



## SUPPORT FOR CARERS - PHASE 2

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# EXECUTIVE SUMMARY

## Introduction

Following the submission of the Phase 1 Support for Carers report, Healthwatch Staffordshire undertook the Phase 2 engagement to support ongoing involvement with carers to explore their perspectives towards developing carer support systems in Staffordshire, specifically a Carers Hub. This executive summary provides a brief overview of the approach, findings and recommendations of the engagement and study.

## Methodology

The methodology employed for this study focused on maintaining contact and engagement with carers from the Phase 1 study by applying a multi-methodological framework comprising of questionnaire surveys and focus groups. Overall, this approach engaged with 146 carers in Staffordshire (137 from the questionnaires and 9 from the focus groups).

## Main Findings

The main findings from this engagement and study explore a number of interesting themes which can be broadly categorised into three key areas: (1) priority of issues for carers; (2) issues underpinning support services; and (3) the design and delivery of a Carers Hub. The common themes emerging from these strands can be broadly summarised as follows:

- Carers considered that issues relating to their “physical health”, “my caring role”, “managing at home” and “a life outside of caring” were of particular importance and were a priority that required addressing by support services in Staffordshire;
- Young carers in this engagement indicated that the highest priority was “managing at home” to support their caring role;
- Carers noted that there were a number of issues that were missing from the list of 8 key themes, which included respite care; information and advice; and one-to-one support for carers who are having difficulty coping with their role;
- Access to GP appointments when needed, gaining respite care and access to alternative and holistic therapies was essential to improve the health and wellbeing of carers as well as provide carers with a life outside of caring;
- Money and finance were particular issues of concern for those attempting to apply for financial benefits and those who are supported by the Carers Allowance which was considered insufficient to support their role;
- Peer support networks were viewed as essential to improve carers ability to manage at home with their caring role;

- Carers suggested that a Carers Hub should be an accessible contact centre that individuals can visit. Rather than a centre open 24 hours, carers suggested that it was more important that a Carers Hub be open 7 days a week, specifically at the weekends and in the evenings;
- Participants suggested that whilst the Carers Hub is closed, other support could be offered that could be provided such as ringing up an emergency after hours Freephone line;
- Carers considered that the staff at the Carer Hub should be knowledgeable, reassuring, informed and friendly whilst addressing the queries and concerns of carers in a timely manner;
- The concept of a Carers Hub from the proposed support services outlined to Carers was well received noting that this would alleviate stress and be personally beneficial;
- The Carers Hub should be delivered through a multitude of approaches: a physical contact centre that is delivered locally to enhance accessibility; through a Freephone support system; provision of online information; and face-to-face drop ins and support groups.

## Recommendations

1. A Carers Hub should offer services which address issues relating to be “physical health”, “my caring role”, “managing at home” and “a life outside of caring”, particularly offering respite care and exploring the use of holistic therapies to support carers continued physical health and wellbeing;
2. Underpinning particular issues, support services should offer activities that alleviate the stress and pressure from caring and provide a space for carers to meet to share information, experiences and an area where they can receive face-to-face support;
3. Specifically, commissioners should engage with more young carers to seek their views and experiences of caring and the systems in place to explore the ways in which support services can be tailored to them;
4. The Carers Hub should have a physical presence that is accessible to carers in Staffordshire, and be open 7 days a week with cover over weekends and evenings so that carers can contact the Hub when it is needed most;
5. Whilst the proposed services should be delivered via a Hub, they should also be distributed in local areas through the use of community assets as well as online information; telephone support services; face-to-face drop in sessions; and support groups;
6. The Carers Hub should seek to actively communicate and promote its activities and services to carers. Within this, the Carers Hub should offer a friendly and reassuring service that acts as a “one stop shop” that can provide tailored and precise information;
7. Commissioners should continuously engage with carers to seek their views and experiences of using the Carers Hub. Developing such co-design and co-production panels of users of a Carers Hub would allow for the continued improvement of services offered and resulted in a “best practice” approach.

## INTRODUCTION AND BACKGROUND RESEARCH

Staffordshire County Council, Stoke-on-Trent City Council and Clinical Commissioning Groups are working together to review how support for carers is delivered across Staffordshire and Stoke-on-Trent that meets the needs of young and adult carers. Caring for a family member, friend or neighbour who has an illness, disability, is frail or has mental health needs can be rewarding but also challenging for many carers, and can have substantial impacts in terms of physical health; emotional wellbeing; finances; employment; and school. Within Staffordshire and Stoke-on-Trent existing support includes:

- Young Carers Support
- Adult Carers Support
- Carers Respite
- Emergency Respite
- Carers and Stroke Survivors Services

In February 2014, Healthwatch Staffordshire had been invited by the Staffordshire Carers Partnership to lead on the engagement, insight and co-production as part of the large scale review of the outcomes in the Strategy for Carers (2011-2016). This earlier report (Phase 1) on support for carers highlighted the challenges and difficulties faced by carers in Staffordshire and provided a number of recommendations that would enable carers to cope, continue in their role and prevent them from reaching crisis point. The Phase 1 report highlighted a number of main findings:

- There is a lack of communication between carer organisations which leads to a lack of coordinated effort to provide support services;
- There is an extensive need for financial support, predominately because carers sacrifice work and find applying for benefits difficult;
- The role of carers needs to be taken into consideration by employers and wider family networks as carers juggle both work and caring responsibilities;
- Carers find it difficult to enjoy a life outside of caring;
- Transition from child to adult carer services and from caring to bereavement is weak and requires better support and management;
- Carers felt excluded by clinical specialists resulting in them feeling undervalued;
- GP's need to acknowledge the issues faced by carers and provide access to timely appointments, that is convenient for them and the person cared for;
- Support groups and peer networks are valued but there ought to be greater flexibility in opening hours;
- There is a need for more robust and flexible carer's assessments;
- Carers acknowledge a lack of emergency planning support and the need for emergency care plans;
- The absence of relevant information results in a healthcare industry which is difficult to navigate for carers. Improved signposting and a single point of contact is required;

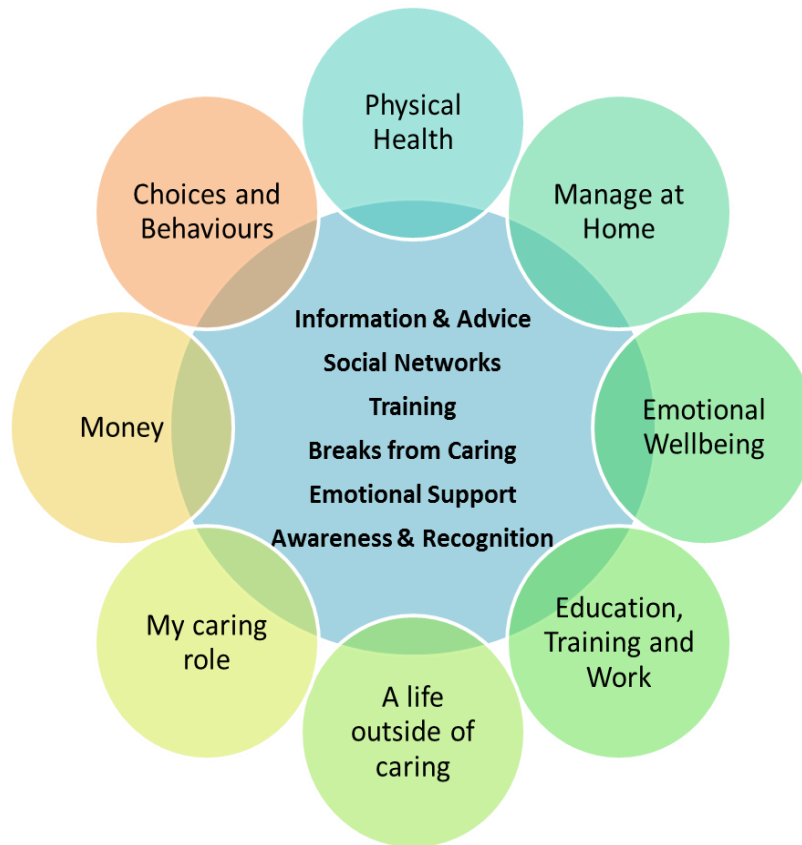
Alongside these findings, the Phase 1 report made a number of significant findings regarding young carers. A key consideration for future work with young carers, is how to effectively engage with a

varied cohort of young people when many have a perceived fear of talking about their responsibilities with officials. Carer's assessments provide young carers with an opportunity to inform social services about the things that would make caring easier for them. Yet the Phase 1 study highlighted that many young carers could not remember the last time they had an assessment. Additionally, schools presented an opportunity to identify the level of support young carers might need.

It was stated that support groups provided a valuable mechanism for engaging with young carers regarding their fears, worries or concerns. In addition, support groups provide an opportunity for carers to talk to other carers about their role and how they manage their caring responsibilities. Carers and professional organisations both agreed that support services are fragmented across Staffordshire and Stoke-on-Trent, support groups are valuable and carers feel tired and fatigued. It was noted that carers do not value their own needs and that carers can be reluctant to ask for help. This often leads to carers feeling depressed, suffer from sleep deprivation and isolation. Overall, there were three priorities emerging for carers from the Phase 1 study:

1. Respite care provision: as most carers need a break from their caring role
2. Finance: information on what financial support carers are entitled to receive and support to fill out forms. Many carers felt that if it wasn't for support groups they would not have realised their entitlements to specific benefits
3. Information, advice and support: currently carers have to find information for themselves rather than have it in one central location regarding their own health

Our earlier work on supporting carers (Phase 1) outlined 8 areas that were of direct importance to carers in Staffordshire. These areas reflected concerns around issues that influenced their experience as a carer. These are highlighted in Figure 1 below.



**Figure 1:** Issues affecting carers in Staffordshire

Staffordshire County Council identified 8 key issues that carers feel would make the biggest impact on their lives (Figure 1) and Phase 2 emphasises re-engaging with carers to establish more detail about what carers have to say about these issues. These results are summarised below.

*Physical Health*

Carers stated their health suffered as a result of their caring role, indicating the foremost issues were sleep deprivation; stress; depression; and tiredness.

*Managing at home*

As a result of existing support carers receive they feel “more confident and safe”, expressing how they value breaks; information; advice in accessing appropriate aids; and live more independently.

*Emotional Wellbeing*

Carers noted obstacles to emotional wellbeing as not having time to themselves resulting in fatigue, stress and depression. Providers should focus on emotional, physical and spiritual health.



### *Education, Training and Work*

Carers frequently juggle work with challenging caring responsibilities and require support from employers. Young carers noted they missed school or were bullied as a result of their caring role.

### *A life outside of caring*

Support and social networks delivered by voluntary organisations were deemed as vital for carers and information and support from other carers built contacts.

### *My caring role*

Carers stated they struggled to find information, advice and guidance they need and a single point of contact would help carers find the information they need.

### *Money and finance*

Access to financial support and information was viewed as essential as some carers reported not knowing what assistance might be available.

### *Choices and Behaviours*

Carers felt that they did not feel valued or listened to by professionals, and that their relative expertise was not acknowledged.

The Phase 1 report was presented to Staffordshire Carers Partnership in September 2014. Staffordshire County Council service commissioners utilised the feedback and recommendations contained in the Phase 1 report to support a commissioning process based on a co-production model with continued involvement of carers. A summary document of the key issues and outcomes, objectives and feedback from carers in the Phase 1 report along with the proposed support for carers can be found in Appendices 4 and 6.

Following the submission of the Phase 1 report to the Staffordshire Carers Partnership, Healthwatch Staffordshire has undertaken a second engagement to support the ongoing involvement of carers engaged with in Phase 1 to revisit the issues identified and explore their perspectives towards developing a Carers Hub in Staffordshire.

## **Towards developing a Carers Hub**

Phase 2 of the continued engagement with carers focuses on the key questions identified in Phase 1 as well as exploring what carers think a Carers Hub should look like, and what it should consider, include and provide for carers.

The outline for a Carers Hub provides an overview of what should, or could, be included in the final model. This model has been developed with consideration of the feedback from carers during Phase 1 and illustrates the needs of carers and what support services should be included. As such, this outline places carers at the heart of the developing carer services.

The developing model for a Carers Hub aims to include children, young people and adults who have caring responsibilities, providing personalised, integrated and holistic support; emotional and practical support to carers; improve carers quality of life; physical and emotional wellbeing; and advocate on behalf of the carer when required. Consequently, the service will be a first point of call for all carers, become a host of activities that support carers and feature a Carers Assessment Centre.

The Carers Hub will be made accessible through physical bases such as an office or walk in centre. A virtual Carers Hub will also be established to eliminate the need to travel to a centre alongside outreach centres in locations such as GP surgeries, hospitals, schools, faith organisations and leisure centres.

The Carers Hub service will:

- Identify the ways in which carers wish to be supported;
- Provide personalised information and advice;
- Provide a break from the caring role, whilst reducing carers social isolation;
- Recognise carers as expert partners and ensure that they are placed at the heart of designing the services that they want to support them
- Offer signposting and referral support and coordination (for example, GP appointments or counselling support);
- Practical support including access to benefit advice; financial, housing, training and employment support
- Work collaboratively with organisations in the local community, offering peer support with other carers to develop a carers' community.

In providing these services, the Carers Hub will work with carers of all ages and their families working together. Each carer who accesses the service shall have a personalised care and support plan that is developed in conjunction with the carer that reflects their type of care role. This plan will provide a network of support by making best use of the services that are available.

The Carers Hub will also identify individuals who do not consider themselves to be "carers", and provide them with appropriate support to continue with their caring role. Additionally, the Hub will work with carers from rural communities, mental health carers, carers of individuals with learning disabilities, autism or substance abuse issues. Alongside this, this single point of contact will be able to make appropriate referrals with social care providers, if required by the carer.

The Carers Hub will provide individual carers with up to date, relevant and personalised information and training. This information will be available through face-to-face support; peer support networks; webpages and paper-based materials. Additionally, such information will be provided at key points in time through a carer's journey, for example becoming a carer for the first time or moving from child to adult services.

If the carer is in crisis or near crisis, the Carers Hub will ensure there is intensive support for individuals. Alongside this, the Carers Hub will provide emergency and contingency plans to provide support to carers in the event of an emergency or to plan for the future when they are no longer able to care.

The Carers Hub will raise awareness of carers, the issues they face and their rights through public events and activities, whilst also providing training for professionals and volunteering opportunities for those wishing to work with carers. This will raise the awareness of carers and the support services available both locally and nationally.

For both young carers and older carers alike, the Carers Hub shall enable carers to take a break from their caring role. For young carers, this may include activities in community locations facilitated through clubs and excursions.

## PLAN AND METHODOLOGY

This section of the report outlines the objectives of the Phase 2 engagement, the methodological approaches used during the study and the justification for why these approaches were chosen alongside what measures were taken to ensure quality in the research design and execution.

### Objectives

The objectives of this study are two-fold. Firstly, to explore carer perspectives towards the 8 issues/outcomes to identify what were priority areas that carers considered were most important to them and whether they consider any issues to be missing from the 8 themes highlighted from the Phase 1.

Secondly, this study explored what carers would want a specific “Carers Hub” to ‘look’ like. As part of this, carers were asked what they wanted a Carers Hub to include and provide as a single point of contact and how this should be delivered.

In so doing, Healthwatch Staffordshire has re-engaged with carers who participated in the Phase 1 Support for Carers study to provide, and demonstrate, meaningful and genuine engagement through the process of developing carer support services in Staffordshire. This engagement is valuable as it promotes carers at the heart of developing support services noting that a “what works well” approach for carers should be integrated into future provision.

### Methodological Approaches

To achieve the objectives, this project utilised two main methodological approaches to explore carer perspectives towards the development of dedicated support services in Staffordshire. These two approaches were: (1) focus groups and (2) questionnaire surveys. Table 1 indicates the groups of carers we engaged with throughout the study.

<b>Table 1: Groups of individuals engaged</b>		
<b>Method</b>	<b>Group</b>	<b>Date</b>
Focus Group 1	Katherine House Hospice (Stafford)	11 <sup>th</sup> November 2014
Focus Group 2	Crossroads (Shelton)	3 <sup>rd</sup> December 2014
Total number of carers engaged with via focus groups = 9		
Questionnaire Survey	Approach Café (Silverdale)	11 <sup>th</sup> November 2014
Questionnaire Survey	Approach Café (Leek)	18 <sup>th</sup> November 2014
Questionnaire Survey	Living well with Dementia (Burton)	19 <sup>th</sup> November 2014
Questionnaire Survey	Living well with Dementia (Burntwood)	20 <sup>th</sup> November 2014

Questionnaire Survey	Approach café (Cheadle)	21 <sup>st</sup> November 2014
Questionnaire Survey	Living well with Dementia (Codsall)	25 <sup>th</sup> November 2014
Questionnaire Survey	Tamworth Carers Association Locality Links (CALL) group (Tamworth)	26 <sup>th</sup> November 2014
Questionnaire Survey	Dementia Support Group (Blythe Bridge)	26 <sup>th</sup> November 2014
Questionnaire Survey	CASS Young Carers group	Early December 2014
Questionnaire Survey	CASS Young Carers group	Early December 2014
Total number of carers engaged with via questionnaires = 137		

The rationale and justification for using each of these methodological approaches is provided in the following sections. A qualitative-led approach was chosen as the principle method to highlight the main priorities carers wanted a support service to address and what a Carers Hub model should ‘look’ like, the service to be provided and how they should be delivered.

### *Questionnaire surveys*

The first stage of this engagement and research employed questionnaire surveys. These were conducted with carer support groups to address the first objective and note the areas carers consider a support service in Staffordshire to address immediately. The questionnaire asked carers to rate in order of priority what were the most important issues in the context of their care role, what was missing from this list identified in the Phase 1 report and whether any of the issues are not relevant to them.

Questionnaires are particularly useful for eliciting people’s perspectives towards complex issues, and valuable for exploring previous experiences (Parfitt, 2005; McLafferty, 2007; Bryman, 2008). As such, questionnaire surveys were employed to explore a wider group of individuals’ responses towards the proposed carer support services, which reinforced and corroborated the findings from the focus groups. These results are incorporated into the Findings and Results section. Whilst individuals who were part of the focus group are referred to as “participants”, those who completed the questionnaire are referred to as “respondents” to highlight the distinction.

### *Focus groups*

The second stage of, and principal data collection tool applied to, this engagement and study was the use of focus groups. This study used two different focus group templates. The first group discussion sought to understand whether the 8 key issues/outcomes model was accurate, if there were any details missing, and whether the proposed suggestions for services to address these issues by Staffordshire County Council and Stoke-on-Trent City Council commissioners are appropriate. This first focus group discussed each of these issues/outcomes in depth. The second focus group specifically focused on what a Carers Hub should ‘look’ like, the ways in which it should deliver support services

within Staffordshire, the meanings this would have for carers and whether this would meet carers' needs. Both focus groups followed a template of predefined questions with prompts for participants and were also given a factsheet with information specific to each focus group. The first focus group factsheet outlined the previous feedback from carers in the Phase 1 study and the proposed methods outlined to address these, whilst the second factsheet provided an overview of what services would comprise the Carers Hub and how this could be delivered.

There are a multitude of advantages of utilising focus groups. For example, focus groups allow for flexibility within the engagement schedule; the ability to adapt and accommodate more or less participants; they can create a more relaxed environment more conducive for individuals to share their viewpoints; and can reveal new areas of debate that may not be explored in one to one in depth interviews (Bryman, 2008; Berg and Lune, 2014). Importantly, focus groups allow participants to express their beliefs, feelings and behaviours in their own words and expose how individuals construct changes in health and social care provision by drawing on different forms of knowledge, values and experiences (Wisker, 2001; Conradson, 2005). Focus group findings can give indications of what is likely to be acceptable to people, and more importantly why or why not. Therefore, focus groups are an ideal methodological tool to explore public perspectives towards the development of carer support services in Staffordshire.

### *Data Analysis*

The findings from the focus groups and questionnaires were analysed using thematic analysis (Braun and Clarke, 2006; Bryman, 2008), once transcribed. This process of analysing data provides a number of phases that should be undertaken to analyse predominately qualitative data. In this study, qualitative data was coded around researcher and participant defined themes (Crang, 2005; Cooper and Endacott, 2007; Saldana, 2012; Berg and Lune, 2014). Thematic analysis has the capacity to capture conversational outputs at a precise point in time, in this case at a pivotal point in the development of carers support services in Staffordshire. This method was applied to the focus groups and the questionnaire survey, which used open-ended questions to provide respondents the opportunity to discuss their views.

### **ECS Quality Plan**

ECS has a responsibility to ensure that the research it undertakes and creates is of high quality and aligned to best practice across the industry. Research ultimately provides the evidence on which sound decisions should be made, which is why it is important to state up front how quality will be ensured during this project.

The Research and Insight Team underpins its research activities by applying the Market Research Society Codes of Conduct (MRS, 2014), which allows us to demonstrate that we are credible, fair and transparent. ECS is a company partner and accredited by the Market Research Society.

ECS also adhere to a strict data protection policy to ensure that:

- Everyone handling and managing personal information internally understands they are responsible for good data protection practices
- There is someone with specific responsibility for data protection in the organisation
- Staff who handle personal information are appropriately supervised and trained
- Queries about handling personal information are promptly and courteously dealt with
- The methods of handling personal information are regularly assessed and evaluated
- Necessary steps are taken to ensure that personal data is kept secure at all times against unlawful loss or disclosure

ECS have firm guidelines for data storage, data retrieval, data security and data destruction. There is also a strict process in place should a data breach occur (which includes containment and recovery, assessment of ongoing risk, notification of breach, evaluation and response).

To further ensure the quality of the final report, an internal peer review process will be initiated to ensure that the report is fit for purpose before submission. Where data is not robust it will be statistically suppressed to prevent disclosure.

## FINDINGS AND RESULTS

### Priority of Issues for Carers

Carers were asked to rate the issues from 1 to 8 (1 being the highest priority and 8 the lowest) based on which were most important to them in the context of their caring role, choosing from the 8 themes previously identified by carers. The resulting ratings of these priorities were achieved by analysing the data through the “three averages”: mean, mode and median (Dancey *et al.*, 2012; McKillup, 2012). The mean indicates the ‘typical’ average calculated by adding all the values together and dividing them by the total number of values (in this instance 137). The mode is simply the number within all the values that occurs most frequently and the median is the middle value. The median arranges all of the values in order (from lowest to highest) and chooses the middle value. Table 2 demonstrates the ranking of these priorities.

<b>Table 2: Carers ranked priorities by average, mode and median</b>				
<b>Rank</b>	<b>Theme</b>	<b>Average</b>	<b>Mode</b>	<b>Median</b>
1	<b>Physical Health</b>	2.85	1	2
2	<b>My caring role</b>	3.38	1	3
3	<b>Managing at Home</b>	3.53	3	3
4	<b>Emotional Wellbeing</b>	3.84	2	4
5	<b>A life outside of caring</b>	4.66	5	5
6	<b>Money and Finance</b>	5.27	7	6
7	<b>Choices and Behaviours</b>	5.55	7	6
8	<b>Education, Training and Work</b>	6.30	8	8

*\*based on a total of 137 survey respondents*

Table 2 demonstrates that the three measures average, mode and median produce consistent results in terms of the rating of priorities. As a result, these findings clearly indicate that “physical health”, “my caring role” and “managing at home” are the three most important priorities to be addressed by carer support services in Staffordshire. Consequently, carer support services that are to be developed by Staffordshire County Council and Stoke-on-Trent City Council should address these three areas as a priority. Whilst this may indicate that these three areas are priorities above all other themes, the remaining areas such as “emotional wellbeing”, “a life outside of caring” and “money and finance” for example are all parts of the carer role that need to be reinforced to support individuals undertaking caring duties.

Whilst Table 2 demonstrates the priorities rated in order of priority for carers, there are some limitations that need to be acknowledged. Principally, physical health is rated as the highest priority



while education, training and work are accorded a low priority. This may reflect the sample of carers that responded to the survey, which undoubtedly influenced these results. Specifically there was a predominance of older respondents who considered that their physical health and was related to the impact on the person cared for if they became ill and unable to fulfil their carer role. This was a major priority whereas education and work was rated as a low priority given that these respondents had retired.

Despite this, however, it should be acknowledged that the sample is still indicative of the wider population of Staffordshire carers. In Staffordshire, a quarter (23.7%) of unpaid carers are above the age of 65, but the vast majority are in the 50-64 age group (38.3%). In comparison there are just over 1,500 unpaid carers under the age of 15.

Given the predominance of older generations who took part in the survey, the responses provided by the older and young carers were extrapolated separately to indicate the priorities that both groups of carers have with respect to their role (see Table 3).

<b>Table 3: Carers (by group) ranked priorities by average, mode and median</b>				
<b>Rank</b>	<b>Theme</b>	<b>Average</b>	<b>Mode</b>	<b>Median</b>
<b><i>Older carers ranked priorities</i></b>				
1	<b>Physical Health</b>	2.48	1	2
2	<b>My caring role</b>	3.35	1	3
3	<b>Emotional Wellbeing</b>	3.66	2	3
4	<b>Managing at Home</b>	3.75	4	4
5	<b>A life outside of caring</b>	4.90	5	5
6	<b>Money and Finance</b>	5.18	7	6
7	<b>Choices and Behaviours</b>	5.80	7	7
8	<b>Education, Training and Work</b>	6.91	8	8
<b><i>Younger carers ranked priorities</i></b>				
1	<b>Managing at Home</b>	2.91	1	2
2	<b>My caring role</b>	3.22	1	3.5
3	<b>A life outside of caring</b>	3.91	1	3.5
4	<b>Education, Training and Work</b>	4.16	1	4
5	<b>Physical Health</b>	4.28	8	3.5
6	<b>Emotional Wellbeing</b>	4.59	4	4
7	<b>Choices and Behaviours</b>	5.00	8	6
8	<b>Money and Finance</b>	5.69	8	7
<i>*based on a total of 137 survey respondents, 105 within the older group and 32 as young carers</i>				

Table 3 demonstrates that there are differences between what older carers and younger carers view as their priorities. While there are some consistencies in the analysis, such as both groups indicating that “my caring role” is very important and “choices and behaviours” are not such a high priority for them. Surprisingly, both groups of carers indicated that issues related to “money and finance” were not a priority in the context of more immediate issues that carers face on a daily basis, related to their own health, wellbeing and ability to cope with their caring role. As such, the support services that should be established first should relate to these areas. Corresponding with the results in Table 2, the combined data indicates that physical and emotional health and wellbeing; managing at home and the caring role are immediate concerns that require addressing.

In contrast, the differences between the two groups of carers can be explained as a consequence of what each group requires. It is unsurprising that older generations consider their physical health is a priority given their life stage and physical activity being demanding for older generations. Yet younger carers noted that managing at home was their top priority. This may be a result of younger carers having to juggle their compulsory education and training careers with their caring responsibilities within, and beyond, the home. A life outside of caring was considered to be a higher priority for younger carers, in order to increase social networks, yet older carers may use their caring role as a method to meet other carers given that it is their primary role. Emotional wellbeing is noted as being more important to older carers than younger individuals.

#### *What additional issues impact on your life as a Carer?*

The questionnaire survey asked carers if there was anything missing from the list of issues identified and if there were any additional issues that would impact on their life as a carer that should be included. Specifically, respondents indicated that there were areas that particularly stood apart and were worthy of more focused attention. Principally among these was the issue of respite care:

*“Respite should be a category in their own right and good information runs through everything”,*  
*“Respite needed frequently. A carer is also an NHS recipient and should be cared for by NHS by being provided with respite at reasonable cost”.*

Respondents believed that although elements of respite care were interwoven within other areas, this demanded more specific attention. Carers suggested that respite for carers was needed more frequently noting that the carer was equally important as those who are being cared for. Out of the areas that carers suggested were missing, respite care was the most common theme.

#### *Information and advice*

The quotes above demonstrate that underpinning respite care, there should be consistent and coherent information. This result highlights that a common theme throughout the feedback was the

need for consistent, accessible information and advice. Therefore this may suggest that there is a need for increased levels of awareness and information provision related to the carer journey, particularly around respite care, but also surrounding more practical aspects of the care role:

*“More specific information and advice locally and professional help for dealing with behaviour issues/aggression of the cared for as well as progression of disability conditions. Especially if there is a crisis”.*

Information provision was viewed by respondents as fundamental to carers who require support with more physical aspects of their care role alongside disabilities that could get progressively worse. More importantly, carers would appreciate such information in times of emergency so that they are prepared to deal with any issues to the best of their ability. Without knowing how to respond to emergency issues, carers feel underprepared to address these aspects of their care role. It is interesting to note here that respondents use the term “locally”, suggesting that carer support services should be more accessible to those carers who may not be able to travel great distances and require specific advice or professional support.

#### *Tailored advice and one-to-one support*

Carers suggested that there was a need for dedicated and accessible one-to-one support for carers who were having difficulty coping with the demands and stresses of their care role, which takes into account the carers role:

*“Tie in with mental health and physical health services enhanced with the "need to be listened to" and acted upon quickly”,*

*“Long term planning. What happens to children when I am not physically able to care for him and need care myself? What happens when I am gone? This must be at the back of every carers mind and can make people very anxious about the future. What can be done about this?”*

Whilst one-to-one support should be accessible, carers advocate that there is a need for the interrelationships between mental and physical health to be acknowledged and services regarding such problems be more prevalent so that carers are aware of how to respond to these issues. Though there is a need for information to address this gap, there may also be a role for the provision of training to support carers who look after those who have mental and physical healthcare needs.

Alongside this carers considered that long term planning was an essential part of their role that they were uncertain about how to do this and who they should be seeking advice from and wanted support with this. The comments indicate that there are a substantial number of questions and concerns that carers have that need to be addressed to provide both the carer and those who are cared for with an understanding of what needs to be done in the short, medium and long term. Not only would this

address a substantial concern by carers but also provide peace of mind and allay fears over future care provision for those who are cared for.

What carers suggest indirectly here is a single point of contact where they can receive a broad array of support that is sufficiently focused and provides practical support to carers. It is important to carers that this service be provided “locally” and is accessible. The following sections related to how a single point of contact or Carers Hub provide depth of understanding relating to what carers believe should be incorporated into a dedicated service.

### *General Issues*

Although not directly related to carer support services, respondents noted that there should be more awareness of the impacts on families:

*“Recognition of the strain upon marriages, difficulties with Grandparents who may not understand hidden disabilities like ADHD, may take on quite a bit of the care burden themselves with no formal acknowledgement of their role. Siblings may bear the brunt of their brother or sisters frustration, feel neglected as much time and energy is focused on their brother or sister [and]... are overlooked as their own problems and anxieties steadily increase [and] may have to perform a large chunk of the caring role especially if parents work/have disabilities themselves”.*

Carers felt that there needed to be a greater appreciation of the role of the family as a whole rather than just the carer in isolation. This finding is important as it highlights that underpinning the carers role to support an individual is the wider family network and the associated positive and negative dimensions that result. Consequently, there are a number of negative impacts on carers with families consisting of other children that may take on part of the care role and could become neglected. This finding could provide a single point of contact or Carers Hub with a role to support the wider family, particularly in terms of strengthening family relations by suggesting activities that the carer, those cared for and the wider family can participate in, in order to address these concerns raised by respondents in this study.

### *Are any of the issues not relevant to you?*

In addition to issues that carers considered were missing, respondents were also asked to indicate which issues were not relevant to them personally in their caring role. Table 4 indicates the number of carers who responded to the question? “Are any of the following issues no relevant to you, and why?”

**Table 4: Issues considered not relevant to them personally in their caring role**

Areas of carer support	Number of carers who consider area irrelevant
Education, Training and Work	31
Money and Finance	7
Choices and Behaviours	4
Managing at Home	2
A life outside of caring	2
My caring role	1
Physical Health	1
Emotional Wellbeing	0
<b>Total</b>	<b>48</b>

*\*based on a total of 137 survey respondents*

The results in Table 4 demonstrate that Education, Training and Work is the main issue that carers feel is not relevant to them. This finding reflects the life stage and age profile of those surveyed as part of the study. As previously highlighted, there is a predominance of older participants who have progressed through their own education and work careers. Consequently, just under a third of carers believe that this is not personally relevant to them. Yet, despite this result, there were young carers who suggested that support with education, training and work would be advantageous. This suggests that carer support services should not discount this area completely but take into account the diversity of carers in Staffordshire and focus this area towards younger carers in the county.

### Issues underpinning support services

Participants in the first focus group were asked to consider whether the proposed support services were sufficient, appropriate and relevant in order to support them in their role as a carer. Please see Focus Group 1 template in the Appendix 3. Accompanying the focus group template, a factsheet was made which was provided to carers summarising the feedback provided in Phase 1 and the suggested services to address the issues identified. The fact sheet (see Appendix 4) was provided to carers to read through prior to starting the focus group. Each issue area aligned to the Key Issues/Outcomes model was discussed by participants and the findings are outlined in the following subsections.

#### *Physical Health*

There were mixed experiences with carers accessing GP appointments and health checks, with some individuals facing particular difficulty:

*“Yes very good because... you’re just like a cancer patient and there is never an issue”,*

*"It's the same with my dad, it's different with my own doctors... trying to get in I get an appointment easier to see the Queen",*

*"I must admit I am fortunate to have my doctors if I ring up in the morning they shall always arrange for somebody to come",*

*"I think that if you made an appointment with your doctor and said that you were a carer they would put it notes that you are a carer and to get an appointment quicker",*

*"If you go to the doctors as a carer they put it on your notes and if you need an appointment quickly they can usually try and fit you in",*

*Because if you need the appointments... to see them in a time you can get in as quick as you can because [you] can't wait days otherwise it just goes out the window",*

*"I'm quite lucky with family close to and our own doctor has put us on... a special list whereby if I need to speak to the doctor she would ring me... so I feel as if I've got a lot of help there".*

Some carers stated that they had good experiences with gaining appointments with their GP as they informed their local medical practice that they were a carer and they would arrange an appointment the same day or a home visit. This was viewed by carers positively yet it was noted that this was not a uniform practice. Others indicated that they had substantial difficulty trying to access a health check or appointment to maintain their physical health. In some circumstances, it was stated by some carers that if they were not seen in a particular timeframe when they first arranged a health check it would become obsolete.

In the focus groups, carers suggested that they have a range of existing therapies, activities and support that are available but not all carers have access to this. As a result, participants suggested that supplying additional therapies and activities for carers to boost their emotional wellbeing and physical health would be of value:

*"We have Rachel... that really is good for us she does reflexology she comes to our home... and she's there for an hour and it's time for yourself and she's just chilled",*

*"You know that night when she's done that I have a good night's sleep".*

Carers referred to this support as time off to themselves and temporarily relax before they return to their care role. As part of supporting carers' physical health participants suggested that respite care was of particular importance to attend to doctor's appointments or carer support groups:

*"There's people that aren't here today because they haven't got... someone to sit with the person they care for",*

*"It's a change of scenery that helps you to unwind a bit".*

Respite care was a recurring theme in this study which underpinned carers' ability to take time away from their care role to look after their own physical health and emotional wellbeing. These suggestions were raised in order to avoid serious health concerns of their own such as sleep deprivation, stress and depression. Yet carers acknowledged that there were particular barriers to proposed support services being implemented:

*"Unfortunately as carers you are a bit limited really... in the time you can get away from the caring role",*

*"It is not straightforward, it's not easy... their time is precious".*

Carers were concerned for the support and wellbeing of the person they cared for and any impact time away would have:

*"You've not got appointments just in the home, you have got hospital appointments, I mean I've been to the chemo unit this morning, it's not just the physical side of that... you go to the chemo unit and just sit there and wait".*

Despite the potential barriers to accessing support for their physical health, carers identified that these elements contribute to the pressure of being in a care role particularly in terms of having to juggle multiple priorities:

*"You know it's only like say[ing] to someone else it's probably nothing but on top of what you're going through..."*,

*"Yes but everything else on top all these little things add together don't they",*

*"You sometimes think it's the last straw".*

The pressure felt by carers whilst undertaking their care role means they often feel overwhelmed by the responsibility they have. This often results in carers neglecting their own health for a number of reasons, principally as a result of not being able to take respite care and time away from their care role to attend appointments or visit their doctor. Consequently, some carers often feel like they reach breaking point as a result of increasing responsibility, pressure and lack of capacity to attend to every need of the person cared for.

### *Managing at Home*

Participants noted a range of assistive technologies and support that they had already received to support their care role, not just for the person that they care for but for themselves also:

*"I've got a bed that goes up... and those chairs we have that... lift",*

*“You have a £300 help towards buying them from CASS. That would help out towards buying them”,*

*“I had to have all the half steps put in because Barry can’t lift his legs to get in the door and doorways so we had to have rails so he can get in and out the doors”,*

*“Social services came around and said “you’ve got to have a new rail, you’ve got the stairs” next thing I knew the chaps at the door the following morning saying “I’ve come to fix that rail”, ok”.*

At present, participants indicated that gaining support for assistive technologies and managing at home was derived from social services and The Carers Association Southern Staffordshire (CASS). Alongside assistive technologies, focus group participants suggested that additional support was required:

*“I think peer support we get from each other... [and] useful information. But the support we get is mainly via the hospice services but there are also a lot of carers out there that haven’t got access to that service”,*

*“At the carers meetings for support each other we give information we talk about these things we pick up on different things how to help each other”.*

The diversity of approaches that participants suggested to support their role (through respite care, peer support and assistive technologies) with respect to managing at home was viewed as mutually beneficial as each aspect improves the ability of carers to provide care to those they look after. To further enable support for carers, participants noted that other support structures needed to be in place to enable individuals to choose and access peer support and general carer services, such as respite care and the flexibility of services to develop this support system.

Whilst most participants considered specific elements of support that would improve their ability to manage at home, there were some carers who suggested that specific circumstances and events in their role and life would determine what aspects of support they would use:

*“I don’t think you always know until that circumstance actually happens to you, you might think I wouldn’t use that, you don’t know further down the line like you say you just come wham bam, you’ve just hit’s a brick wall, something new has happened to you, what you think you do and what you do can end up doing can be totally different”.*

Whilst the quote above suggests that some carers may not actively draw upon the support services proposed, it should be acknowledged that some carers may wish to use it at particular points in time or when they need specific advice or support. Participants suggested that support services for carers needed to be delivered with flexibility given that the needs of carers do not follow a typical working



day between 8am and 6pm and the 24 hour nature of the caring role needed to be taken into account when services are designed otherwise these will be insufficient to support carers:

*“As and when you want it rather than they will come for two hours when they can”,*

*“When it’s convenient”,*

*“Yeah you’re grateful anyway don’t get me wrong if you are a 24 hour carer and they can come from 10 till 2”,*

*“But I don’t think the carers should fit in with the service the services should fit in with the carers”.*

It was considered essential that proposed support services should fit in with carers and not vice versa to best address the needs of those who it will serve. To become successful, the factors underpinning specific elements of the proposed support service should be incorporated into its design and delivery to respond to what carers identify as convenient for them. This “what works” approach would introduce services for carers that have been co-designed by carers, so that they are fit for purpose delivering appropriate and timely support that suits the needs of carers in Staffordshire.

Participants also made reference to the benefits of a sitting service that could provide some level of respite and allow time to themselves for the carer knowing that the cared for person is safe and being looked after. Whilst there is access to a sitting service there may not always be a choice of time and sufficient amount of sitters to provide the carer with respite as and when the carer would like it. This was particularly observable when carers wanted to attend meetings for peer support but this results in increased demand at specific time for sitting services.

### *Emotional Wellbeing*

Carers noted that their emotional wellbeing often suffers as a consequence of their care role. Participants are particular elements that participants suggest that should occur to support their emotional wellbeing:

*“Rachel sees to you physically [and] mentally... she focuses on you as a person physically, she is relaxing you mentally. She’s chillingly you down as well”,*

*“That’s the main thing mentally, physically I can manage more so but mentally it does me a bit of strain sometimes, like I say I feel for June but oh there are times when I could crawl up the walls...”,*

*“You try to be strong...”,*

*“It doesn’t do any good does it”,*

*“You’ve got to walk on egg shells you don’t know what you’re going to do or say is going to flip them”,*

*“That’s the only way you can do it, that’s the only way to cope with having a laugh, that’s the way we cope”.*

Fundamentally, participants suggested that they had to be cautious in front of those they care for to not let their emotions overwhelm them given that there could be additional impacts resulting on the individual they care for. As a result, participants noted that their coping strategies to maintain their emotional wellbeing was through a senses of humour and optimism. These findings demonstrate that carers find it challenging to maintain healthy levels of emotional wellbeing and support in this area would be of specific value to carers. One area that participants suggest has been useful was reflexology, indicating that focusing on relaxation techniques physically also helped to relieve people’s negative feelings and strengthen individuals emotionally developing their resolve. It was also noted by participants that holistic therapies were missing from the list of proposed services and that these would be beneficial to carers.

The interrelationships between the physical health and emotional wellbeing of carers was highlighted at various stages throughout the study. This should be acknowledged when developing services to help carers that one dimension can, and does, support another aspect of carers’ lives and their roles, making it easier for them to cope.

It was suggested by some participants that having other individuals look after those who are cared for resulted in time off for the carer and peace of mind. The social interaction experienced by both the carer and those cared for resulted in boosting the emotional wellbeing of both individuals:

*“My situation is slightly different. My husband’s got friends who will take him to a football match so I’m not quite as worse off as some people”.*

#### *Employment, training and work*

Participants not only considered the influences that need to underpin their own education, training and work but also those related to those they care for to improve this aspect overall. Particularly, it was suggested that there is a gap between young children’s care plans and schools implementing particular aspects of the plan, resulting in the carer being stressed whilst having to juggle other caring responsibilities:

*“I mean if the child is ill it has got to have an operation you’ve got to have a care plan in place, and if the headmaster or headmistress won’t accept meeting to sort out the care plan, what’s the parent supposed to do, they are hitting heads all the time”,*

*“It’s a bit of a vicious circle, because if your daughter’s stressed she comes to you, and then your stressed [and] your looking after your husband and your mum”,*

*“Family assessment would be beneficial”.*

From a wider perspective, participants noted that there were issues arising from carers who leave work:

*“If you’re giving up work and its £60 a week, the hours, oh its 30-35 hours minimum care, to get carers allowance, I’m sorry it’s not enough”,*

*“You know from a full time wage to suddenly that...”,*

*“Well I think the carers allowance should be more”,*

*“If you think of what the carers are paid, and what they are doing and saying”,*

*“And of course once you are over a certain age you can’t have it anyway”,*

*“No you lose it”,*

*“But you’re still doing it”,*

*“It’s harder as you get older”.*

There was agreement with sentiments that the allowance was “not enough” to support carers in their roles and that it should be increased to reflect the activities that carers undertake. However, participants noted that when they reached a certain age they lose the allowance as this can be affected by their pension and are not allowed to claim the carers allowance whilst collecting their pension, despite undertaking the same level of caring responsibilities as before. The arguments underpinning the quotes above are not referring to education and work but rather money and finance, specifically about the financial support for carers undertaking substantial roles. It was noted by one participant that in order to receive financial support, carers and those who are cared for needed to fill in a lot of paperwork:

*“I mean my mum’s 84, but because it went to her house, she opened it... it was only because I said it might take ages, but she [was] entitled to it... and now we’ve got a blue badge for the car. I think a lot of people they see these forms and they think, “oh I can’t be bothered”. They bin them”.*

Participants viewed filling in substantial quantities of paperwork time consuming and demanding yet they saw this as a necessary means to an end in order to receive what they were entitled to e.g. blue badges for disabled individuals. However, participants also acknowledged that given the excessive amount of forms that are required and the time taken to complete them, it was considered that a lot of individuals do not receive benefits that they are entitled to receive. Participants noted that Age Concern and Disability Solutions had been of great help when dealing with these issues.

### *A life outside of caring*

Throughout the study, it has been noted that respite care is of immense support to carers in Staffordshire to enable them to take time to prioritise their own mental and physical health. However, it was indicated that getting time away from caring responsibilities was a difficult task:

*“I try and get out once a month with my friend just once a month I try, and if I’m lucky I see if I can take him with me as well and go as a group with the 4 of us even if it’s only for a couple of hours... it’s out”.*

Whilst the Phase 1 research noted that respite care was needed to help carers recuperate from their demanding role, carers further acknowledged that in some circumstances it is impossible to gain time away from caring and instead plan their own time with friends and take the person who they care for along with them. Despite this, carers stated that even though this was the case, it was still viewed as a different activity that was broadly seen as contributing to time away. This finding indicates that support services should respond to these circumstances and that respite care and a life outside of caring is achieved. The following quotes further demonstrate the importance of a life outside of caring:

*“On Tuesday I pick my daughter up, she’s a widow and we go and do a bit of shopping... have lunch together then we chat about everything... but we don’t talk about Mum. That’s all she asks, how is Mum and that’s it then”,*

*“There’s a world outside that”,*

*“We forget about that and oh mum is well cared for yes”,*

*“And if you were needed you’d get the phone call”,*

*“That’s what I told her, that’s it so we don’t talk about Mum”,*

Specifically, it is noted that despite the fact that they are aware that there is a world outside of caring, this is often forgotten about. This could be explained by respite time being accorded a low priority amongst carers in the context of more immediate (and tangible) concerns relating to the wellbeing of those who are cared for. Consequently a life outside of caring may be viewed as a “back of the mind” issue. However, those carers who stated that they did have some time to themselves commented on how fortunate they were when they were aware that others were not as lucky:

*“We realise how lucky we are to just to be able to come because as I say we’ve got friends that aren’t here that we feel for and that we are concerned about because we haven’t seen them for a while”.*

### *My caring role*

Participants felt that they needed information via traditional print forms as well as online materials to account for the different types of individuals who have access to the Internet. It was noted that some elderly people may not be IT literate and as a result, this would isolate those carers from being able to access information that would be of value to them:

*“What about the elderly that aren’t... they can’t get out they can’t use the hub they can’t use the internet, your isolating them”,*

*“I think it’s taken for granted that everyone has got a computer [and] everyone can use the internet*

*“We’ve haven’t got one”,*

*“We’ve got one but I don’t use it and I don’t like using the internet for private things”,*

*“I think that is just presuming everyone goes on the internet... and they don’t”,*

*“They don’t there are a lot of elderly people”,*

*“It’s that DWP it’s all done by internet now”,*

*“I love the internet but just because I do, [it] doesn’t mean that everybody does”.*

Participants exemplified that some other organisations use the internet as their primary method of disseminating and accessing information, for example the Department for Work and Pensions. This indicates that existing services do isolate carers by only providing information online and not via other media. Whilst participants considered that accessing information was important to services being developed, they also suggested that they should take a more proactive role to support carers:

*“Just to pop in even if it’s just for half an hour quarter of an hour”,*

*“Even if somebody phoned up and said are you alright how are things going”.*

The proactive role that participants identified was viewed as being responsive to carers’ wellbeing and provide general support to reassure individuals that a point of contact does exist and that this can be used to help support their role.

As part of a their caring role, participants suggested that they desired a contact centre with a Freephone with staff that are knowledgeable, friendly and informed to provide relevant information about their role. Additionally, participants noted what they felt was missing from the proposed services which related to transitioning to and from caring. With respect to becoming a carer some participants felt like they were unsure of what to do in the early stages of their role and a contact centre would provide advice and support during this period. Following the end of their caring role, participants wanted support with how to deal with the void after caring and likened this to feelings surrounding bereavement and the uncertainty of how to cope.

### *Money and Finance*

Participants noted that there were substantial limitations relating to accessing money and finance information and advice. Previously, there were concerns that the carers' allowance was insufficient to maintain carers in their role and needed to be increased. However, there were concerns that without the allowance, carers would struggle financially:

*"When you reach a certain age and the carers allowance stops, that has a detrimental effect",*

*"Well that's income you are losing isn't it",*

*"I was almost 70 when I started to look after my husband so I've never had it, it wasn't that it stopped",*

*"Some people may have had it for years then all of a sudden, that's something else that's taken away from you",*

*"When you needed it most".*

Participants stated that they felt that money was important to enable them to fulfil their role as a carer and removing a number of financial benefits left carers struggling financially. It was further identified that not being able to access particular benefits was a result of the amount of paperwork required to receive financial aid:

*"I think sometimes it is down to wording on the forms",*

*"It's how you answer the questions".*

Participants felt that filling in forms to receive financial aid was very problematic and resulted in financial hardship for some carers not knowing what they were entitled to receive. Participants commented that missing is a lack of consistency in the wording on forms and the different types of forms and carers need skilled support in helping them complete forms. As previously mentioned, a single point of contact supporting carers could help individuals complete applications for financial benefits to overcome the difficulties outlined in this study that have been experienced by carers across Staffordshire.

### *Choices and behaviour*

It was noted that carers should be listened to by medical professionals and other practitioners given they have direct contact and responsibility for the day-to-day care for those cared for:

*"I think people need to listen to carers, because they are the experts, they're doing the jobs 24 hours a day, we're getting a snapshot... you are with the people for 24 hours a day".*

As part of recognising carer expertise and experience, putting this in practice was viewed as a positive dimension to providing care to those the carer looks after as well as acknowledging their role:

*“We’re going up Tuesdays to the specialist and I must admit the specialist I see I mean he’ll ask her questions and he’ll look at me... and I nod or I go... and he knows exact. I don’t have to speak and he knows it, he’s very good”,*

*“It’s almost that you’re undermining them as a person to make decisions isn’t it. I mean it’s an awful situation to be in because you do not want to undermine them you want them to be as independent as possible for as long as possible”.*

Despite the positive feelings that some carers have that medical professionals and practitioners acknowledge their expertise, one participant noted that they felt that they were undermining the person they care for. Yet participants conceded that although this may not be the best approach, carers felt that their overriding responsibility was to provide a high level of care and support to the individual. Wider medical professionals were also referred to, particularly named nurses who carers felt that they can talk to in order to discuss specific information in a way that does not demoralise or undermine those who are cared for:

*“Well if you have got a named nurse, who understands the condition, you as a carer have also got access to the named nurse. So you can phone them, obviously when they’re out the way. But not all areas have got a named nurse that specialises in what you’re talking about”,*

*“If you have got a named nurse that specialises, that person can speak to and you can also get access to. Then you will sit with them but you will have access possibly the next day, phone on the side [and say] ‘I know this is what was said but this is what’s really is going on”.*

While the cared for and carer can form different interpretations of what has been said to, and by, professionals, participants considered that carers wanted their choices and behaviours to be understood by medical professionals without undermining the person cared for. However, it was suggested that there is often difficulty in having candid conversations to discuss the reality of the health conditions of those cared for if carers feel that more could be done to support them.

### Additional feedback about proposals

Participants did express some concerns about the proposals for support services put forward:

*“I think these proposals reports are utopia aren’t they, we would like this to happen, you know... in an ideal world”.*

Having reflected on the proposed support for carers to be implemented in Staffordshire, participants believed that the suggestions were too idealistic. Whilst this may be viewed as carers holding a sceptical attitude towards the proposals being implemented, it also demonstrates that carers believe that the proposals would be of direct benefit to them personally and their care role:

*“Exactly and like I say all these sound ideal but in an ideal world and we don’t live in one”,*  
*“But that is ideal for carers who are known to the hospice, there’s a lot of carers out there that can’t access that”,*  
*“It’s a real concern...”,*  
*“They could do with investing some money into that”,*  
*“Yeah they could...”.*

The concerns regarding the proposals also reflected the view that all support services should reach a wider network of carers than existing facilities and services currently do now. This notion of inclusivity indicates that participants are aware of carers in Staffordshire who are in need of such services and can access them with relative ease as well as those who can’t. In addition, participants suggested that there were particular accessibility considerations that need to be taken into account prior to the proposed support services being implemented, given the constraints that many carers face as part of their role:

*“It’s got to be that certain time because that time is not flexible because you come at two and you go home at any time afterwards that fits in with what’s going on at home”.*

The design and delivery of the proposed carer support services was of particular importance. It was stated that the services should not be a one size fits all model and this needs to be flexible around the needs of carers that is easily accessible at a time that suits them.

Alongside the suggested proposals, participants noted that they were not aware of support and facilities that already exists and recommended that awareness raising should accompany the development of new services in Staffordshire:

*“Again its ignorance isn’t it, this is what I think you need is people to go out there to go out there selling and telling us”,*  
*“Perhaps if they could put a notice in the surgery are you a carer or something...”.*

## The need for a single support service

The first focus group reflected upon the issues underpinning support services that carers felt needed addressing. However, in this focus group, without directly referring to a Carers Hub, focus group



participants suggested that a coordinated service would provide multiple advantages that would be able to deliver the specific help that carers in Staffordshire require:

*“You don’t always know where to go, because we are here now we know what we’ve got it’s the people who don’t know”,*

*“I mean let’s face it families aren’t all together anymore are they”,*

Participants considered that there was a need for one central point of contact where access to all carer services could be gained. This notion of a “one stop shop” was considered by participants to be of substantial value and would address the gap in awareness towards where information about activities and support can be found. However, participants also recognised the diversity of families that exist and that a central point would be of particular value to these individuals.

## Developing a Carers Hub

The second focus group predominately focused on what a Carers Hub would ‘look’ like, how it should deliver support services to Carers in Staffordshire and whether this would meet their needs. The following subsections outline these results. Similar to the first focus group, a template for the discussion and factsheet was made for participants to read through prior to starting the focus group, and is referred to as Focus Group Template 2 (see Appendix 5) and Factsheet 2 (see Appendix 6) in the Appendices.

### *Accessibility of a Carers Hub*

Participants discussed what they believed a single point of contact or Carers Hub should look like and operate. Specifically, carers suggested that the Carers Hub should take the form of a physical building where carers could visit:

*“So I suppose if you’ve got a local centre you could then put the hub somewhere there, you know what I mean? Stoke on Trent it could be Hanley”,*

*“Yeah that would make it easier”,*

*“Yeah and they could say, “Right we’ll meet you at the local centre” so everybody can access these”.*

*“I suppose really they would have to access it like people use a GP Surgery, so you can get a room in the local area”.*

Suggestions of a physical building reflect how carers access existing services and what they find to be easier for them to incorporate into their caring role. The notion of a “local centre” demonstrates the importance of accessibility to carers. Participants want a centre that they can meet other carers and access relevant information and support from the service via a face-to-face method of delivery.

Alongside these deliberations, conversations also discussed specific dimensions of accessibility, particularly around times when carers could access support:

*“I know I’d say 24-7”.*

Focus group participants reflected on whether it was more important to have a Carers Hub open 24 hours for 7 days a week or rather if the priority is that the service is open every day. Carers suggested that they preferred a service to be open every day rather than 24 hours, and considered that other support could be put in place:

*“Maybe Monday to Friday and Saturday”,*

*“Maybe for the times when it isn’t open, if a message could be left it it’s urgent and one person could be “on call” and then you’d always have somebody to talk to”,*

*“Obviously if you had a massive emergency you’d call the hospital or an out of hours doctor”.*

Participants suggested that they believed a 24 hour service staffed 7 days a week would be appropriate to support the carers in Staffordshire. Yet upon reflection, and being realistic about the constraints of available resources, it was considered that rather than being open 24 hours, a service that operated 7 days a week would be the most acceptable and appropriate. This was agreed upon because carers noted that in an emergency situation late at night or in the early morning there was support in terms of the 111 and 999 numbers or even an out of hours doctor. However, some participants considered that the times of accessibility should reflect the needs of carers. Specifically, participants noted that there was difficulty accessing support during weekends and in the evenings.

The needs of carers were considered to be of paramount importance when designing and delivering specific services. Consequently, participants noted that services should be based on when carers are more likely to need particular information and advice and that facilities and services should be available at these specific times. However, carers also noted that when a Hub is not open there would be capacity to leave a message for a member of staff to respond to the individual as soon as possible:

*“Maybe for the times when it isn’t open, if a message could be left if it’s urgent and one person could be “on-call” and then you’d always have somebody to talk to”,*

*“Yeah that would be acceptable”,*

*“If it’s non-urgent and out of hours somebody would ring you back ASAP also”.*

The idea of a member of staff who was on call to respond to urgent issues was considered acceptable by carers.

### *Delivering Carer Support Services*

Participants suggested that the Carers Hub should be adequately staffed and have information available to readily disseminate to carers in a manner which is easy to understand:

*“Surely you’d expect whoever’s on the end of the phone to have all that information, to understand readily what is it that you were referring to, so it’s important that they have got all of that information to hand when you are phoning them. So that it’s somebody who is informed”,*  
*“It’s no good speaking to somebody if they’re like “oh I’ll get back to you” or something”,*  
*“Well if it’s a medical issue you speak to the doctor or the hub, or the pharmacy, well it’s no good saying if you’ve got a problem come back to us”,*  
*“The social workers are helping bless them, but they’re struggling as well because this area has got nothing for disabled and learning difficulty”,*  
*“So it doesn’t matter how many people are in for advice, if there are not the facilities there, what can you do?”.*

Participants suggest that carers expect a single point of contact to be a “one stop shop” of information, advice and support that is readily available. Earlier findings demonstrate that carers have difficulty in applying for financial benefits to support their role and as a result participants consider this to be a beneficial aspect of service provision for carers. Yet participants also considered that a Carers Hub should be proactive in addressing carers enquiries whilst not ignoring issues and forwarding queries to other services. Here, participants discussed the need for a comprehensive range of support that carers in Staffordshire can trust to provide a valuable service and have the confidence in that they will deliver the things they need to support them in their role.

It was considered useful by participants that a single point of contact should provide the right information at the right time. Without doing so, carers felt that this increased levels of stress and confusion about their responsibilities and finance decisions:

*“You worry yourself sick about finance nobody else did because it all fell on you and we thought well she knows what she’s doing.... But the worry because of responsibility is awful”,*  
*“It’s all coming from various sources and it’s got to be done properly”,*  
*“Bank statements and receipts, and I just got the point where I was like “I can’t be doing this” I can’t be doing it because I can’t deal with it... It’s too much. It was a cheque here, cheque there... It was just cabbaging my head and that was making me worse because I couldn’t function then as a carer because I’ve got all this pressure from finance”.*

Participants mentioned that they felt worried and pressured about specific aspects of their caring role. In particular, applications for financial benefits was viewed to be a challenging task where participants

felt that they did not have the capacity or understanding to complete the associated paperwork is required.

### *Personal meaning of a Carers Hub*

Within the focus group, participants suggested how a Carers Hub would personally impact on them and their role:

*“Alleviate stress”,*

*“Saving the searching and everything, you’d feel far less stressed. You’d know that there wouldn’t be as much pressure and you’d be a lot better off. If you tell them the needs and the capabilities required they should deliver the expertise and the proper services”,*

*“You just want a bit of a panic button for you”.*

Notably, participants suggested that the Carers Hub model proposed would be immensely beneficial suggesting that it would alleviate stress and make life easier. These findings relate to earlier results in this report that the emotional wellbeing of carers needs to be addressed and that carers in this study identify that a Hub would help to achieve this. Specifically, participants said that this would help carers in Staffordshire save time and feel less stressed and pressured. Interestingly, one participant noted that they felt like they needed a “panic button” that they could press for support. This is an interesting analogy as participants felt that they needed a life line not just for the person they care for but for them when facing the challenges and pressures associated with their caring role.

### *Further services and support*

Alongside their personal feelings of what a Carers Hub means to individual carers, participants considered whether the services were appropriate for carers in Staffordshire:

*“It’s where people are unsure whether to visit the HUB or another service etc. and they Freephone and can get the information there straight away (at the hub) and it’s either on the website or via a telephone call. It’s very helpful”,*

*“I feel really comfortable that they will contact me, so long as everything is going smoothly and I’m happy with it”.*

Participants suggested that the model presented would be appropriate and acceptable to carers as it delivers a service that would be used to gather information and support when carers need it most. Consequently, participants described their feelings towards the proposed Carers Hub model as being “happy”. This positive sentiment justifies the model suggested by the County Council for a Carers Hub as this was viewed to be a positive and valuable service that would be used by carers. Alongside this, carers considered what else a Carers Hub could, and in some cases, should, offer:

*“Perhaps somebody there that you could talk to just drop in and talk session, somebody could say I need this and I need this information as soon as on a one-to-one”,*

*“I suppose it’s like Citizens Advice”,*

*“I mean for the hub you need some sort of drop in and if I needed the information quite quickly it would be easier in person, and they could talk you through it easier”.*

Notably, participants considered that the Carers Hub should provide a service where carers can simply talk to another individual, much in the same way Citizens Advice Bureaux operate. This identification of a peer support dimension to a Carers Hub suggests that carers value a face-to-face method of delivery and a more “human” touch than a simple phone call to an advice service could offer. Moreover, carers specifically stated that they would value members of staff talking through aspects about their role so that they would be clearer about particular things that they may not understand in great depth.

#### *Methods of delivering services*

Considering the specifics of delivering a Carers Hub, participants suggested what they would like the qualities of a Hub to offer:

*“Well you want a friendly delivery”,*

*“I don’t suppose one person can pick up the phone and answer everybody’s questions: if it’s a finance problem fine if they ring you back”,*

*“Just sort of having to look things up and they would know. It saves time”,*

*“If they say “Don’t worry we’ll get back to you” then it would be fine. That’s what you want”,*

*“Reassurance”,*

In terms of delivery, participants wanted access to different services and products that are local to them that provides a friendly service and can answer carers’ queries and provide reassurance. These results are important as it highlights an important gap in the carer journey that has not been considered previously; providing a coordinated network of services through one conduit such as the proposed Carers Hub. Participants suggested that a Carers Hub would be a good service to refer to but this was predicated on a number of issues that needed to be taken into account when delivering the service:

*“I think that (calling a service) would be alright if you get through or you didn’t get through and they answered and you get one of these irritating musical things”,*

*“Especially if it’s a number that you’ve got to pay for”,*

*“Because that’s something else, it should be a free number”,*

*“Its fine having a hub but then being able to get out and get to the hub”.*

Participants considered that a Carers Hub would only work if accessibility to services (in a number of forms) reflected the ways in which carers choose to contact and use the service. Specifically, participants believe that they should be able to access a Carers Hub via a Freephone number instead of paying a premium charge given that the majority of carers do not receive particularly high levels of income. Additionally, there were concerns that whilst a Carers Hub would be a positive idea, being able to physically to it was dependent upon whether individuals had their own personal transport, weather and access to public transport. Another issue relating to accessibility was the manner in which carer enquiries would be dealt with:

*“I think that if it was a phone and it was a friendly voice on the other end to listen to what carers have got to say”,*

*“Even if it’s just to direct them to another service or number or contact. But you’ve got to have that”,*

*“Have the advice they need [and] not just have another phone number to ring”,*

*“Or they pass the information on to a person to contact the carer and not having to think that you’ve got to ring another number”.*

Carers felt that their needs should be dealt with sensitively and sympathetically whilst being addressed in a suitable timeframe without being passed between different support services leading to confusion and uncertainty that their enquiry has been dealt with sufficiently.

## CONCLUSIONS

The findings from this engagement and study demonstrate the multiple issues carers in Staffordshire consider with respect to developing specific carer support services. The main themes arising concerned what issues carers say should be addressed as immediate priorities and what a Carers Hub should look like, whether it is an appropriate support services model and how it can be delivered.

### *Issues to be prioritised*

Related to the 8 issues/outcomes themes, carers suggested that the priority issues affecting them in their caring role were “physical health”, “my caring role”, “managing at home” and “emotional wellbeing”. Whilst these categories reflect the priorities for older carers given the predominance of these in the engagement, younger carers had differing priorities that also included “a life outside of caring” and “education, training and work”. Consequently, the priority areas to be addressed immediately by a dedicated carer support service should be “physical health”, “my caring role”, “managing at home” and “a life outside of caring” given the number of carers who suggested that respite care was of particular importance and reflect the needs of carers.

### *Issues underpinning support services*

With respect to “physical health”, participants noted that access to GP appointments when needed as well as gaining respite care and access to alternative treatments such as reflexology was essential to improve the health and wellbeing of carers. The use of assistive technologies and peer support networks were viewed as essential to improve carers “managing at home”. This influenced carers’ ability to access information and alleviate feelings of loneliness and isolation, thus providing a forum for carers to share their experiences with one another.

Carers noted that their “emotional wellbeing” suffered as a result of their care role, but stated that alternative treatments like reflexology helped improve their ability to relax as well as maintaining a sense of humour and optimism. Participants felt that without this approach and support to their care role, they would have a detrimental effect on the people who they cared for. Whilst “education, training and work” was accorded a low priority as part of the issues to be prioritised, carers considered that a family assessment would be beneficial.

Respite care was discussed frequently throughout our engagements with carers suggesting the difficulty of having “a life outside of caring”. Carers noted that despite this difficulty they often take those that they care for with them when they attempt to take time away from their role. Subsequently, carer support services should explore ways in which respite care can be offered to all carers. In contrast, carers referred to “my caring role” as being an important issue that needed to be reinforced with timely information and the ability to talk to people who could offer a listening and support service. These findings therefore suggest that carers need to understand the condition of the

person they are caring for more clearly through the provision of relevant and timely information as well as access to professional, sometimes medical, advice.

Carers suggested that “money and finance” were issues of concern, particularly as financial benefits were essential to maintain carers’ incomes. Yet carers indicated that after a certain age, financial benefits are no longer provided and this has a detrimental impact. Carers felt that leaving a full time position to care for an individual with financial support as part of a Carers Allowance was not sufficient to support their role. As a result, there were substantial concerns about (applying for and receiving) financial benefits to support carers. Finally, carers indicated that the behaviour of professionals did take into account the role of carers but believed that improvements to “choices and behaviours” could be made to fully acknowledge the expertise and experiences of carers and develop a partnership approach to care.

### *Developing a Carers Hub*

A Carers Hub was perceived to be the best approach to addressing the needs of carers in Staffordshire by participants in this engagement study. Specifically, carers believed that the Hub should have a physical presence that they could access to speak to a person face-to-face. It was this aspect of the proposed carer support services that was well received, particularly reflecting the “local” dimension of support. The accessibility of the Carers Hub was discussed at length with some carers suggesting it should be open 24 hours a day, 7 days a week. However, under further reflection, carers considered that a service open 7 days a week with a high degree of evening and weekend support would be acceptable with any other urgent issues to be dealt with by an out of hours doctor or emergency services.

It was highlighted that a Carers Hub should first and foremost meet the needs of carers in Staffordshire if it was to be successful. Participants further stated that the meaning behind a Carers Hub resonated happy feelings, knowing that a substantial degree of support in the guise of a “one stop shop” would be created for carers specifically.

Carers suggested that the activities and methods of delivering services should be diverse. These suggestions were predicated on supporting carers making applications for financial benefits, needing face-to-face advice and talking to an individual who would listen to their experiences and offer support. Overall, carers noted that the Hub should provide these services in a friendly and reassuring manner that directly addressed carer enquiries in a timely manner.



## RECOMMENDATIONS

1. A Carers Hub should offer services which address issues relating to be “physical health”, “my caring role”, “managing at home” and “a life outside of caring”, particularly offering respite care and exploring the use of holistic therapies to support carers continued physical health and wellbeing;
2. Underpinning particular issues, support services should offer activities that alleviate the stress and pressure from caring and provide a space for carers to meet to share information, experiences and an area where they can receive face-to-face support;
3. Specifically, commissioners should engage with more young carers to seek their views and experiences of caring and the systems in place to explore the ways in which support services can be tailored to them;
4. The Carers Hub should have a physical presence that is accessible to carers in Staffordshire, and be open 7 days a week with cover over weekends and evenings so that carers can contact the Hub when it is needed most;
5. Whilst the proposed services should be delivered via a Hub, they should also be distributed in local areas through the use of community assets as well as online information; telephone support services; face-to-face drop in sessions; and support groups.
6. The Carers Hub should seek to actively communicate and promote its activities and services to carers. Within this, the Carers Hub should offer a friendly and reassuring service that acts as a “one stop shop” that can provide tailored and precise information;
7. Commissioners should continuously engage with carers to seek their views and experiences of using the Carers Hub. Developing such co-design and co-production panels of users of a Carers Hub would allow for the continued improvement of services offered and resulted in a “best practice” approach.

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## APPENDICES

### Appendix 1: Phase 1 Main Findings

The main findings of the Phase 1 engagement and study into carers exploring the main issues facing carers in Staffordshire. The common themes emerging from the various strands of research undertaken by Healthwatch Staffordshire can be broadly summarised as follows:

- Carers feel excluded by clinical specialists and as a result they feel undervalued.
- A lack of communication between carer organisations leads to a lack of coordination.
- The absence of relevant information results in a healthcare industry which is difficult to navigate. Better signposting and a single point of contact is required.
- There is an extensive need for financial support – predominantly because carers have to sacrifice work and find applying for benefits difficult.
- More employers need to acknowledge the role of carers, especially given that carers need to juggle both work and caring responsibilities.
- The transition from child to adult carer services, and from caring to bereavement, is weak and requires better management.
- Support groups are valued but there ought to be greater flexibility in opening hours.
- A lack of support for incontinence is a significant area of concern, especially as it affects so many people.
- Carers acknowledge a lack of emergency planning support, as well as the need for emergency care plans.
- More robust and flexible carer's assessments would be welcome.
- Recruitment of personal assistants can be complex, particularly when there are trust issues.
- GPs need to acknowledge the issues faced by carers.
- Carers find it difficult to enjoy a life outside of caring.
- Carers have difficulties in getting GP appointments that are convenient for both them and the cared for person.

In addition, whilst many young carers could not remember their assessments, none of those surveyed were concerned about being reassessed. There was also significant concern with the support that young people had within schools which tended to be inconsistent. This was primarily related to a lack of communication and awareness that they were carers.

We also made a number of significant findings in relation to young carers. The first point that stands out, and is a key consideration for any future work with young carers, is how to effectively engage with a varied cohort of young people when many have a perceived fear of talking about their responsibilities with officials. This represents a significant problem because services are unlikely to improve without in-depth feedback from young carers.

A carer's assessment presents young carers with an almost perfect opportunity to inform social services about the things that could make caring easier for them. However, this research highlighted how many young carers could not even remember the last time they had an assessment.

Young carers spend a considerable part of the day in schools and therefore schools present an ideal opportunity to identify the level of support an individual might need. However, at the moment very few individuals actually received any meaningful support and it is suspected that there is a sizeable cohort that are hidden carers.

Knowing that young people are carers helps doctors to understand their health needs and may even give them better access to GP services. Yet this research highlighted that not everyone knew of their caring responsibilities or offered any meaningful support when they did.

Support groups provide a valuable mechanism for engaging with young carers regarding their fears, worries or concerns.

The main findings also concluded that there was significant alignment between the messages given by both carers and professional organisations. For example, both parties agreed that services are fragmented, support groups are valued and that carers feel tired and fatigued. There is also agreement that carers don't value their own needs and that carers can be reluctant to ask for help.

Overall, Healthwatch Staffordshire could identify three priorities emerging for carers:

1. *Respite care provision* – as most carers need a break from their caring role
2. *Finance* – information on what financial support carers are entitled to receive and support to fill out forms. Many carers felt that if it wasn't for support groups they would not have realised their entitlements to specific benefits.
3. *Information, advice and support for carers own health* – currently carers have to find information out themselves.

In terms of next steps it is important to understand how carers should be involved in the design and delivery of services so that providers and commissioners can better meet their needs. This requires the establishment of an ongoing mechanism for young carers, adult carers and professionals so that they can benefit from co-production opportunities.

## Appendix 2: Questionnaire Survey

engaging communities  
**Staffordshire**

**healthwatch**  
Staffordshire



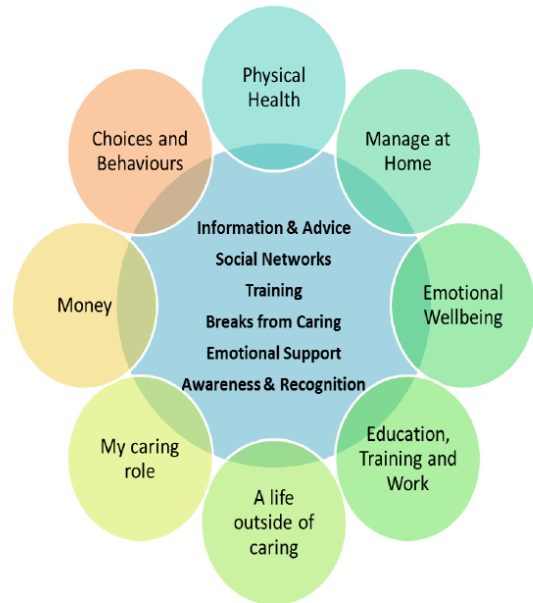
### SUPPORT FOR CARERS (PHASE 2) DROP-IN QUESTIONNAIRE

**Q1: Please rate in order of priority 1 (the highest) to 8 (the lowest) which of the following issues are the most important to you?**

Physical Health: \_\_\_\_\_ A life outside of caring: \_\_\_\_\_  
 Managing at Home: \_\_\_\_\_ My caring role: \_\_\_\_\_  
 Emotional Wellbeing: \_\_\_\_\_ Money and finance: \_\_\_\_\_  
 Education and work: \_\_\_\_\_ Choices and behaviours: \_\_\_\_\_

**Q2: Are there any categories missing in the diagram?**

**Q3: Are any of the issues in the diagram not relevant to you?**



## Appendix 3: Focus Group 1 Template

### SUPPORT FOR CARERS FOCUS GROUP TEMPLATE

#### 1. Before Starting

- Ensure the room is conducive to promoting discussions. A round or oval table is best
- Make sure you (the facilitator) set the tone for discussions and put the group at ease
- Ensure that every participant is given a chance to air their opinions (including the quiet ones)
- Make sure you monitor time closely and allocate enough time to each question.
- Inform people that they have a right to leave the group at any time
- Set ground rules: switch mobile phones off, everything will remain confidential, only one person to speak at a time, there is no right or wrong answers etc.
- Do not nod or agree with any statement given by a respondent as this may put others off from giving alternative views or perspectives.
- Capture all observations including non-verbal body language and morale

#### 2. Introduction

Activity	Introduction
Guidance	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this activity</b></li> <li>• Welcome the Group               <ul style="list-style-type: none"> <li>○ Thank them for attending</li> <li>○ Invite them to sit wherever they wish</li> <li>○ Remember the points in red above</li> </ul> </li> <li>• Introduce the purpose and context of the focus group               <ul style="list-style-type: none"> <li>○ Explain what Healthwatch is</li> <li>○ Explain how the project came about</li> <li>○ Explain the format and duration of the focus group session</li> <li>○ Explain how the information will be fed back</li> </ul> </li> <li>• Explain how the information will be recorded               <ul style="list-style-type: none"> <li>○ Inform them that a note taker will be recording the information</li> <li>○ Inform them that no names will be recorded or comments attributed to any individuals</li> <li>○ Assure them that there is no audio or video recording equipment</li> <li>○ Explain how information will be analysed and used</li> <li>○ Offer the opportunity for people to leave contact details IF they wish to receive a copy of the report. Reassure them that their details will not be linked in any way to the discussions</li> </ul> </li> <li>• Make introductions               <ul style="list-style-type: none"> <li>○ Introduce yourself and co-facilitator</li> <li>○ Ask group to introduce themselves</li> </ul> </li> <li>• Ask if anyone has any questions before you start</li> </ul>
Observations	

#### 3. Physical Health

Question	<b>Are the proposed support services relating to Physical Health sufficient, appropriate and relevant to support your role as a carer?</b>
Guidance	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> </ul>

	<ul style="list-style-type: none"> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your physical health</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use for your physical health?</li> </ul> </li> </ul>
<b>Feedback</b>	

#### 4. Managing at Home

<b>Question</b>	<b>Are the proposed support services relating to Managing at Home sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for managing at home</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use to manage at home?</li> </ul> </li> </ul>
<b>Feedback</b>	

#### 5. Emotional Wellbeing

<b>Question</b>	<b>Are the proposed support services relating to Emotional Wellbeing sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your emotional wellbeing</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use to your emotional wellbeing?</li> </ul> </li> </ul>
<b>Feedback</b>	

#### 6. Education, training and work

<b>Question</b>	<b>Are the proposed support services relating to your education, training and work sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your education, training and employment needs</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use to your education, training and work?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 7. A life outside of caring

<b>Question</b>	<b>Are the proposed support services relating to your life outside of caring sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your life outside of caring</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use to your life outside of caring?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 8. My caring role

<b>Question</b>	<b>Are the proposed support services relating to your caring role sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your caring role</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use for your caring role?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 9. Money



<b>Question</b>	<b>Are the proposed support services relating to your Money and Finances sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your money and finances</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use for your money and finances?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 10. Choices and Behaviours

<b>Question</b>	<b>Are the proposed support services relating to your Choices and Behaviours sufficient, appropriate and relevant to support your role as a carer?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Consider whether you would use the proposed support services frequently for your choices and behaviours</li> </ul> </li> <li>• Additional Questions: <ul style="list-style-type: none"> <li>○ Is there anything that you think is missing from the proposed support services that you would like to see?</li> <li>○ Are there support services proposed that you do not think you would use for your choices and behaviours?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 11. Focus Group Close

<b>Activity</b>	<b>Focus Group Close</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 5 minutes on this question</b></li> <li>○ Summarise key findings for each question</li> <li>○ Seek clarification on any ambiguous areas</li> <li>○ Offer a last opportunity to provide any additional comments</li> <li>○ Thank them for their support and input</li> <li>○ Reassure them that we will keep all info confidential and non-attributable</li> <li>○ Inform them of next steps</li> <li>○ Leave Healthwatch leaflet with e-mail and Freephone details in case they think of anything else of use</li> <li>○ Close meeting</li> </ul>
<b>Feedback</b>	

## Appendix 4: Focus Group 1 Factsheet

### SUPPORT FOR CARERS (PHASE 2) FACTSHEET

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This factsheet provides a short overview of the feedback carers provided in early 2014 about the areas and types of support services they would find appropriate in supporting them in their role. This factsheet also indicates what local commissioners are proposing to establish to support carers in Staffordshire.

#### **1: Physical Health**

Feedback: Carers stated their health suffered as a result of their caring role, indicating the foremost issues were sleep deprivation; stress; depression; and tiredness.

Proposed support: Carers/Family Assessment to identify needs of support and solutions; guidance on exercise activities, healthy foods and social activities; access to health care and GP health checks. Training for carers on managing stress and dementia awareness, carer breaks/respite and GP referrals.

Objectives: The physical health of carers is improved, through eating healthy; taking regular exercise; access to medical, dental and optical appointments; and GP health checks as necessary.

#### **2: Managing at Home**

Feedback: As a result of existing support carers receive they feel “more confident and safe”, expressing how they value breaks; information; advice in accessing appropriate aids; and live more independently.

Proposed support: Carers/Family Assessment to identify needs at home; training around assistive technologies; emergency and contingency planning support; and support to build social networks.

Objectives: Carers have support in accessing appropriate aids, adaptations, assistive technology and wider technology (i.e. web applications and social media), and are able to live independently.

#### **3: Emotional Wellbeing**

Feedback: Carers noted obstacles to emotional wellbeing as not having time to themselves resulting in fatigue, stress and depression. Providers should focus on emotional, physical and spiritual health.

Proposed support: Training for carers (emotional health and managing stress); emotional support and referrals to counselling; peer and support groups; and emergency planning support.

Objectives: The emotional wellbeing of carers is protected or improved, to develop skills to build resilience and have someone to talk to and listen to them.

#### **4: My employment/education/training/learning/volunteering**

Feedback: Carers frequently juggle work with challenging caring responsibilities and required support from employers. Young carers noted they missed school or were bullied as a result of their caring role.

Proposed support: Carers/Family Assessment to identify employment, educational, training and volunteering needs; information and guidance on flexible working policies, financial support; CV writing and recruitment websites; and employer support (i.e. carer awareness and flexible working).

Objectives: Carers are supported through their (and have access to higher and community) education; getting back into education; get back into or maintain employment; have access to training; and supported to access volunteering opportunities.

## **5: A life outside of caring**

Feedback: Support and social networks delivered by voluntary organisations were deemed as vital for carers and information and support from other carers built contacts.

Proposed support: Carers/Family Assessment to identify social needs; provision of advice on respite, breaks and social networks; and establish peer support groups and networks.

Objectives: Carers have a break from their caring role; feel less isolated; supported by their peers; participate in meaningful and enjoyable activities; and connect with family, friends and communities.

## **6: My caring role**

Feedback: Carers stated they struggled to find information, advice and guidance they need and a single point of contact would help carers find the information they need.

Proposed support: Staffordshire carers website and contact centre and Carers Hub providing a central and first point of contact, a host for activities supporting carers and a walk in facility and virtual hub for carers to access information.

Objectives: Carers receive timely advice information and advice, are able to make informed decisions based upon the information they access and able to manage emergency situations effectively.

## **7: Money**

Feedback: Access to financial support and information was viewed as essential as some carers reported not knowing what assistance might be available.

Proposed support: Carers/Family Assessment to identify financial needs, support options and solutions; provision of advice surrounding benefits, pensions, debt and financial information; and training for carers for managing budgets and personal finances.

Objectives: Carers receive timely advice about debt, benefits and finance, and are able to take part in activities with their peers, friends, family and community networks.

## **8: Choices and behaviour**

Feedback: Carers felt that they did not feel valued or listened to by professionals, and that their relative expertise was not acknowledged.

Proposed support: Carer awareness training for medical professionals; advocacy support; and carers provided with opportunities to have their voices heard by commissioners, service providers and medical professionals.

Objectives: Carers are actively involved in decisions about themselves and their lives and the support planning of those cared for; policies shaped by carers experiences; receive advocacy; and recognised as an “expert partner in care”.

## Appendix 5: Focus Group 2 Template

### SUPPORT FOR CARERS FOCUS GROUP TEMPLATE

#### 12. Before Starting

- Ensure the room is conducive to promoting discussions. A round or oval table is best
- Make sure you (the facilitator) set the tone for discussions and put the group at ease
- Ensure that every participant is given a chance to air their opinions (including the quiet ones)
- Make sure you monitor time closely and allocate enough time to each question.
- Inform people that they have a right to leave the group at any time
- Set ground rules: switch mobile phones off, everything will remain confidential, only one person to speak at a time, there is no right or wrong answers etc.
- Do not nod or agree with any statement given by a respondent as this may put others off from giving alternative views or perspectives.
- Capture all observations including non-verbal body language and morale

#### 13. Introduction

Activity	Introduction
Guidance	<ul style="list-style-type: none"> <li>• <b>Spend no more than 10 minutes on this activity</b></li> <li>• Welcome the Group               <ul style="list-style-type: none"> <li>○ Thank them for attending</li> <li>○ Invite them to sit wherever they wish</li> <li>○ Remember the points in red above</li> </ul> </li> <li>• Introduce the purpose and context of the focus group               <ul style="list-style-type: none"> <li>○ Explain what Healthwatch is</li> <li>○ Explain how the project came about</li> <li>○ Explain the format and duration of the focus group session</li> <li>○ Explain how the information will be fed back</li> </ul> </li> <li>• Explain how the information will be recorded               <ul style="list-style-type: none"> <li>○ Inform them that a note taker will be recording the information</li> <li>○ Inform them that no names will be recorded or comments attributed to any individuals</li> <li>○ Assure them that there is no audio or video recording equipment</li> <li>○ Explain how information will be analysed and used</li> <li>○ Offer the opportunity for people to leave contact details IF they wish to receive a copy of the report. Reassure them that their details will not be linked in any way to the discussions</li> </ul> </li> <li>• Make introductions               <ul style="list-style-type: none"> <li>○ Introduce yourself and co-facilitator</li> <li>○ Ask group to introduce themselves</li> </ul> </li> <li>• Ask if anyone has any questions before you start</li> </ul>
Observations	

#### 14. Personal meaning

Question	<b>What does having a carers hub and/or access to more specific carer support services mean to you as a carer?</b>
Guidance	<ul style="list-style-type: none"> <li>• <b>Spend no more than 15 minutes on this exercise</b></li> </ul>

	<ul style="list-style-type: none"> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ What difference would this make to your caring role?</li> <li>○ How beneficial would this be to your role?</li> <li>○ If such services were put in place, in what ways would this support your caring role?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 15. The right services for carers

<b>Question</b>	<b>Are the services that have been outlined in the factsheet right/appropriate for carers?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 15 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Do these services adequately address your needs for support?</li> <li>○ If not, why not and what would carers seek to improve them?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 16. Service provision

<b>Question</b>	<b>From what has been outlined, would this meet your needs as a carer? Do you think that there is anything missing from the proposal?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 15 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ Essentially, what do you (as carers) want a single point of contact to include and provide?</li> <li>○ What is essential to support individuals in their role that a carers hub should provide?</li> <li>○ Essentially, carers should consider what has not been considered that would improve their care role</li> <li>○ Carers should also consider what is not relevant to them and if that</li> <li>○ Are the services that they suggest are missing or not relevant for all carers, i.e. young and older carers alike?</li> </ul> </li> </ul>
<b>Feedback</b>	

### 17. Methods of delivering services

<b>Question</b>	<b>How do you think that these services could, or should, be delivered?</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>• <b>Spend no more than 15 minutes on this exercise</b></li> <li>• Make sure everyone contributes</li> <li>• Prompts: <ul style="list-style-type: none"> <li>○ How would you like to access this service? What is the best method of accessing it for you?</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ Should this be delivered by an outreach centre; by phone; text service; websites/virtual presence; 24 hour advice and guidance service; should the service be staffed by qualified individuals?</li> </ul>
<b>Feedback</b>	

### 18. Focus Group Close

<b>Activity</b>	<b>Focus Group Close</b>
<b>Guidance</b>	<ul style="list-style-type: none"> <li>● <b>Spend no more than 5 minutes on this question</b> <ul style="list-style-type: none"> <li>○ Summarise key findings for each question</li> <li>○ Seek clarification on any ambiguous areas</li> <li>○ Offer a last opportunity to provide any additional comments</li> <li>○ Thank them for their support and input</li> <li>○ Reassure them that we will keep all info confidential and non-attributable</li> <li>○ Inform them of next steps</li> <li>○ Leave Healthwatch leaflet with e-mail and Freephone details in case they think of anything else of use</li> <li>○ Close meeting</li> </ul> </li> </ul>
<b>Feedback</b>	

### OUTLINE OF SERVICES FOR SUPPORTING CARERS

Our earlier work on supporting carers (Phase 1) outlined that carers wanted a single point of contact to access relevant services that would support their caring role. In this new phase, we want to discover what carers think a single point of contact (or Carers Hub) should look like, and what it should consider, include and provide for carers.

This factsheet provides an outline of the services that have been proposed to supporting carers in Staffordshire and Stoke-on-Trent. This outline provides an overview of what should, or could, be included in the final model. This model has been developed in conjunction with what carers want to be established as part of a carers hub, and illustrates what it might “look” like and what it will do. As such, this outline places carers at the heart of the developing carers services.

The aim of the Carers Hub will include children, young people and adults who have caring responsibilities, providing personalised, integrated and holistic support; emotional and practical support to carers; improve carers quality of life; physical and emotional wellbeing; and advocate on behalf of the carer when required. Consequently, the service will be a first point of call for all carers, become a host of activities that support carers and feature a Carers Assessment Centre.

The Carers Hub will be made accessible through physical bases such as an office or walk in centre. A virtual Carers Hub will also be established to eliminate the need to travel to a centre alongside outreach centres in locations such as GP surgeries, hospitals, schools, faith organisations and leisure centres.

The Carers Hub service will:

- Identify the ways in which carers wish to be supported;
- Provide personalised information and advice;
- Provide a break from the caring role, whilst reducing carers social isolation;
- Recognise carers as expert partners and ensure that they are placed at the heart of designing the services that they want to support them
- Offer signposting and referral support and coordination (for example, GP appointments or counselling support);
- Practical support including access to benefit advice; financial, housing, training and employment support
- Work collaboratively with organisations in the local community, offering peer support with other carers to develop a carers community.

In providing these services, the Carers Hub will work with carers of all ages and their families working together. Each carer who accesses the service shall have a personalised care and support plan that is developed in conjunction with the carer that reflects their type of care

role. This plan will provide a network of support by making best use of the services that are available.

The Carers Hub will also identify individuals who do not consider themselves to be “carers”, and provide them with appropriate support to continue with their caring role. Additionally, the Hub will work with carers from rural communities, mental health carers, carers of individuals with learning disabilities, autism or substance abuse issues. Alongside this, this single point of contact will be able to make appropriate referrals with social care providers, if required by the carer.

The Carers Hub will provide individual carers with up to date, relevant and personalised information and training. This information will be available through face-to-face support; peer support networks; webpages and paper-based materials. Additionally, such information will be provided at key points in time through a carers journey, for example becoming a carer for the first time or moving from child to adult services.

If the carer is in crisis or near crisis, the Carers Hub will ensure there is intensive support for individuals. Alongside this, the Carers Hub will provide emergency and contingency plans to provide support to carers in the event of an emergency or to plan for the future when they are no longer able to care.

The Carers Hub will raise awareness of carers, the issues they face and their rights through public events and activities, whilst also providing training for professionals and volunteering opportunities for those wishing to work with carers. This will raise the awareness of carers and the support services available both locally and nationally.

For both young carers and older carers alike, the Carers Hub shall enable carers to take a break from their caring role. For young carers, this may include activities in community locations facilitated through clubs and excursions.