the Needs Assessment attempted to identify if a person is in a caring situation and clarify their perception of the “carer” terminology using the Scottish Government definition of carer. The results of this are as follows:

- 82% (123) of sample said they helped care for someone with 61% (91) identifying themselves as carers.
- Only 26 of these self identified carers (29%) were linked with carer support services.
- 25% (37) were found to be “hidden carers”, 32 cared for someone but did not identify themselves as carers while 5 initially said they were not carers, but when shown the definition, identified themselves as a carer
- 15% (22) were not carers

Comparing to those questioned in 2010, there has been a marked increase in the number of hospital users who identify themselves as carers - Figure 1.

Figure 1: Comparison of Carer Identification from 2010 and 2013 Needs Assessments



This represents a 26 percentage point increase in the number of people who identify themselves as carer. However, only 29% of these are linked to carers support services.

Specific links to carer support services were not included in initial Needs Assessment and therefore could not be compared to the 2013 results.

Caring Status:

Question 3 explored the wider caring situation.

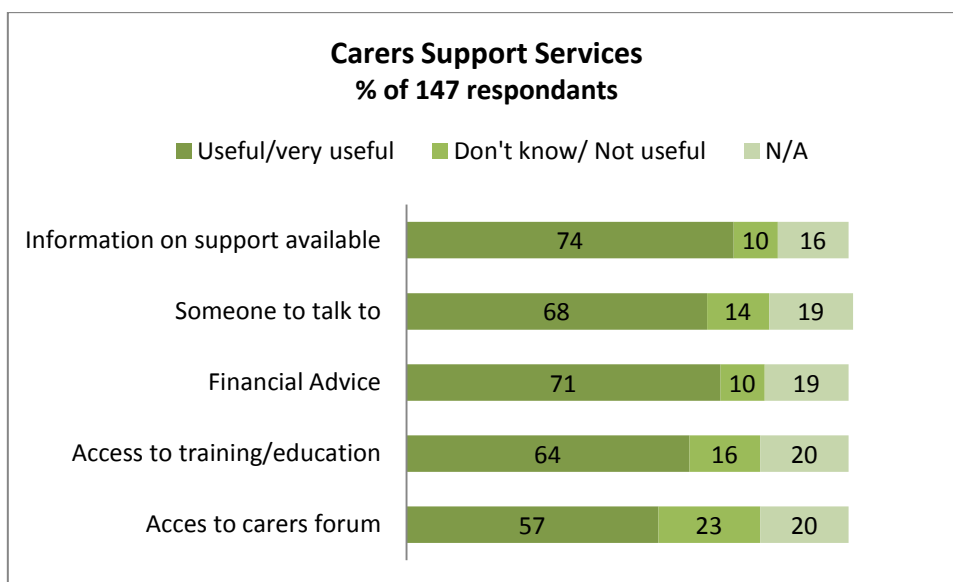
- Of the 147 respondents, 85 out of 123 (69%) had others assisting with caring
- Young carers were identified by 17 (20%) of the 85 adult respondents.

Whilst there was an increase in the self identification from adult carers there has been no change in identification of young carers since 2010.

Carers Support Services:

The remaining questions attempted to identify if the core components offered within established carer support services would be beneficial to users of RHSC Outpatients Department. Analysis of this is provided in Figure 2. Again, this demonstrates the unmet link to carers services of carers identified at RHSC.

Figure 2: 2013 Carers Needs Assessment Required Carers Support



**Conclusions**

Given the increase of awareness of parent/guardian/kinship caring since 2010, with little progression in the number of Carers being linked to appropriate support services, it is essential that NHSGGC RHSC address the carers needs redefined in 2013. Although considerable development has been made regarding carer self identification and Financial Inclusion services for Carers, there remain several outstanding recommendations. These are as follows:

- A systematic process for identification of carers within RHSC clinical pathways
- Access to support for those who are identified as carers, as close to diagnosis as possible.

- Improved awareness of the definition of young carers by both the staff and public
- Information provision for both adults and children who are identified as carers to access local support e.g. from Carers services / support groups.
- Increase availability of the appropriate support and information in order for them to carry out and maintain their caring role.

In light of the 2010 and 2013 results and in order to progress this work in line with the Acute Division's Carers Outcomes, the 'On The Move' programme for the New Children's and adult Hospitals and the Clinical Services Review for Hub and spoke children's services model, further work is required. The recommendations for the work programme are as follows:

1. Further investigate how clinical teams identify and support patients and families in their caring role.
2. Provide appropriate Carer Awareness training, including referral pathways to RHSC staff – work with teams to establish systems for identifying adult & young carers, providing relevant information, signposting/referring to support.
3. Re-align Family Support and Information Service (FSIS) at RHSC to reflect the unique carer support role they provide for inpatient users, improving the visibility of FSIS to all hospital users and staff.
4. Develop systematic recording of all carers (young and adult) in line with Acute priorities from Corporate Plan.
5. Further work is required alongside the adult carer recommendations to identify young carers in a systematic way across the Acute Operating Division.